

# **When an infant grandchild dies : family matters**

by

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## ABSTRACT

When a child dies the main focus of both clinical practitioners and researchers is on the parents and, to a lesser extent, the siblings. In contrast grandparents have been called the "forgotten grievers". Are grandparents "forgotten"? If so - by whom? My interest in this study, as a nurse working with bereaved families, was to explore how grandparents, parents and health/bereavement professionals constructed grandparent bereavement when an infant grandchild died unexpectedly. The 26 participants, living in New Zealand and the United Kingdom, included 16 grandparents and 6 parents from 11 families, in addition to 3 health/bereavement professionals.

As a theoretical framework I used constructivist inquiry informed by writings on nursing, storying and postmodernism. Through an exploration of the methodological and ethical issues that arose and were addressed during the study, this work adds to knowledge of how constructivist inquiry can be used in nursing and bereavement research. In addition, the context of this research as a partnership with multiple family members contributes to the ongoing debate about whether participation in bereavement research may be harmful or therapeutic. Our conversations in this research formed a series of interviews and letters, which led to the development of a joint construction and each individual's story.

A grandchild's death was constructed as a challenge which grandparents faced, responded to and then managed the changes that arose from the challenge. When facing this challenge, grandparents felt "*pain*" and had a strong sense of "*being unprepared*", despite extensive life experience. The context of their bereavement was seen as underpinned by their relationship as "*parents of the adult parents*" of the grandchild who died. This meant that grandparents placed their own pain second to their wish to support and "*be with*" the parents. Parents and health/bereavement professionals appreciated the support that grandparents offered at a time when they, too, were bereaved. It was outside the family where



many grandparents found friends, colleagues or their community forgot, or chose not to acknowledge, their bereavement.

From this work the stories of individuals offer previously unspoken voices, to appreciate the multiple meanings and ways in which grandparents are bereaved. In particular, recognising that some grandparents help to create a space within the family which maintains a continuing relationship with the grandchild who died. Combining the stories with the joint construction offers us as clinicians, researchers and members of communities, a perspective to consider in acknowledging grandparent bereavement as an ongoing part of people's lives.

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## DEDICATION

*This thesis is dedicated, in alphabetical order, to the lives and*

*memories of:*

*Bernadette*

*Christopher*

*Conor*

*Daniel*

*Gracie*

*Jordan*

*Martin*

*Matthew*

*Matthew*

*Ruby*

*Samuel*

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# CHAPTER 1

## AN INTRODUCTION TO THE WHOLE

### WELCOME

I would like you to imagine coming into a sunny, warm room with apricot walls and a large window looking out onto a woodland garden with a pond where five ducks are swimming. There is a backdrop of the Pacific Ocean on one side and on the other side a series of undulating hills with a mixture of green pasture grazed by deer or goats and then steep slopes of native New Zealand bush. I want to welcome you to this room in our house, which is my study. It is in this room that this thesis has developed and come to full growth.

In welcoming you I want to outline what this chapter is about. It is, in many respects, a foreword. It does not follow the traditional form of introduction to a research thesis with full discussion of the research aim and justification for undertaking the research. This information is in Chapter 2 "*A story of the beginning*". Instead, this chapter is another form of introduction. It locates the context of the thesis by providing an overview of the content and the beliefs that position this research and have subsequent consequences for writing style. I believe that signposting the location of specific content within the thesis offers a sense of the whole text and of the critical issues, before starting to explore the areas in detail. Most importantly, the latter part of this chapter introduces the people who have created this research **with** me.

Before turning to the content of this thesis I want to explain why this thesis is in three parts, thereby making it a large document. The three parts reflect the interrelated aspects of the research. The first part, starts with Chapter 2, and discusses the journey of this nursing research as an exploration of grandparent bereavement using constructivist inquiry. The following chapters in Part 1 unravel what this journey meant in terms of research relationships, conversations with participants, ethical issues and the ongoing debate of rigor in research. The second part contains the stories of the 26 participants, from New

Zealand (NZ) and the United Kingdom (UK), who shared their individual experiences and constructions of grandparent bereavement in a series of interviews and/or letters. The third part is the story of the joint construction, which developed from conversations with participants as **one** construction of grandparent bereavement in the context of the family. This joint construction is explored in relation to existing literature, the context of infant death in the 1990s and the implications that this research could have for families, society and nursing practice.

## **WHAT IS THIS THESIS ABOUT?**

It is about two things. First, it explores the issue of grandparent bereavement, when an infant grandchild dies unexpectedly. This issue is not widely acknowledged by either society, clinicians or researchers, as evidenced by the handful of published research and clinical articles in this field (DeFrain, Jakub & Mendoza, 1991-92<sup>1</sup>; Donnelly & Haimes, 1993; Fry, 1997; Gyulay, 1975; Kalish, 1987; Ponzetti, 1992; Ponzetti & Johnson, 1991). Second, this thesis makes a contribution to academic knowledge through the use of the constructivist paradigm proposed by Egon Guba and Yvonna Lincoln (1989), which has not been widely used in the area of health research (Appleton & King, 1997). In particular, the positioning of this study at the point where three areas of research meet, bereavement, family and nursing, meant that a number of methodological and ethical issues arose and were addressed.

### **About grandparent bereavement**

In the last 25 years there has been an increasing awareness amongst nurses in practice, other health professionals and researchers about the impact of the sudden death of a baby on parents (Benfield, Lieb & Vollman, 1978; Conway & Valentine, 1988; DeFrain, 1991; Farnsworth & Allen, 1996; Riches & Dawson, 1996a, 1996b; Vance, Boyle, Najman & Thearle, 1995). More recently, attention

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<sup>1</sup> The journal OMEGA uses this date format for issues that span the end of one year to the beginning of the next year.

has focused on siblings (Doka, 1995; Irizarry, 1997). However, grandparents who are one generation removed from the baby have received little attention except for the few published articles cited above. James Ponzetti and Mary Johnson (1991) re-used the phrase "*Forgotten Grievors*" when titling their article 15 years after Jo-Eileen Gyulay (1975) first used it to describe bereaved grandparents. Whilst Ponzetti and Johnson did not state by whom the grandparents are "forgotten" the implication is that it is researchers and potentially society, not the grandparents' family, who have forgotten the triple grief which grandparents may experience (see further discussion in Chapter 2).

Existing articles about grandparent bereavement, cited earlier, have tended to focus on grandparents' reactions to the death, such as feelings of pain or disbelief. There has been less emphasis on the ways in which grandparents "see" (construct) their bereavement. Similarly, there has been little exploration to date of grandparent bereavement located within the context of the family. Holding a family focused perspective of grandparent bereavement can lead to a number of questions. How do grandparents "see" a grandchild's death, both as individuals and as members of the family in which the bereavement occurs? Conversely, how do bereaved parents "see" grandparent bereavement within the context of the family? In addition, given the idea of grandparents as "forgotten grievors", how do the health/bereavement<sup>2</sup> professionals who work with families when a child dies "see" grandparent bereavement? This research has worked with these questions, which are discussed further in Chapter 2. During this research I explored with 22 members of 11 families (16 grandparents and 6 parents) in addition to 3 health/bereavement professionals, their constructions of grandparent bereavement. Parents and health/bereavement professionals were involved because I wanted to explore the ways in which grandparent bereavement is constructed both **within** the family context by others in the family, and by those working **with** the family. I was particularly interested in the research having a family focus given the emphasis on "family" in relation to constructing reality (Reiss, 1981), as the context for family nursing practice (e.g., Wright & Leahey, 1990; Whyte, 1997) and as a focus for research (e.g., Boss, 1987; Gilgun, Daly and Handel, 1992).

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<sup>2</sup> I have commented on the use of this term in the section on definitions on p.18.



The 11 infant grandchildren, whose family members took part in the research, all died unexpectedly for a range of reasons such as stillbirth and sudden infant death syndrome (SIDS). Whilst the reason for their death brought a particular range of experiences to the family, such as SIDS meant the Coroner was involved, these differences were not a large issue in the discussions that I had with participants. What was outstanding was the shared definition of grandparent bereavement when an infant dies unexpectedly.

This exploration of grandparent bereavement has two aspects; the individual stories of the experiences of 26 participants and the joint construction of grandparent bereavement which was developed by 26 participants and myself. The strength of this research lies in the combination of the stories and joint construction providing a perspective on grandparent bereavement which has both depth and breadth. The participants and I share a goal to raise awareness and acknowledgement of grandparent bereavement. We hope that the stories, read in conjunction with the joint construction, will achieve our goal.

### ➤ **The stories**

The stories are a gift which 26 people have shared; first with me, then with each other, and now with readers of this thesis. They give a voice to individuals' experiences and the ways in which they have constructed their reality of grandparent bereavement (see pp. 8-9 and p. 58 for further detail on constructions). The stories are powerful, upsetting and vivid; they represent what this research is about. To give a sense of this I have included, at this point, Marie's construction of her grand-daughter, Ruby's, death.

I am sure that it is usual to look forward to a new birth with happy confidence, if there had been no indications of problems during the pregnancy. So, when my twelfth grandchild, Ruby, was born, I expected that, as usual, it was the beginning of a happy new life. Therefore, I was not prepared that, this time, it was going to be different. I was looking after the other two little girls and this occupied a lot of my attention. But when the news came, a few hours after the birth, that my daughter, Rosemary, and her baby had to fly to a hospital in Auckland, I found it hard to accept the implications. I was glad that I took the girls to the hospital in Dunedin to see the baby, even though it was not easy for us to see her wired in an incubator, and we had only a short time to see her. Of course we couldn't touch her, and I longed to hold her even if only for just a second. It was so hard during the

next few days to feel my daughter's sorrow, and not to be able to be near her and comfort her except over the telephone. Not having known Ruby as a person, meant that I hadn't the same feeling of loss, so my grief which is still so much a part of me, has not been as intense as that of Rosemary. I still have sudden tears, though I am a person who rarely shows emotions, and I mostly cry only when alone. I can talk easily with my daughter about Ruby, but I find it difficult to give her all the comfort she needs. Really, the only things I have to remember Ruby by are photos of her in her coffin, and strangely an umbrella. During the grave-side ceremony the rain was pouring down and I held this umbrella over the girls and me. This umbrella I will never use again but I have put it in a place I pass by most days, and I touch it and remember. (Marie 3:1-2)<sup>3</sup>

The decision to place all 26 stories in this thesis is based on two separate but connected beliefs. First, that multiple constructions of reality exist; and second the importance of partnership and respect in relation to Other (see Chapter 3). Holding these beliefs means that all the stories belong here; no one story is a better example than another. The power of the stories is the effect of the juxtaposition between the diversity and the shared aspects of grandparent bereavement. This offers a window into different contexts and constructions of grandparent bereavement, which sets the scene for Chapter 6, the joint construction developed from dialogue with all the participants. The stories are cradled in the centre of the thesis as Part 2. They are not placed in the appendices, or as a separate volume, because the positioning of the stories in the text reflects the position of Other, which I have held during the research. Namely, that people's voices and participants have been central to this work. Placing all the stories together in Part 2 reflects the process of this research, which involved working with participants to construct their stories as voices to be heard making a claim for grandparent bereavement to be acknowledged. In contrast to a lone voice, there is strength in the companionship of the stories when grouped together which contributes to the claim for grandparents to be heard. Reading the stories can leave images, memories and understandings that can be taken forward into life, work and relationships. Part 2 is, perhaps, a place to visit after this chapter, to read several stories and hear what this research was about, before reading the details of the research journey in Part 1.

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<sup>3</sup> Refers to research text notation, see Figure 1.1 (p. 16).

### ➤ The joint construction

The second aspect of the exploration is the joint construction developed using the constructivist paradigm proposed by Guba and Lincoln (1989) and presented in Chapter 6. It is **one** construction of grandparent bereavement, from this group of people. It does not claim to be the definitive, or only, construction of grandparent bereavement. In contrast to the stories, which offer voices of individuals' experiences, the joint construction offers a conceptualisation of ways of being a bereaved grandparent. It was built from the dialogue across the three participant groups (grandparents, parents and health/bereavement professionals) commenting on each other's perspectives. The construction provides the opportunity for debate about the positioning of grandparent bereavement in relation to both clinical and research literature and the context of societal views of bereavement and grief (discussed in Chapter 7).

### Using constructivist inquiry

Working in the field of evaluation research in education, Guba and Lincoln (1989) proposed the constructivist paradigm in their book "*Fourth Generation Evaluation*" which developed ideas from their previous work (Guba & Lincoln, 1981; Lincoln & Guba, 1985). Although Guba and Lincoln's focus was on the area of evaluation, they presented the constructivist paradigm and methodology of constructivist inquiry as a development of "Naturalistic Inquiry" (Lincoln & Guba, 1985) which is about inquiry for any reason in the natural setting.

Exploring the process of using and adapting this research approach, informed by a range of readings from areas including feminism, postmodernism, nursing research and bereavement research, was not my original focus of attention. However, it has become an important part of my doctoral study, which is why it is part of the stories of this research.

Particular areas of interest that emerged during this study included family research, ethical considerations and establishing, or not, the quality of the research. The initial focus of the study of grandparent bereavement was research **about** the family, since grandparents are members of families. The participation of multiple members of the same family, such as maternal and paternal grandparents and the parents of the grandchild, opened the door to

another aspect of research **with** families which included conjoint interviews, issues of confidentiality and the effect of research within the family (see Chapters 4 and 5).

Ethics became a focus within this constructivist inquiry because bereavement research is often perceived as either likely to cause harm to participants or difficult to manage in terms of ethical requirements to make the research "safe" for participants (Cook, 1995; Parkes, 1995). In Chapter 5, I explore some of the emerging dilemmas and the decisions, which contribute to the debate about whether bereaved people should be protected from taking part in research, and whether such research has therapeutic outcomes for participants. The decisions about ethical issues have been guided by the two roles I held in this research as both nurse and researcher. These roles guided the positioning of research relationships as a balance between the "human instrument" (Guba & Lincoln, 1989, p. 175) and the imperative for the research which came out of my nursing practice.

Finally, the ongoing debate, which opens in Chapter 3 and threads through the whole thesis, is about how do you, or I, know if this is both a "good" piece of research and a "good" piece of writing? This debate centres on the potential (in)congruency of a relativist ontology with the concept of criteria as stable entities with a fixed constructed reality. This outline of the thesis content, provides clues as to the positioning of the research and the beliefs which underpin it. The section that follows provides some further detail.

## **THE PREMISES WHICH UNDERPIN THE STUDY**

To explain how this thesis is put together and how the research developed I have outlined the key beliefs which I have held during the research and writing. This is part of the introduction because it frames the way in which the rest of the thesis is written and structured. I am not claiming that this the "right" or "only" way to do research but I am asking you to use these beliefs as the "lens" through which the study is viewed. If I use the metaphor of gardening, which has been the other parallel activity in my life, then these beliefs are like the climate and soil type which determine how and what we grow. Hence the beliefs

underpinning the research determine the decisions that I made during the research and during the writing of this thesis. The key beliefs I have held are that constructions are created realities, relationships are central to this research, stories offer a means to explore and re-present constructions, and bereavement is a "normal" part of life. The first three beliefs are discussed in detail in Chapter 3 and the effect of these beliefs on processes and practices is discussed in Chapter 4. The belief that bereavement is part of life is explored further in Chapter 5 in relation to distress occurring during the research.

### **Constructions as created realities**

This research rests on a central belief that we, as individuals, interpret and make sense of situations, events, ideas and objects that occur in our social worlds. In doing this we create for ourselves a reality which is a construction of the situation, event, idea or object. By way of example, the stories in Part 2 show that the same event of having a grandchild die unexpectedly led to different experiences and meanings for different grandparents who hold different constructions of the reality of grandparent bereavement. As Guba and Lincoln (1989) wrote,

*constructions are, quite literally created realities ... which are created by the interaction of a constructor with information, contexts, settings, situations ... using a process that is rooted in the previous experience, belief systems, values, fears, prejudices, hopes, disappointments, and achievements of the constructor. (p. 143)*

Believing that multiple constructions of reality exist has a number of consequences. First, if multiple constructions exist, then there is not one objective truth of grandparent bereavement to be "discovered". If realities are created then every individual's construction(s) is meaningful and no one person's construction is more "valid" than another. That is not to say we all, necessarily, hold totally different constructions of something such as grandparent bereavement. We hold shared definitions in our constructions of many realities. Hence, in the joint construction all participants supported the shared definition that death of a grandchild is followed by "pain". However, where, how, and with whom grandparents share that pain varies considerably according to how individuals construct their bereavement.

Second, because constructions are embedded within things such as the constructor's particular beliefs and values then constructions need to be considered in relation to the context from which they come. This becomes clearer by looking at how grandparent bereavement is constructed. Jenny's first grandchild, Jordan, was stillborn. Jenny struggled with whether his death meant she was no longer a grandmother. In contrast, Ruby was Marie's twelfth grandchild and her construction of grandparent bereavement did not include questioning the legitimacy of her role as a grandmother. This is the reason the stories in Part 2 are central to the research, in order to share some of the "context" from which the joint construction has developed. Just as constructions are embedded in their context so they are time-bound, in that our constructions of reality can change. Generally, constructions are stable but they do change with new information or re-interpretations of the reality on which the construction is based. A point that Colston, a grandmother in the UK, made when she explained that taking part in this research meant re-viewing, and re-constructing events from the position of "now", "all the words and thoughts, some dredged up from the past and reflected on in the light of life as it is now" Colston 9(4). Given the time-bound nature of constructions I would note that the stories in Part 2 reflect the constructions of participants between 1996 and 1998, and this thesis represents a construction of the research written in 1999.

### **Relationships and storying**

The other key beliefs which blend with the ideas about constructions are the importance of relationships and storying which contribute to positioning this research. I believe relationships are the centre of this research, and this text. The relationships I held in the research were with the participants. I also believe that through this text I have a distanced relationship with you, the reader, of the thesis. Relationships are about how I (Self) view, treat and "am" with (Other) people. The importance of the relationship between participants and myself is that it is the context in which this research is constructed. As I explain in Chapter 3, I believe this research is grounded on relationships of respect and partnership. This means respect for individuals by recognising and valuing that we can all construct reality to some extent differently. In the case of participants, this meant that I respected the gift they chose to share in this research, which



had a number of ethical consequences (see Chapter 5). I used ideas of partnership within the research relationship to make this research a joint endeavour between the 27 of us. This thesis is an outcome of that work and it is through this text that we have a relationship with you, the reader, as you read and re-construct the ideas that we have presented.

Within the context of relationships I believe stories are an important way of sharing, discussing and knowing about the world. By telling stories to ourselves and to others, we create constructions of the world and we re-interpret and re-construct events in stories (e.g., Churchill & Churchill, 1982; Frank, 1995; Polkinghorne, 1988). Stories can re-present constructions in, what Tina Koch (1998) called, a “research product” (p. 1182). Hence stories are not just a way to re-present participants’ constructions but also to explore my constructions of this research, which is why I have structured this thesis in three parts, as three groupings of stories.

### **Bereavement as normal**

As constructions about the nature of research exploring grandparent bereavement can vary, I need to make explicit my construction of bereavement research. I believe that bereavement is a normal, not abnormal, part of life. This differs from the perspective taken by some clinicians and researchers who have explored bereavement by working from clients’ abnormal grief in order to describe normal grief (discussed further in Chapter 2). Accepting bereavement as normal means I accept that it brings pain and distress. I have worked with participants in this research to acknowledge the pain expressed in people’s stories, and have not tried to avoid or suppress it. However, viewing bereavement as normal does not mean that I have dismissed my responsibilities to participants who were extremely distressed, at times, during the research. As I discuss in Chapter 5, one of the issues I had to distinguish between was distress **caused by**, versus **pre-existing** distress expressed during, the research. In viewing bereavement as normal, I have sought to avoid the “homogenization of grief” (Leon, 1992, p. 366) where there is a firm sense of how grief/bereavement “should be” within normal parameters. Instead, I worked with participants to explore how they constructed grandparent bereavement which,

as I discuss in Chapter 7, does not entirely fit with models of bereavement or grief where there is an endpoint of detachment from the relationship with the deceased.

In the context of justifying the value of undertaking bereavement research, which enters the painful and private areas of people's lives, I believe in research for use and practice. Marja-Liisa Swantz, cited by Peter Reason (1996), said,

*I do not separate my scientific inquiry from my life and that for me it is really a quest for life and to understand life and to create what I call living knowledge and it is knowledge which is valid for the people with whom I work and for myself. (p. 16)*

This statement sums up how I feel about this research and thesis. This research has been grounded in my nursing practice and as a nurse-researcher it has been important to me that this research can make a difference by being of use to participants, to future bereaved grandparents, to health professionals and researchers, and to my own life and practice. This is the reason that the participants and I wish to publish the stories in Part 2. It would create a resource that currently does not exist for grandparents (discussed further in Chapters 5).

## **THE BELIEFS UNDERPINNING MY WRITING OF THIS THESIS**

My beliefs in constructions of reality, respectful relationships and the importance of stories in this research, influence the writing style, sequence and structure of this thesis. I have discussed these in three overlapping areas of voices, audiences, and constructions of this research. These areas form part of the "crises of legitimation and representation" (Lincoln & Denzin, 1994, p. 576), which are discussed further in Chapter 3. The crises relate to two questions: *"What claim can this research make to 'know' about grandparent bereavement?"* and *"What is the position of Other (participants) in both the research and this text?"* So, what do the beliefs I hold mean for the presentation of this thesis as text?

I believe the choices I have made about writing a text which seeks to be congruent with the beliefs outlined earlier, are best described by Lincoln and



Denzin's paraphrase of,

Thomas Berry who has noted that we are *between stories*. The Old Story will no longer do, and we know it is inadequate. But the New Story is not yet in place. And so we look for pieces of the Story, the ways of telling it, and the elements that will make it whole, but it hasn't come to us yet. (p. 583-4)

This text is my struggle to step outside the "Old Story" which, in my previous writings, has been an objective, distanced discourse designed to enhance the claims of the research to be unbiased and valid. This thesis is another way of storying, perhaps even a part of the "New Story" struggling to represent both participants and myself in its creation.

### **The voices**

The role of voice in a textual re-presentation of multiple realities is one of the many postmodern debates (e.g., Lincoln, 1997; Richardson, 1994; Tierney, 1997). Part of sustaining relationships which are respectful and regardful is about acknowledging and differentiating the different voices, in order to avoid the researcher taking a dominant voice which speaks "for" participants (Fine, 1994). This is, in part, reflected in language (Reinharz, 1992). So, I have used words which have a meaning which I feel represents the relationship and the research. Therefore, I have used "participants", "people", "grandparents" and not used the terms such as "subject". It is also about making the thesis multivocal (Lincoln, 1997) so that the reader can hear the different voices in this research.

Participants have three voices. They have individual voices in their stories in Part 2, which are represented using this font. I recognise that 26 fonts would be congruent with 26 different voices, but for ease of editing I have used one. Participants also have a voice as a group, in the joint construction (see Chapter 6), which is different to their individual constructions and represented by using this font. Individual participants also have voices in the form of short quotations that are excerpts from their letters and interviews. These quotes do not have the context that their stories have, so they are distinguished in this font.

There is also my voice, changing over time. I have claimed my place in the thesis by writing in the first person rather than the distanced third person style which can imply an objectivity or objectification (Berkenkotter, 1993; Webb,

1992) that does not exist in this research. I have been an active part of participants' development of constructions, the interpretation of categories and the movement towards a consensual construction (Guba & Lincoln, 1989). I am also aware that "I" have different voices which I can convey when I speak. These are much more difficult to make clear on paper, hence I have used different fonts. As part of a conversational approach (see further discussion p.14) I have used three fonts for my voice. This font being the main text story of the research written in 1999 and *another font for writings from the earlier years such as the research proposal and excerpts from transcripts*. There is also the voice, from the Welcome section of this chapter, which reflects a shift in position to one that is more personal. This represents what Yvonna Lincoln (1997) called, "choosing identity" (p. 41). By using different fonts, I am seeking to make shifts in voice explicit, in the way I could in a face-to-face conversation by intonation or facial gestures.

There are also the voices of other researchers. Whilst the relationship is a distanced one, of reading, critiquing and interpreting other writers' work, it is a very important relationship. This research is framed by the writings of others, hence I have chosen to *differentiate their quotations and texts from the main text by using this font*. I also believe names are a very important part of even such a distanced relationship. I can still recall feeling, at the age of 8 years, that I lost part of my identity when a form teacher called me by my surname only. So, the first time I have referred to people in the main text, as opposed to in parentheses, I have used their full names and subsequently their second names only in the interests of document length. Finally, I am aware that over the months I have become familiar with the use of fonts as a means to visually recognise different voices. In order to assist readers of this thesis to differentiate the fonts to the context of the different voices I have included a bookmark<sup>4</sup> with examples of the fonts. It is placed on the inside front cover of this thesis.

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<sup>4</sup> Acknowledgement to Alison Dixon for this idea.

## Who is the audience?

I have placed an emphasis on the research being for “living knowledge” (see p. 11), so, when writing this thesis, I have borne in mind the different audiences of readers. I am aware that the reader may be a participant in this research; or a member of the self-help groups for bereaved families; or a health professional who wants to read the whole study to inform practice; or a member of the academic community who wants to explore the content, process and outcomes of the study. The need to be clear about the audience for whom the work is being written is commented on by various researchers (e.g., Lincoln, 1997; Richardson, 1990, 1994). My decision to use stories and conversation as structure and style seeks to make different aspects of this thesis accessible and interesting to different audiences. I accept that one piece of writing is not going to completely suit four diverse audiences. However, I hope that it can be read in different ways; as a story of a research journey and as a discussion of the wider issues involved in constructivist inquiry researching grandparent bereavement. By emphasising the role of stories I hope it will enable the reader of this text “to be drawn into a story to find a place or way of seeing through participating in the story” (Clandinin & Connelly 1991, p. 277). The structure of the thesis follows a conversational style to avoid the sense of distanced academic discourse (Ellis, 1997, p. 115). It means that I have consciously used words like “so,” as a tool for the unfolding of stories, and I have used questions as part of the text to reflect the way in which questions form part of conversations. Similarly, in the participants’ stories we have used sufficient punctuation to aid meaning, whilst trying to retain the flow of a story shared in conversation.

## Constructions of this research

This thesis is written as a current construction of the research, which was completed in December 1999. As I wrote this thesis I was aware that I could have written it solely constructed from the position of where I sit today with the hindsight and knowledge that I did not have at the beginning of the research. In so doing, I could make it a smoothed narrative where the research appears sequential and straightforward. However, to be “honest” to the research as it has happened, and to explore some of the uncertainties (Lincoln, 1997; Tierney 1997), I want to share with some of the decisions and dilemmas (Punch, 1994)

and the changes in my thinking which are the context of this research. I have constructed the text, in Part 1, as a reflexive account of the research. In doing this I am not seeking to present a self confessional tale of the field (van Maanen, 1988) nor to engage in "methodolatry" as Valerie Janesick (1994, p. 215) called the idolatry of methods where they become ends in themselves. I also fully appreciate that most of Part 1 is written from the position of 1999. However, I have included critical reflections, constructed from my ongoing research journals and excerpts of the research proposal, to show how the construction of this research has shifted in several areas. The decision to uncover the changing research journey means that I have not included a "full" literature review chapter, because that is not what I did. I first reviewed the literature at the beginning of the study, for the purposes of supporting the research proposal in order to ground the research ideas within a review of what was, at that time, known of grandparent bereavement (see Chapter 2). I reviewed the literature again towards the end of the research in order to position the outcomes and insights from this research with respect to published literature and other material (see Chapter 7). My focus was different at each time, so that is how I have presented the material. I also started with the intent to use collective case study (Stake, 1995) but made a shift to constructivist inquiry at the time I met the first participant. Constructivist inquiry uses case study to facilitate the development of a joint construction, instead of developing three separate constructions from the three participant groups as I had originally planned (see Chapter 3).

Believing that constructions can change over time means that this text is a construction that participants and I have put out for public view at the end of 1999. Our constructions may have changed by the time this thesis is read, and there is no way of knowing if we have changed some of our ideas. Equally, a reader's construction of grandparent bereavement from this text may change on re-reading parts or with the addition of new ideas. Therefore, I believe it is important to note that whilst the text is fixed, the constructions created from the text are not. To reflect this I have chosen to refer to the work of other authors in the past tense because I am conscious that authors' thinking shifts over time. Hence, I have written "Yvonna Lincoln (1997) suggested....." because I do not

want to claim that this is what “Yvonna Lincoln (1997) suggests ...” when it may no longer be the view which Yvonna Lincoln holds.

Finally, given the belief in the existence of multiple constructions of reality, I have presented the underpinning definitions used in this thesis in the next section. I have also presented the context in which I have used notations to re-present and reference texts relating to the research (see Figure 1.1).

**Figure 1.1<sup>5</sup>: Thesis text notations<sup>6</sup>**

[pause]	-	pause in conversation or letter
...	-	text omitted to facilitate meaning
[ ]	-	additional language added to facilitate meaning
Colston 2:1	-	reference to interview or letter, in this case Colston's second letter, page one
Alex & Benita	-	the use of "&" indicates conjoint interviews
(see p.322)	-	see page 322 of this thesis for relevant information <sup>7</sup>

## Definitions

In everyday conversation we often use the words “bereavement”, “grief” and “mourning” interchangeably and intermingled. Even within the professional literature concepts, such as grief, are ambiguous (Cowles & Rodgers, 1991;

<sup>5</sup> Acknowledgement to Alison Dixon for the format of Figure 1.1.

<sup>6</sup> In preparing the notation and style of this thesis, such as the use of numbers in text, I have used the conventions of the Publication Manual of the American Psychological Association (1994).

<sup>7</sup> I have used extensive cross referencing in this document to facilitate discussion and to evidence multiple constructions of reality.

Jacob, 1993). The definitions from the New Oxford Dictionary of English (1998) provide a distinction that is widely accepted in society.

- ◆ Bereavement is the situation where someone has had someone or something taken away. To be bereaved means “*to be deprived of*” (p. 164).
- ◆ Grief is the emotional response to bereavement which may take different forms, defined as “*deep or intense sorrow*” (p. 807).
- ◆ Mourning is the way in which the grief is demonstrated, hence it is socially and culturally determined (Kastenbaum, 1991). As a verb “*to mourn*” it means “*to feel or show deep sorrow or regret ... typically by following conventions such as the wearing of black clothes*” (p. 1208).

However, J. William Worden (1991) distinguished between affective, cognitive, behavioural and physical expressions of grief. The cognitive aspects of grief and bereavement have increasingly been emphasised by clinicians and researchers to explore how bereaved people make sense of their experience (e.g., Braun & Berg, 1994; Riches & Dawson, 1996a, 1996b, 1998; Walter, 1996). Instead of entering the complexity of distinctions between the conceptualisations of professionals and researchers, I have worked with how participants constructed their experiences. This means I have mainly used the term “grandparent bereavement” which participants accepted as being the situation of “When a grandchild dies”. In this respect Alice Sterner Demi & Margaret Shandor Miles (1986) proposed a definition of bereavement which is pertinent to this research. They suggested that bereavement is “*the state of having experienced the death of a significant other*” (p. 105), where I believe “state” can reflect physical, emotional, cognitive and behavioural aspects of experiencing the death, and in this sense it subsumes mourning and grief. I have also written about “grief” because some participants included this in their construction, and others did not. I have rarely used “mourning”, except in relation to other writings, because this was not part of the constructions. The title of the thesis reflects the focus of the people in this research on the event of “When a grandchild dies”, as opposed to describing it as “grandparent’s grief”.

Similar to thanatological definitions, there are extensive debates around the term “family”. These reflect changing family structures (Cheal, 1991), different



theoretical perspectives (e.g., Boss, Doherty, LaRossa, Schumm & Steinmetz, 1993) and the questioning of discourses surrounding the construction of family (Hartrick, 1998). I have used "family" in this thesis as a self-defined group of people. This is the way in which participants constructed it in Chapter 6 and is congruent with Lorraine Wright and Maureen Leahey's (1994) view of family.

As a final comment on definitions I note that, when writing this thesis, I decided to use the term "health/bereavement professionals" as opposed to "health and bereavement professionals". I made this decision because I read the "and" as distinguishing "health" and "bereavement" into two separate groups of professionals. Whilst this was how participants joined the study with Barry and Jane coming from child health services and Diane coming as a bereavement support co-ordinator. However, from the discussions of their practice it became apparent that all three focus on the overlapping aspects of health and bereavement, by working with bereaved families to promote their potential for health in a situation of bereavement. Therefore, I decided to use the forward slash in "health/bereavement" to illustrate the two interrelated aspects of practice with bereaved families.

## GENERAL INTRODUCTIONS

Having set the scene of the research, which culminated in this thesis I want to now introduce the people who made this study possible. These introductions are written from the position of mid-1998, whilst finalising everyone's stories. Any further information which people have wanted to share since this time is included in the postscript section of Chapter 8. The following introductions are put forward by participants, as an introduction to you, the reader, as though in the social context of first meeting someone. The introductory paragraphs answer a few of the locating questions that we often ask in conversation, such as "Where do you live? Do you have family? Do you work? Any particular interests?" And, as age is something that can be assessed on a face-to-face meeting, this is also included in the text introduction. This information provides a first impression, but not a full picture of the people. When reading the introductions please remember the participants are not all grandparents. There are grandparents, parents and health/bereavement professionals and, as with all introductions, some

participants provide more explicit details than others. The sequence of introductions follows that of the stories in Part 2, which are organised into family groups according to the age at which the grandchild died.

**Jenny.** I was born in 1946 and live in a small town in England. I have two children, Andrew and Sue, both of whom are married. My first husband, Bob, died in December 1987 and I have remarried, Tony has three sons and seven grandchildren. My first born grandchild, Sue and Chas' son, *Jordan*, was unexpectedly stillborn in 1995. In 1996 Sue and Chas were approved to adopt a child and, in January 1998, Lee came to live with them with a view to being adopted [he was adopted on February 4<sup>th</sup> 1999]. I enjoy time with all the family and am busy with my seven step-grandchildren. I am also involved in the local church and voluntary work at the local hospital.

**Colston.** I was born in 1930 in England. I trained as a nurse, and married John, an engineer. We live in a small town in England where I am actively involved as a lay minister at the local church. We have three children: Neville, Christine and David. David was born slightly premature and died a few days later. In 1992 Christine and Kenneth's third son, *Christopher*, was unexpectedly stillborn. Despite rheumatoid arthritis I keep very busy spending time with our two grandchildren who live nearby. I have extensive pastoral responsibilities and enjoy travelling abroad, when we have the time.

**Terese.** I was born in 1935 in New Zealand. I now live in one of the main cities in New Zealand. I married Ross and we had three children; Tina, Donna and Ray. Donna's first child, *Bernadette*, was our third grandchild and third granddaughter. Bernadette was stillborn on my birthday in 1982. Subsequently Donna had three more children who are growing up fast. I have always spent a lot of time with my family and our five grandchildren and increasingly so after the death of my husband several years ago. I am a keen tramper and go on various walks in



different parts of the country. I also have interests in floral art, patchwork and like working in the garden.

**Elisabeth.** I was born in Scotland in 1934 and now live in a town in Scotland. I trained as a nurse and married Robin, a GP. We have three children: Robbie, Lorna and Cathy. In 1994, Lorna and Geoff's first baby, *Martin*, was born prematurely and died an hour later. Lorna and Geoff have since had two more children, Eilidh and Madeline, who are full of energy. I enjoy visiting our granddaughters and watching them grow up. I am interested in art and I travel to see various exhibitions, as well as helping as a volunteer to catalogue the library contents of country houses.

**Pip and Donald.** We were born in the 1960s in New Zealand, both growing up on farms and we now manage our own farm in the high country of the South Island. Pip trained as nurse and works as a Plunket nurse in the local area. We have four children; Lachie, Jessie, *Gracie* and Megan. *Gracie* was born on Jessie's birthday, in 1995, and died shortly afterwards. Megan was born 18 months later and is now "into everything". We both have very busy lives on the farm and in the local community, particularly keeping up with all the children's activities.

**Betty.** I am *Gracie's* paternal grandmother. I grew up during the Depression in New Zealand and worked as a School Dental nurse in the 1950's. I then married, moving to a high country farm, where we had four children; Donald, Catherine, Rob and Colin. My husband died whilst the children were still young and I managed the farm until Donald took over. Then I moved to one of the main cities in New Zealand. Whilst I was living there *Gracie*, who was my seventh grandchild and third granddaughter, died. I see my family and eight grandchildren regularly and keep the family in knitting. I am busy with the local church, spinning, Red Cross work, Garden club and tapestry. I also enjoy gardening and travel overseas.

**Diana & Rupert.** We are *Gracie's* maternal grandparents. We were born in the 1930s. **Diana** trained as nurse in the city, **Rupert** worked on the family farm. After our marriage **Rupert** farmed in partnership with his father and now farms with his son, **Paul**, and his wife, **Bridget**. We have three children; **Paul**, **Joanne** and **Pip** (**Philippa**) and ten grandchildren. **Gracie** was our ninth grandchild and fifth granddaughter. As the families all live within a 60km radius of us, we are busy with opportunities which the family and farm present. Overseas travel is something we also enjoy.

**Sarah & Frazer.** We were both born in 1960 in Dunedin, and at present we live there with our family. **Frazer** is a lawyer and **Sarah** worked as a nurse before the births of our four children: **Rochelle**, **Rose**, **Matthew** and **Jessica**. **Matthew**<sup>8</sup> was born in 1992 and died, at the age of 3 days, from a hypoplastic left heart. We, and our children, are involved in many activities at school, church and in our local community. We enjoy the opportunity to spend time out of Dunedin, at our holiday home at Naseby. The Dunedin Baby Bereavement Group was started in November 1994 and **Sarah** is actively involved in it.

**Margaret & Keith.** We are *Matthew's* maternal grandparents. We grew up in the 1930s in New Zealand and after marrying eventually moved to our own farm outside Balclutha. We have four children; **John**, **Alastair**, **Sarah** and **David**, and 12 grandchildren. **Matthew**, was our tenth grandchild and fourth grandson. He died on the day that **Granny Rose**, **Keith's** mother, was buried. We retired from the farm several years after **Matthew's** death and continue to help out our sons who both have farms. We are involved in the local community, **Margaret** enjoys golf and we both spend time with our families.

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<sup>8</sup> In this research there are participants from two families where a son/grandson **Matthew** died. In the interests of confidentiality I have not distinguished each **Matthew** with the initial of a surname. Instead, I believe the stories of the two families are distinct and separate.

**Alex & Benita.** We are *Matthew's* paternal grandparents. We were born in the 1930s in New Zealand and now live in Dunedin. **Alex** has been a hospital chaplain for many years and is now a part-time minister. **Benita** works as a nurse in the local hospital. We are both very involved in the local community and parish. We have 3 children: Frazer, Peter and Andrew. We spend a lot of time with our grandchildren, Frazer and Sarah's children, and we helped to care for *Matthew* at home before he died.

**Rose.** I am 43 years young. I was born and now live, again, in Dunedin. I married John and worked at Smith & Smiths until the birth of our first child. We have four children: Amber, Emma, *Ruby* and Nathan. Ruby was born in 1993 and died, aged 9 days, because of a rare congenital abnormality with her heart and lungs which could not be treated. I am involved in the local community and church and am studying part time to be a social worker of the future.

**Marie.** I am *Ruby's* maternal grandmother. I was born in 1920 in the North Island and worked until retirement as a kindergarten teacher. During my married life with Colin, we lived in Dunedin. We have five children, fifteen grandchildren and one great grandson. *Ruby* was the third child of our daughter Rosemary [also called Rose], and our twelfth grandchild. When Ruby was born we saw her only briefly before she was transferred to Auckland for treatment and she died there 8 days later. I spend time with our family, am a keen reader and am involved in doing a range of crafts.

**Ailsa.** I was born in 1936 and have lived all my life in Dunedin. I worked with my husband, Harold, in our own business for 6 years, and then with New Zealand Post for 18 years. I have three children; Stuart, Vikki and Laurie; and nine grandchildren. My eighth grandchild, **Conor**, Laurie and Suzanne's third child, died in 1995 as a cot death. My husband had died after a long illness not long before Conor's birth. I spend most of my time with my children and grandchildren,

including Jonathon who was born after Conor, or doing knitting and sewing for the family.

**Elwyn.** I am Daniel's paternal grandmother. I was born in the 1930's, in Balclutha, and currently live there. I married Lindsay, and we had five children; Ellen, Lillian, Blair, Grant and Leslie. We had a small farm outside Balclutha which Elwyn continued to run after Lindsay's death and whilst the children were growing up. I moved from the farm to run my own coffee-shop business, in partnership with my daughter and son-in-law, until I retired in 1998. I have nine grandchildren. My second grandson, *Daniel*, who is Leslie and Rosanna's son, was born prematurely at 24 weeks. He was cared for in Neonatal Intensive care until he was 7 months. Plans were being made for him to go home when, the week before, he became ill and unexpectedly died. I spend time with my family, do a wide range of handicraft work and am a keen gardener.

**Beth.** I am *Daniel's* maternal grandmother. I was born in the 1940s in New Zealand. We have five children; Desmond, James, John, Lynne and Rosanna; and nine grandchildren living throughout New Zealand. My daughter, Rosanna's, second child, *Daniel*, was my second grandson. He survived many setbacks and breathing problems before his death in 1993. I work part-time, spend time with my family and enjoy creative work and nature.

**Maxine.** I was born in the 1960s in New Zealand. I have a daughter, Sharmane, from my first marriage. I remarried, Steve, and we have two children *Matthew* and Andrew. *Matthew*, died unexpectedly, at 9 months, of cot death. In addition to caring for our family I work as a carer and run a business with Steve.

**Rachel.** I was born in the 1960s in New Zealand. Keith and I have been married for 10 years and have four children Alyce, *Samuel*, Hayley and Dayna. *Samuel* was born in 1990 and died, at the age of 9 months, of cot death. I juggle family life and studying for a midwifery degree which I plan to finish in 1999.

**Catherine.** I am *Samuel's* maternal grandmother. I was born in the 1940s and grew up in the North Island. I have four children; Derek, David, Yvonne and Rachel, and 11 grandchildren. *Samuel*, who was the second child of Rachel and Keith, died suddenly in 1991. I work as a counsellor, spend time with my family and am a keen gardener. Paul, my partner, and I have just built a house.

**Diane.** I am a bereavement support co-ordinator employed as part of funeral director services. I follow up families who have made contact for funeral services, and help bereaved families find support from health professionals and within the community. I am also involved in running support groups.

**Barry.** I work as a paediatrician, in New Zealand. I have a particular interest in SIDS research and offer follow-up to families who have had babies die of cot death. I also work in Neonatal Intensive Care and am involved with families who have babies die in the unit or at home.

**Jane.** I work as a Clinical Nurse Specialist in paediatrics and am involved with families who have children with acute and life threatening illnesses both in the ward and at home. My particular area of work includes families of children who have cancer.

**Alison.** I was born 38 years ago in London. I worked in the UK, in the 1980s, as a nurse, midwife and health visitor. For several years I was involved in cot death research, and with bereaved families who had had a baby die. I came to New Zealand for a 6 month research sabbatical and stayed when I met John. My parents moved to New Zealand, and now share the 6 acre garden on which we built a house. I have been a nursing/midwifery lecturer for the last 7 years. I have kept my clinical practice with bereaved families which has included establishing, with the neonatal unit social worker, the Dunedin Baby Bereavement Group.

## CONCLUSION

This chapter has set the scene for the next three parts of the thesis by providing an overview of the direction and content of the thesis. I have identified the contribution this work makes as an exploration of the content area of grandparent bereavement and the use of constructivist inquiry as a theoretical framework for this piece of research. By outlining the key beliefs that underpin this research I have explained the reasons behind the decisions to present the thesis in this form and style. In particular, positioning the participants' stories at the heart of the thesis where they re-present the voices, which were developed through the research relationship. The subsequent three parts of the thesis focus on the different aspects of the research in detail. Part 1 is the story of this research as the context from which the participants' stories (Part 2) and the joint construction (Part 3) developed. The next chapter opens the story of the research by exploring the beginnings of the research.

## **PART 1**

# **THE RESEARCH STORY**



## CHAPTER 2

### A STORY OF THE BEGINNING

#### ARE YOU SITTING COMFORTABLY?

As a pre-school child "Listen with Mother" at 1:30pm on Radio Four was an event in my life every week day for several years. It always started with the reader saying "Are you sitting comfortably?" Then a pause for the listener to say "yes" and the reader went on "Then I'll begin ...". So, I will begin the story of where this research started in 1995. The story explores from where the imperative for this research came, why I believed it was research which was justified in being undertaken and where it fitted with existing clinical and research literature. It ends with the aim, and objectives of the research which are framed from the previous discussion.

#### WHY A STUDY OF GRANDPARENT BEREAVEMENT?

When people ask me what my area of research is, the reply, "grandparent bereavement" is generally followed by a pause in the conversation, as people work out what the phrase means. This involves identifying who is dead and who is bereaved. Then, they often comment along the lines of, "That's interesting, but isn't it unusual? I've never thought of that before". So, why don't we think about grandparent bereavement? The first part of the story traces the impact, extent, and context of grandparent bereavement in NZ, and then turns to look at how the research was generated by my nursing practice.

#### **The impact of grandparent bereavement**

When I wrote the research proposal, which went to regional health authority ethics committees in December 1995, I opened it with a quotation from a participant in one of the three published American studies of grandparent bereavement (Ponzetti & Johnson, 1991). I wanted to help the members of the regional health authority ethics committees<sup>1</sup> to realise just how devastating the death of a grandchild can be. It serves as a reminder of where this study began.

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<sup>1</sup> Details of this process of ethical approval in Chapters 4 & 5.

I truly believe there can be nothing more sorrowful in our lives. My agony is for my son and his wife; the terrible emptiness for them. I would do anything to make it easier for them. I am never quite sure which makes me more desolate, the child's death or her parents' sorrow. (p. 164)

It is poignant to hear this grandmother's view of her grand-daughter's death; yet it is not a situation of extreme grief. The quotation has been mirrored in the stories of all the grandparents in this study. Given the tremendous pain caused by having a grandchild die I am continually reminded how little thought we, as health professionals and as communities, have given that pain. It was 1975 when Gyulay, a nurse, wrote the article entitled "Forgotten Griefers", which has been widely cited in a wide range of subsequent articles and books. It was 10 years later when Richard Kalish (1987) noted that, despite extensive literature at that time on dying children, there was little mention of bereaved grandparents or great-grandparents. It was 4 years later when Ponzetti and Johnson (1991) re-used the term "Forgotten Griefers" in the title of their research article. It is now 7 years after their work and are we any more aware of grandparent bereavement? Aside from the three American studies (DeFrain et al., 1991-92; Ponzetti & Johnson, 1991; Ponzetti, 1992), from the early 1990s, there has been only one further published study of grandparent bereavement (Fry, 1997). Is this, perhaps, because being a bereaved grandparent is "rare"?

### **The extent of grandparent bereavement**

Our awareness of the number of people who are grandparents and who have been touched by the death of a grandchild is like the tip of an iceberg because, as health professionals and as a society, our contact is primarily with parents of the child. Part of the justification for undertaking this research study was the high infant mortality rate<sup>2</sup> in New Zealand.

*Research into grandparent bereavement is of particular importance in the New Zealand setting given the high rate of infant mortality, predominantly due to cot deaths in the 1980s and 1990s. This means that there are few families without some experience of child death amongst close or extended family members. Figures from the New Zealand Cot Death Study illustrate the extent to which family and grandparent bereavement has occurred recently. Within the three year duration<sup>3</sup> of the study which, was nationwide covering 78% of all livebirths, there were 485 babies who died as SIDS (Mitchell et al., 1992). Allowing for*

<sup>2</sup> Deaths of infants aged 1-365 days per 1000 live births.

<sup>3</sup> The 3 years of the study spanned 1 November 1987 to 31 October 1990.

*three living grandparents in NZ<sup>4</sup>, it means a potential 1455 bereaved grandparents in a three year period, without considering other causes of infant death such as accident, infection or congenital abnormality. This indicates a wealth of family bereavement in a country with a population of only 3.5 million people. (Research proposal, 1995, p. 5)*

When I wrote the proposal the 1995 statistics for fetal and infant deaths had not been released; they were published in 1998. With the uptake of the cot death risk reduction message in the early 1990s there was a fall in the NZ infant mortality rate in 1995 to 6.7 per 1000 live births, which was the lowest ever recorded. There were 388 infant deaths in 1995 (New Zealand Health Information Service, 1998) which means in that year alone there were over 1000 bereaved grandparents, if we assume three grandparents per infant were alive. If stillbirths are added to this, then the estimated number of bereaved grandparents almost doubles. Using the 1995 statistics based on the definition of stillbirth as greater than 28 weeks gestation<sup>5</sup> (defined as late fetal deaths) combined with infant deaths, then 607 NZ babies died. This illustrates that the number of bereaved grandparents who may be bereaved is much larger than is, perhaps, appreciated. The other point that I did not identify in the proposal is that many families experience multiple reproductive losses,<sup>6</sup> such as, grandparents whose daughter has a miscarriage and whose son has a baby die are twice bereaved. In addition, the changing population structure, based on the 1996 NZ Census, anticipates a rapid growth in number of people older than 45 years in the next 20 years (Statistics NZ, 1999). This means that more people will live to become grandparents. Increased life expectancy combined with smaller families is shifting the population shape from a pyramid to a beanpole where fewer numbers are born in each successive generation, which potentially places more emphasis on between-generation kin (Giarrusso, Silverstein & Bengtson, 1996). This could mean, that whilst fewer grandchildren are being born, over the next 20 years more people will become grandparents, and the loss of one of those "few" grandchildren may have a different meaning to previous decades when more grandchildren were born. This suggests that grandparent bereavement is going to be an issue of continuing importance within our society.

<sup>4</sup> I estimated this to give a picture of "NZ grandparent bereavement" since many families will have one grandparent who has died.

<sup>5</sup> Legislation changed in September 1995, stillbirth became after the 20<sup>th</sup> week of gestation or greater than 400gm in weight. This change in definition is not reflected in the 1995 statistics.

<sup>6</sup> Reproductive loss extends from miscarriage to death of a baby/child.

## The context of grandparent bereavement in this study

In relation to the event of grandparent bereavement there are three points to consider. First, "bereavement" occurs when something or someone is taken away. Hence, bereavement occurs with the death of a grandchild but also with the loss of a dream about the grandchild such as, having an ill or disabled grandchild in place of the anticipated healthy grandchild or having a grandson in place of longed-for granddaughter. Within this study, the focus was on grandparent bereavement which occurred with the death of a grandchild. Second, the mode of death resulting in grandparent bereavement can vary. In particular, the bereavement surrounding a grandchild who has died of leukaemia can be different to the bereavement associated with a stillbirth. The focus of this study has been on unexpected death, as opposed to anticipated deaths, such as child cancer, where families may go through a different experience of knowing that the child is going to die. I wrote in the research proposal (1995),

*The significance of the focus on the "sudden" or unexpected nature of a grandchild's death is that it brings immediate, unanticipated changes in family dynamics and involvement with medical and/or judicial<sup>7</sup> processes and personnel such as police, coroner and pathologist (Wright, 1991). All of which can make the experience for the family particularly complex, bewildering and anger/guilt producing. Hence the importance for professionals working in health and the judiciary to be aware of the family members' experience – in this instance grandparents who are often perceived as the support people for parents. (p. 6)*

Third, grandparent bereavement can occur when a grandchild of any age dies. Clearly the situation where a newborn baby dies and an 18-year-old dies can be very different; one is at the beginning of life and the other is at the beginning of adulthood. I originally focused the study on the event where a young child had died.

*"Young child" refers to babies, infants and children less than 12 years of age. This age limit is taken as an indicator that this is a dependent child in a family, rather than a teenager gaining independence and therefore having different roles and relationships with family members. "Sudden death" refers to death that is not anticipated over a period of weeks or months and therefore was unexpected. Used in conjunction with "young child" it refers to a range of circumstances where a child has been anticipated to be liveborn and therefore been celebrated as part of the family, with the resultant change in roles and then dies suddenly as with cot death, infection or accident. (Research Proposal, 1995, p. 6)*

<sup>7</sup> Occurs because of the NZ Coroner's Act 1988, amended 1996, which requires that sudden deaths, where a doctor has not seen the person in the last 2 weeks for reasons of illness, have to be investigated by the Coroner.

In practice, the grandparents and parents interested in taking part in the research all had a grandchild/child die aged less than one year. This reflects the commitment to the research of the members of the infant death support groups. So, it became a study of "When an infant grandchild dies".

Having outlined my justification for this study based, on the evidence discussed that grandparent bereavement is relatively uncommon and largely unresearched, then the next question becomes, why was I interested in this area of study?

### **Where did the research topic come from?**

As I wrote in the Welcome chapter, the study arose from my nursing practice.

*The impetus to undertake this study has come from the clinical experience which I have had in both the UK and in NZ. In the UK, I practiced as a nurse/midwife, working with a paediatrician in the Avon Infant Mortality Study offering support to approximately 60 families per year who had an infant die suddenly or who were having a subsequent child after a previous child had died. In the course of supporting one family, whose 9 month daughter had died suddenly, I met the maternal grandmother who responded hysterically to the idea that her daughter wanted to see and dress her dead baby. When we talked about why the grandmother felt like this, it became clear that the only dead bodies that she had seen, had been mutilated in the second World War. So, she assumed that her granddaughter would look like this in death. With other families and grandparents different issues arose; previous bereavements (especially where grandparents had had a child die, no place to talk about their feelings, and the expectation of being strong for their children. In the UK we established a support group for grandparents and training for health workers about grandparents' issues. In NZ, concerns for grandparents are voiced by parents in the self-help groups that I support and the families with whom I work. The intention of this study is to explore and establish a research base to an issue that arises in many health professionals' practice. (Research Proposal, 1995, p. 7)*

The proposal was brief, but the content highlights why this is a nursing thesis; from the outset the research was grounded in, and driven from, my nursing practice. The research in this thesis was originally planned for the UK, as a chance to establish a research base to the resources we developed in clinical practice. The study was undertaken in NZ because I unexpectedly moved here to work and then marry. As part of the consultation process I talked with many individuals and self-help groups about ideas relating to the research.

### ➤ **The comments and concerns of self-help groups in focusing the study**

In both the UK and NZ I sought suggestions, over a period of several years, from members of self-help groups about their thoughts on grandparent bereavement. Group members were parents who had had young infants or children die, so they were commenting one step removed from grandparent bereavement as a personal experience. Enthusiasm for the tentative research ideas was universal. Many parents spontaneously contrasted the range of support and resources available to parents with the dearth of material for grandparents. Parents' comments about grandparents' grief varied but had two recurring themes. The first was acknowledgement of the pain, strain and loss which grandparents experienced. The second was a sadness, bordering on frustration, that their parents [the grandparents] did not talk about their feelings and seemed to have either ignored the whole episode, or clammed up as a way of coping (*Research Journal 1, p. 5*).

It was the parents' comments and enthusiasm which made me re-view the idea of including parents in this study of grandparent bereavement which, by definition, occurs within the context of the family. The inclusion of parents in the research offered the opportunity to explore ways in which other family members constructed grandparents' bereavement and whether grandparents were "forgotten" in their grief by family members. Parents' repeated comments about lack of support and resources available for grandparents was mirrored in my own nursing practice. This led me to include health/bereavement professionals as participants, with the aim of exploring their constructions of grandparent bereavement located from their practice.

## **THE CONTEXT OF THE LITERATURE**

So, where did my clinical experience and the issues from self-help groups "fit" with the clinical and research literature? The literature I reviewed at the beginning of the research places my thinking and knowledge at the time I began talking with, or writing to, participants. I returned to explore the sociological, psychological and nursing literature during the study but have not integrated this material into this review, because this review is the context from which the study



started. The additional material is included as part of Chapter 7, which explores where the joint construction fits with existing literature.

I debated whether to undertake a literature review at the beginning of the study. There is a school of thought in qualitative research which believes it should be conducted after the data are analysed, in order to “protect investigators from leading the participants in the direction of what has been previously discovered” (Streubert & Carpenter, 1995, p. 21). However, I undertook a literature review for several reasons. First, I had already reviewed the literature, surrounding infant death, in 1993 when co-authoring a book on working with bereaved families (Stewart & Dent, 1994) so I already had knowledge of some of the current thinking in the field. Second, I wanted to convince the regional health authority ethics committees reviewing the research proposal that there was both a value and a need to complete this research. In particular, I wanted to demonstrate in the research proposal that I was aware of, and could respond to, the range of issues and concerns that can arise in thanatological, qualitative and family research. After completing the literature review, I felt it was too lengthy to go with the standard ethics committee forms. So, I submitted it as an appendix in a summarised form of the full review which follows.

*This review<sup>8</sup> will include literature that is theoretical, research and clinically based. Perspectives explored move from the grandparents' role in the family to the field of bereavement in general, and child death in particular, before considering the limited published material relating to grandparent bereavement.*

## FAMILIES AND GRANDPARENTS

*This section explores the concept of family, the roles grandparents have in families and how these are perceived, in addition to some of the issues related to family research.*

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<sup>8</sup> For ease of reading I have not presented this large excerpt in quotation format of indenting and single spacing.



## Families

*We all belong to families; they are the smallest functioning unit (of two or more people) across culture and time. As a term "family" is widely used in everyday language but, over time, it has gained a wide range of implicit or explicit meanings as to who is a family member (blood kinship or contractual relations); what roles family members have; and what functions the family serves as an economic, emotional or socialising unit (Parsons, 1954; Segal, 1983; Shannon, 1986). Families are the context in which many of the events in life which affect us, both as family members and as individuals, happen. In Western society, since the second world war, emphasis has been placed on the "nuclear" family unit (parents and children only) by legislation, fiscal and health policy. The increasing fluidity in family structure arising from divorce, remarriage, co-habitation meant that since the 1980s the nuclear unit has become more of a typology or ideology than a reality. In particular, this applies to New Zealand where there are different cultural groups who define the kinship networks of "family" as much wider than just parents and children (Shannon, 1986). At the same time there has been increasing interest from sociological researchers on the role of the extended family members; notably grandparents. This seems to have arisen as more people live longer, and are experiencing the role of being a grandparent which means it has become a topical and researchable issue (Barranti, 1985; Hagestad, 1985; Smith, 1991). For the purposes of this research, "grandparent" refers to any person who has a grandparent role or status within the family - whether this is due to biological, marital or adoptive ties.*

### ➤ What are the roles involved in grandparenting?

*Over the decades stereotypical views of grandparenting have included: the worldwide image of the small, silver-haired grandmother of children's books and the media (Hagestad, 1981; Smith, 1991); acting as parent substitutes (Thomas, 1990; Townsend, 1957); and involvement in family relationships and activities (Ruoppila, 1991). The majority of available literature on grandparents is from overseas, in particular from America during the 1980s, with a sociological focus and therefore its relevance to NZ culture needs to be placed in this context.*

*Factors, which can affect the role and relationship of grandparents in the family, include; relationship with grandchild, involvement in childcare, age, employment, and ethnic group (Barranti, 1985; Hurme, 1991; Smith, 1991; Troll, 1985). Several of these points are considered in more detail further on. Joan Robertson (1977) looked at the significance of grandmotherhood in a probability sample of 125 American grandmothers aged 70 years or more. Her results indicated that the role of grandmothers varied according to the individual, and the extent of childcare activities (often sought by parents and child). Eighty per cent of grandmothers enjoyed their role and many felt that it was better than parenting, giving the pleasures without the parental responsibilities. Whilst this research was undertaken nearly 20 years ago, with a sample which is not representative of NZ, it highlights two issues for this study to consider: a) the pleasure which grandmothering brings and therefore the potential loss if the grandchild dies; and b) that the role of the grandparent varies with the individual and the family. Elizabeth Timberlake (1980) conducted a study, similar to that of Robertson, exploring the perceived value of grandchildren to 90 American grandmothers (who varied in geographical proximity and amount of social contact with the child). She found that the grandchild represented positive, abstract conceptions such as "expansion of self beyond their own lifetimes" (p. 67) and that there was considerable variation in both the reasons and extent to which the grandchild was valued. This suggests the individual nature of grandparenting and, therefore, the different meanings the death of a grandchild may have for individuals.*

*Research has sought to take into account the individuality of grandparenting by identifying dimensions, roles and features of grandparenthood. Helen Kivnick (1982a; 1982b) in an American study with qualitative data from 30 grandparents and quantitative data from 286 grandparents (212 women and 74 men), developed five dimensions of grandparenthood meaning; centrality, valued elder, indulgence, immortality, and re-involvement with the past. Although the study was conducted with a motivated group of participants, who were predominantly women from a different social and cultural context to NZ people, the study illustrates the enormous meaning that the role and relationship can have for grandparents and, implicitly, the loss which can occur when a grandchild dies. In an earlier study, B. Neugarten and K. Weinstein (1964) interviewed a sample of 70 American grandparent couples and*

identified five types of grandparenting: formal, fun-seeker, surrogate parent, reservoir of family wisdom, and distant figure. There are similarities between these types and the dimensions identified by Kivnick (1982a) such as "valued elder" and "reservoir of family wisdom". There are also differences that serve to indicate the different derived meanings to grandparenting - a possible substantiation for multiple realities rather than typologies. The corollary of developing typologies from an aggregated sample is that the individual context of each is not considered and this research study wants to include the context of participants with more detail than a demographic variable overview.

### ➤ What are the views of parents about grandparents?

In terms of the family context of research on grandparents the views of parents about grandparents are important since parents are the linking relationship between grandchild and grandparent. Jeanne Thomas (1990) conducted a postal survey in America, with a volunteer sample of mothers with children at day care centres in one city. She found some interesting data to indicate that single mothers focused on grandparent support in childrearing, whereas married mothers (i.e. with partner support) viewed grandparents more as family historians. Both groups agreed that grandparents could create conflict by interfering in childrearing. Interestingly, she proposed that these views could create a "double-bind" (p. 69) in that grandparents try to meet parents' expectations to provide support to parents in different forms but by doing so they might then be perceived as interfering. Double-bind is a concept to consider in this study, given that bereaved grandparents consistently try to provide support to the parents. Entangled within the views and expectations of parents about grandparents is the process by which the family becomes multigenerational as new relationships and roles are established with the birth of a grandchild. Mary-Anne Bright (1992) used grounded theory to explore the intergenerational process which occurred with the birth of the first child in three American families where all the parents and grandparents participated in the 15 month study. The process of making place for the new member of the family involved physical place (such as preparing the baby's room) and social place (such as naming the baby, and the parents and grandparents in their new roles e.g. being called Granny or Grandma). This has implications for this study where grandparents may have been interrupted during this

*process. For example, where a child dies soon after birth, what are the consequences for bereavement where "place" has not been made?*

## **Research with families and grandparents**

*The literature discussed earlier supports the importance of family research that notes the context in which the role of the family member, in this case the grandparent, exists. The proposed focus of this research study is to look at grandparent bereavement from the perspectives of grandparents (maternal and paternal) and of parents, in order to place grandparent bereavement within the family context of relationships, activities and roles. However, as Kerry Daly (1992a) noted, families bring with them complexities in terms of research study.*

Families are a distinctive focus of study. Several characteristics reflect the unique nature of families as social groups: privacy; a collective consciousness that is not readily available to non-family members; relationships rooted in blood ties, adoption contract or marriage and intended to be permanent; shared traditions; intense involvement ranging from the most violent to the most intimate; and a collage of individual interests, experiences and qualities. (p. 3)

*Given Daly's comment based on his own experiences of family research, several questions remain for this study, such as how far families will share their experiences with a non-family person and whether more than one member of a family will choose to take part. In particular, it is important to consider grandfathers' roles and their participation in research. Many of the studies referred to earlier have predominantly included grandmothers, whilst in reality there are four relationships involved in grandparenting; paternal grandmother, paternal grandfather, maternal grandmother, and maternal grandfather. Notably, grandfathers do not appear to have participated in some research studies. Is this because of lack of interest? Or is it related to the extent of their self-perceived role as a grandfather? Sarah Cunningham-Burley (1984) offered some interesting insights about grandfathers' roles. She interviewed, in-depth, 18 couples in the UK as they became first-time grandparents. She commented that there were apparent gender differences in participation (both in interviews and in grandparenting activities). In particular, grandfathers spoke less and left the interviews part way through. She wrote,*

*They talked less about grandparenthood in the interview setting, they lacked an obvious role in the early months of grandparenthood... this did*

not necessarily constitute an accurate portrayal of grandfatherhood. For they did seem to enjoy being a grandfather. (p. 198)

*This comment highlights the complex area that this study seeks to explore. Namely, the meaning of bereavement for grandparents, including both grandmothers and grandfathers. The question, then, is whether the latter will choose to participate or not.*

## BEREAVEMENT

*This section explores different perspectives of bereavement in general, including theories and the associated critique. It moves to explore literature on bereavement outcome and some of the issues in relation to families and grandparents.*

### Loss

*Loss is a feature of human life. It occurs many times and in many forms throughout our lives and many of the losses, which we meet during our lives, occur in the family setting. Loss and the associated grief can be seen as part of the context for self growth which occurs during life (Viorst, 1989; Ward, 1993). From a developmental perspective loss is often part of the normative transitions which are expected, inevitable or even pleasurable, such as growing out of childhood, leaving school, finding a partner or moving house. This means that all of us have experienced bereavements. They are a normal part of life and we all have strategies for coping with them to a lesser or greater extent, which can be used when loss becomes an unwelcome challenge - such as death. Death is generally perceived as the ultimate form of loss because it is involuntary<sup>9</sup> and irreversible. Death of a family member or friend creates a loss for those family and friends who are still living and starts a process of grieving which involves readjustment of identity, roles, status and social organisation (Raphael, 1984).*

*There have been different perspectives in the development of explanations of how individuals respond to bereavement, which I have briefly outlined in the following section. The argument I am presenting is that the theories and models provide valuable insights but none are able to account for all the different factors and*

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<sup>9</sup> Involuntary in that generally people do not create or choose their own death, whereas other losses such as moving house entail a degree of voluntary choice to initiate the loss.



*responses which are involved in bereavement, such as individual differences in grieving, variations in available support, and differing existing coping strategies. So, there is a place for small-scale exploratory studies, such as this one, specific to a particular bereavement event as opposed to developing a grand theory.*

### ➤ **Stages, phases and tasks**

*Some of the widely known theories are stage or phase based theories from different perspectives which imply that grief is linear. The process of grieving is conceptualised as moving through different stages, or phases, to a point of resolution where the bereaved person returns to a state of normality or has "got over it". Erich Lindemann's (1944) work has been a major influence on views held about bereavement in the latter part of this century. He used observations based on his work with psychoneurotic patients who had lost a relative, relatives of patients who died in hospital, and relatives of victims of the fire at the Cocoanut Grove night club in America, to develop an illness-disease framework to account for grief responses. Lindemann viewed acute grief as a "syndrome" (p. 141), which could be "distorted" to become "morbid grief" (p. 144) but with appropriate management it could reach "resolution" (p. 144). The essence of normal grief resulting in a return to normal health was grief work, namely, "emancipation from the bondage to the deceased, readjustment to the environment in which the deceased is missing, and the formation of new relationships" (p. 143). One of the consequences of this work was to create the view of bereavement as something abnormal and requiring expert and/or medical help – which, given the particular experiences of his study participants, is not surprising but does not necessarily apply to all bereavements per se.*

*John Bowlby (1961) in his article "Processes of mourning" drew on work in the fields of ethology and psychoanalysis (after the work of Freud) to propose three phases of mourning with urge to recover lost object, followed by disorganisation and then reorganisation. Bowlby extended his thinking about bereavement in relation to attachment theory (1969, 1980) where he proposed four phases of protest, despair, yearning and detachment. Bowlby's earlier thinking in relation to bereavement was developed and extended by other writers, such as Colin Murray Parkes (1972).*

*Worden (1983, and updated edition 1991) moved to conceptualise mourning as grief*

work, which has specific tasks, instead of phases, to be completed. There are four tasks which include "accept the reality of loss; work through to the pain of grief; and adjust to an environment where the deceased is missing (1991, p. 10-18). In the 1991 version, Worden commented that in 1983 he had viewed Task 4 as "withdraw emotional energy and reinvest it", however, he now believed that "it sounded too mechanical, like one could merely pull a plug and reattach it someplace else" (p. 16). Consequently, he altered Task 4 to become "to emotionally relocate the deceased and love on with life" (p. 18). In both Worden's versions of the tasks of grief, the emphasis is on moving on with life. A similar endpoint to grief is proposed in other models. Elisabeth Kubler-Ross (1969) developed a model of grieving based on her clinical practice with terminally ill people. The stages she proposed were denial/isolation, confusion/anger, bargaining, and depression/acceptance, which are similar to the phases proposed by Therese Rando (1988). Rando presented a model based on clinical observations by grouping responses to bereavement into three phases. The phases were: avoidance, with responses and feelings of shock, alarm and denial; confrontation, with feelings of loss which can include searching for and seeing the deceased person; and re-establishment which involved making meaning or sense of the event and a return to everyday life.

Both clinicians and researchers, including those who proposed these models/theories, have critiqued the idea of a linear stage or phase based grief process, noting that it does not "fit" with the experiences of bereaved individuals who moved back and forth between emotions and stages. In 1987, Warwick Middleton and Beverley Raphael, both experienced clinicians, commented that "the concept of 'stages' of grief is more safely viewed as a model than a fact" (p. 336). Similarly, writers such as Stephen Shuchter and Sidney Zisook (1993) cautioned that grief is not linear and involves a "composite of overlapping, fluid phases" (p. 23). The view of grief that is now widely accepted is that of a circular process (Mander, 1994). The question then, is, how do these perspectives of grief relate to the experiences of bereaved grandparents?



### ➤ Where do bereaved grandparents “fit” into bereavement theory?

*Considering the theories from a research point of view, the sampling design or clinical case-load on which theories have been based have clear biases which we need to consider before findings are extrapolated to different groups of bereaved people. For example, unique bereavement events experienced by the samples studied, such as the fire at the Cocanut Grove (Lindemann, 1944) do not constitute a basis for generalising to deaths in motor cars or chronic illness preceding death. Second, high attrition rates and the process of self-selection (often on the basis of motivation or depression) means that certain people are more likely to participate in bereavement studies, as Margaret Stroebe and Wolfgang Stroebe (1989-90) demonstrated. Given these points I have reservations about the application of bereavement theory to a range of situations from which it was not generated - in this instance grandparent bereavement. On the basis of this literature review I believe that small-scale research is valuable which focuses on the situation, context and factors which are specific to the experience - in this instance being a bereaved grandparent. As Robert Stake (1995) noted using collective case studies without intent to generalise can still find information which adds to existing views and theories..*

## BEREAVEMENT RELATED TO CHILDBEARING

*Some of the literature reviewed here is not just about sudden death or even death. It includes situations of bereavement arising from the loss of the dream of the happy and healthy baby. The focus of most of the literature is on parents and not on the wider family.*

### Infant Death

*Expectations of having a healthy baby and child are high in the Western world; technological advances in obstetrics and paediatrics have meant that infant mortality has dramatically reduced (Mander, 1994; Thearle & Gregory, 1992). Having a child die is no longer a commonplace occurrence in countries such as NZ. So, as individuals, families and communities, we do not have precedents or experience in responding to death, disability or illness of children (Aries, 1974; Mander, 1994). In addition, death of a child violates the societal expectations we hold that parents predecease their children. It can also create a sense of guilt or failure that a child in one's*

*care has died. Therese Rando (1986) wrote at the beginning of her book "Parental Loss of a Child" that, "The loss of a child through death is quite unlike any other loss known ... It impacts on four different dimensions: the individual parents, the marital dyad, the family system and society" (p. 6). In terms of existing research studies the emphasis has been placed on the first two dimensions.*

## **Parental Bereavement**

*Clinical and research reports have focused on parental responses (often including gender differences) to bereavement in terms of both coping strategies and outcome. Many of the studies have small, self-selected or otherwise biased samples with a wide variety of ages at which the child died or particular reasons for the child's death. This hampers attempts at detailed comparison since few studies have used similar samples or tools.*

### **➤ Particular struggles**

*Charles Brice (1991), drawing on case-studies from practice, proposed an approach to mourning which rejects phases/ stages and viewed it as a struggle "with a series of more or less unresolvable paradoxes rather than as a progression through stages that possess relatively distinct and predictable beginning and ending points" (p. 1). In terms of maternal mourning, these paradoxes included feelings of responsibility (even when one knows one is not); unfairness (why my baby?); and relating to the child as part of her and as apart from her. This is an interesting perspective, which draws attention to the tensions surrounding the maternal roles as caregiver and chief mourner. Are there similar paradoxes for grandparents given the variety of roles they may hold in a family? The meaning of loss arising from death was explored by Patricia Conway and Deborah Valentine (1988) who undertook a qualitative research study of 10 couples who had experienced infertility, miscarriage or stillbirth. They found five associated losses – parenting, control, relationships, one's view of oneself and experience of pregnancy, childbirth and breastfeeding. The idea of associated losses is important because we often tend to focus on loss being the death; but it is the meaning of that loss **to the person** that often needs to be clarified. Hence, this study offers an opportunity to find out how grandparents "see" the loss of a grandchild.*

### ➤ Gender differences

*In terms of gender differences related to childbearing loss, the evidence varies. Gary Benfield, Susan Leib and John Vollman (1978) in a study of 50 parents of babies who had died in a neonatal intensive care unit (NICU) in Ohio, found that maternal grief significantly exceeded paternal grief. The sample was predominantly white, middle-class and many of the deaths were not sudden. A similar conclusion was made by Kandi Stinson, Judith Lasker, Janet Lohman and Lori Toedter (1992) from a study interviewing 56 American couples after miscarriage, ectopic pregnancy, stillbirth and neonatal death. They found that women had significantly higher grief scores than men between 1 and 2 years post-loss. They suggested that within the American culture men may deny their grief. Is the same true in the NZ culture? Similarly, of 57 bereaved Canadian couples whose infant died, women rated their grief reactions higher than their spouses (Lang & Gottlieb, 1993).*

*However, grief is a complex concept to study and using different indicators of grief may not always support the idea of gender differences. Ruth Carroll and Sarah Shaefer (1993-94) found, in a study of 34 American parent pairs bereaved by SIDS, that there were statistically significant differences in relation to coping patterns such as seeking support, but not in terms of activities such as accepting support. Similarly, in a study of 54 American SIDS parents there were similarities and differences between parents' views of the situation (Williams & Nikolaisen, 1982). The differing study findings support the direction of this study to explore both grandmothers' and grandfathers' experiences of bereavement.*

### ➤ The impact of a child's death on the family

*The term "death ripple" has been used to describe the flow-on of bereavement into the wider social networks, such as family and community arising from the death of a child (Jordan, Kraus & Ware, 1993). M. Bowen (1978) suggested that bereavement of any nature can result in an "emotional shockwave" (p. 324) in the extended family. However, little is known of the experience, meaning and needs of family members other than those in the nuclear family. The majority of writing and research in the fields of psychology and psychotherapy has focused on parents with books such as "Parental Loss of Child" by Rando (1986), and "Childbearing Bereavement" by*

*Joan Raphael-Leff (1991). Research studies have focused on mothers experiencing miscarriage (Swanson-Kaufman, 1988) or stillbirth (Lovell, 1984), or infant death (Peppers & Knapp, 1980); on mothers' and fathers' grief (Dyregov & Mathieson, 1987); and on siblings' grief (Lansdown, 1987). However, there has been little writing about other family members such as grandparents.*

## **GRANDPARENTS AND A GRANDCHILD'S DEATH**

*Clinical observations of grandparent bereavement have highlighted the potential complexity which can occur because of the role which grandparents have in the family. Gyulay (1975) wrote from her perspective of working with families of a terminally ill child. She included both siblings and grandparents under the heading "The Forgotten Grievers". Her emphasis was on grandparents' triple grief – for their grandchild, child and themselves. Rando (1986) included a comment about grandparents in relation to child death and referred to their double grief for themselves and their child. Moving from perspectives based in clinical practice, there has been limited research in this area.*

### **Research with grandparents bereaved by the death of a grandchild**

*Ponzetti (1992) conducted a study in America, advertising in the newsletter of two national support groups of families who had lost children. The responding sample included 28 grandparents (56% of whom were maternal grandparents) and 36 parents from the same families. The mode of death of the grandchildren varied including cancer, heart disease and other causes. The research focused on a comparison of parents' and grandparents' reactions to the same child's death. Whilst there were no significant differences between reports of physical symptoms, it appeared that parents reported significantly more feelings of shock, disbelief and numbness. Of considerable interest in terms of family grief is the finding that 56% of parents said their feelings towards their parents had changed and 53% of grandparents said their feelings towards their children (i.e. the parents) had changed. Whilst this was a small, volunteer sample which used a structured questionnaire (and therefore could not probe for clarification) it shows the potential for different effects and meaning of the bereavement to exist for different family members. Ponzetti (1992) commented, "these findings emphasise the importance of expanding research efforts to*

include members of bereaved families other than those in the nuclear unit" (p. 69). This comment substantiates the area of planned research for this study. In another article, Ponzetti and Johnson (1991) presented perspectives on grandparent bereavement from a sample of 45 grandparents (34 women and 11 men). Of interest, the data did not entirely support the idea of triple grief (Gyulay, 1975) or double grief (Rando, 1986). Many grandparents centred on their own child, some focused on the loss it represented for the grandchild and most felt grief for themselves. This may either reflect the method of data collection which did not allow for participants to reflect and expand on their answers, or it could support the linking theme of this review - that responses to, and meanings of, bereavement are varied and often individual.

In America, John DeFrain, Deanne Jakob and Betty Mendoza (1991-92) undertook a national study of SIDS grandparents. They used a questionnaire (including qualitative and quantitative items) with 80 grandparents accessed by newspapers, SIDS organisations and SIDS parents. The main findings were that grandparents had personal theories of death and personal guilt associated with the death, that some had difficulty coping with the pain (4% had contemplated suicide) and that the death had effects, generally positive, on their marriages. In contrast to Ponzetti and Johnson (1991), these authors suggested that their data confirmed the double/triple grief models proposed by Rando (1986) and Gyulay (1975). However, given the sparse use of, often, one line quotations, the reader is reliant on the researchers' interpretation of the data. The authors ended, as did Ponzetti (1992), claiming the need for future research. "Results of this study point out the need for future research in the area of grandparents in crisis. This is accentuated by the fact that we are increasingly becoming an older population" (p. 181). Whilst Ponzetti and Johnson focused on the family context of bereavement in terms of changing interactions, DeFrain et al. centred on the individual, not on the roles and relationships in the family. Neither study has explored, in-depth, the meaning, experience and effects on grandparents, as this study intends to do.

### **What about a grandchild's death in relation to other bereavements?**

*It is widely agreed that individual's response to bereavement depends on numerous factors, such as relationship with dead person, mode of death, personality and previous*

experience of change, loss or death (Parkes, 1972; Raphael, 1984; Rando, 1986; Stroebe & Stroebe, 1993). The latter point is important in grandparent bereavement, since given their age, most grandparents will have experienced previous losses. Karren Mundell Kowalski (1987) and Zoe Smialek (1978) undertook research with bereaved families and whilst the focus of their writing was about bereavement in general, and parental response in particular, both authors briefly mentioned grandparents. They noted the effect of previous loss, such as miscarriage, as part of the context of grandparent bereavement. It is worth remembering that reproductive losses in earlier decades were often not acknowledged because the, then, existing climate of health care removed dead babies to help speedy resolution (Thearle & Gregory, 1992). Thus the death of a grandchild may "trigger" some memories and pain for previous losses. From the perspective of this study, one of the strengths of in-depth interviewing is the opportunity it provides for grandparents to tell their stories. This potentially means there is the opportunity to set the context of the grandchild's death within the life of the grandparent and the surrounding family.

### **Grandparents' roles in families bereaved (in relation to the grandchild) other than by death**

Judy Douglas George (1988) noted observations from clinical practice during the setting up of a support group for the relatives of families with children with developmental disabilities. The aims of the group were to provide information, networking and interfamilial support. It became clear to health workers that grandparents who attended placed their issues second to those of the parents.

Family communication patterns and issues emerged as grandparents began to share their difficulty or inability to discuss openly the child's condition with the parents; however, these issues remained "parent-focused"; relatives were reluctant to deal with their own emotional adjustments.  
(p. 373)

With encouragement from group leaders, relatives started to talk about their feelings leading to the following observation from the leaders.

Grandparenting traditionally is thought of as a time of immense joy, pride and satisfaction; instead, these relatives were presented with a situation that required tremendous and ongoing emotional adjustments. One grandfather stated: "I felt that the world had come to an end". (p. 373)

The issues of support and grandparent feelings appear in a study by Susan Blackburn and Lauri Lowen (1986) undertaken to identify the feelings of grandparents and



parents whose preterm child was admitted to the Neonatal Intensive Care Unit (NICU). A questionnaire was sent to a convenience sample recruited through a parent self-help group from the greater Seattle area. With 83 grandparents (70% response rate) compared to 50 parents (32% response rate) it indicates, as the authors noted, a motivation on the part of grandparents to share their feelings. Amongst the main findings was the stress that grandparents felt and which could limit the support they offered to parents. In addition, it appeared the grandchild's parents were the grandparents' main source of information about premature babies. The authors suggested that if this could be offset with other sources of information it would mean that grandparents could more effectively support parents. As might be expected in Blackburn and Lowen's study, 70% of grandparents were concerned about the parents. However, 49% of grandmothers and 23% of grandfathers identified concerns about their own emotional strain and ability to cope which contrasts with the prevailing view of grandparents as supporters of parents as opposed to needing support themselves.

### **What are other people's views of grandparents bereaved other than by death?**

Hazel McHaffie (1991,1992) undertook a study of social support available to families with a very low birth weight baby cared for in any of seven NICUs in Scotland. Questionnaires were sent to doctors, nurses, mothers and other family members nominated by the mother. Replies were received from 198 nurses, 33 doctors, 181 parents and 242 grandparents. All four participant groups strongly identified the role of the grandparent as emotionally supporting the parents. Many doctors and nurses perceived working with grandparents as the least enjoyable part of their role. McHaffie's (1992) interpretation of this was, "The needs and role of grandparents were clearly perceived as principally to support the parents, understanding the stresses of the situation sufficiently well to be sensitive and useful to them" (p. 195). The focus of McHaffie's study means that there is little information regarding grandparents' perceptions of their own need for support, however, it does identify how important it is to consider how others such as health professionals and parents see grandparent bereavement in terms of expectations of their roles. This is the reason for



including cases (parents and health professionals<sup>10</sup>) within this study who represent some of these other perspectives of grandparent bereavement. [source of review above - C:\my documents\ writing up\Full review 95]

## AND SO TO THE BEGINNING

There was no final conclusion to this overview of the literature; the format of it was an appendix to the ethics committee standard proposal form. However, from the review, in conjunction with my nursing practice and comments from self-help groups, I framed the aim of this study as *"to describe the different perspectives of the bereavement which NZ grandparents experience when a young grandchild dies suddenly"* (Research Proposal, 1995, p. 4). In the context of this aim I defined "NZ" as the setting, as opposed to a study representing NZ grandparents. I used the word "describe" to mean synthesising and exploring different perspectives using case study. By "different perspectives" I was referring to how grandparents, parents and health professionals constructed grandparent bereavement, with the main objective to *"To give voices to the stories of grandparents' experiences of bereavement which have remained largely untold"* (Research Proposal, 1995, p. 4). The research aim extended to include an aspect that was important to participants as the reason they took part (see p. 130); to acknowledge, and raise awareness about, grandparent bereavement. This led to the decision, made with the 26 participants, that I should seek a publisher for the stories in the second part of this thesis (see p. 166).

One of the struggles I experienced in writing the research proposal to suit the ethics committee format, was being specific enough in forming the research questions, but not too specific to set up a priori hypotheses and expectations. I tried to think of questions as being framed around issues that would develop in talking with participants. I developed the following research questions.

- *What is the meaning/ construction of the bereavement to NZ grandparents?*
- *How do grandparents respond to the unexpected death of a young grandchild?*
- *How do grandparents "adapt"/ learn to live with bereavement?*
- *How does bereavement affect the role and relationships of grandparents within the family?*

<sup>10</sup> The proposal focused on health professionals, after talking with grandparents I identified the need to include a bereavement professional.

- *What is the construction of grandparent bereavement by parents and health workers?*
- *What are the resources available to bereaved grandparents?*
- *What social or psychological processes assist or hinder grandparents living with bereavement?*
- *What recognition or support might grandparents want from the community or health workers? (Research Proposal, 1995, p. 5).*

As the study progressed the conversations and debates directed what was important to explore further in the research, but it did not take any dramatic shifts away from the original broad area of study. As the ethical issues involved in the use of constructivist inquiry emerged I did mentally add another research question, "*How do participants' construct their experience of taking part in this research?*" This was about making the emerging research process transparent and not wishing to take for granted that it was either harmful or beneficial to take part (see pp. 164-171 for further discussion).

## AND THE BEGINNING ENDS

This chapter has explored the beginnings of the research in terms of the justification, significance and context of some of the existing literature at the time I planned the study. In particular, the high cot death rate of the 1980s in NZ meant that grandparent bereavement was, and is, a part of people's lives. If the definition of grandparent bereavement is extended beyond the view of bereavement resulting from death then it occurs even more frequently than is recognised and, with the rising proportion of older people in the population it is going to continue and become a part of many more people's lives. Yet, there is still little recognition by others that grandparents are bereaved and little known about what it means to be a bereaved grandparent. There has been little writing that has focused on grandparent bereavement and the three published research studies prior to 1995 were surveys (DeFrain et al., 1991-92; Ponzetti, 1992; Ponzetti & Johnson, 1991). These provided a breadth of view regarding grandparents' reactions and experiences, but not a perspective which explored the ways in which grandparents construct their bereavement within a family context. Similarly, whilst there has been extensive reporting of both research and clinical perspectives of bereavement it is unclear how these ideas might illuminate, or even be relevant to, the shape and form of grandparent bereavement. The excerpts from the research proposal in this chapter positioned

my thinking which then shaped the conversations that I had with participants as the research unfolded (see Chapter 4). However, before turning to the details of these conversations I want to explore the philosophical underpinnings of the research in the next chapter.

## CHAPTER THREE

### A STORY OF PARADIGMS, MARSHMALLOWS AND PHILOSOPHICAL DEBATES

#### THE STORY

The previous chapter set the scene from which the ideas and directions for this research came. This chapter is a story of the beliefs which underpinned this study from beginning to end. The intent is to trace the shifts in my thinking, at critical points along the way, which have informed how I have used and adapted the constructivist paradigm proposed by Guba and Lincoln (1989). This chapter has three parts which make up one story of the shift in my thinking and beliefs; from wanting a structured research approach to learning to live in a marshmallow space. The three parts are; why I used constructivist inquiry, ideas which influenced the shape of constructivist inquiry, and responding to critique of constructivist inquiry.

#### **But first, the marshmallow**

The story begins in early 1995, before I wrote the research proposal described in Chapter 2. I was at a PhD school, presenting and discussing my ideas with other students and supervisors.

postmodern, feminist, nursing and thanatological writings, as well as by my own nursing practice. Looking back from 1999, I now appreciate that being in the marshmallow is a reflection of uncertainty within what William Tierney (1997) has called the postmodern "*ideology of doubt*" (p. 30), where texts, such as this thesis, are only "*one version of reality rather than the only version*" (p. 25).

## **WHY I USED CONSTRUCTIVIST INQUIRY**

The journey to constructivist inquiry, and then using it in practice, first started with the decision to use a qualitative research approach. This was refined to collective case study (Stake, 1995) then, at the point of beginning conversations with participants, I shifted to constructivist inquiry as an extension of the use of case study. The final part of this section explores the nature of constructivist inquiry.

### **Choice of research approach at the start**

From the outset I planned to use a qualitative research approach to explore the different realities of grandparent bereavement within families. I made this decision because the survey data in the three previous studies of bereaved grandparents raised a number of questions that I believed could best be addressed as part of ongoing conversations to explore how people saw (constructed) grandparent bereavement. In addition, a qualitative research approach fitted with my practice as a nurse which constantly makes me aware that people hold different views (constructions) of the same event. I also had a personal goal to undertake a journey using a different way of looking at the research world. My previous experiences have been extensive but confined predominantly to surveys, randomised control trials, case-control studies and physiological laboratory studies. All of these can be claimed as conventional inquiry methods, which are grounded on the belief that there is one reality to be "captured" or "mirrored" by the research process.

Nurse researchers have extensively used research approaches other than conventional inquiry methods, because of the "fit" between research areas such as experience of illness and the beliefs underpinning qualitative research approaches. Many texts exist promoting such research for nursing (e.g., Benner,

1994; Holloway & Wheeler, 1996; Morse, 1991) and for health (e.g. Grbich, 1999). I use the term "qualitative research approaches" as an umbrella encompassing various practices and techniques which Streubert and Carpenter (1995, pp. 10-12) proposed have six shared beliefs. These beliefs are; existence of multiple realities, seeking to understand, valuing participants' views, seeking the natural context, acknowledging the research role; and providing vicarious experience generally by using participants' quotations. At this point I should note that, from personal experience, I am fully aware of the dominance of the quantitative research paradigm in many arenas of health research. The consequence of this can be that, "Researchers who use qualitative methods become obliged to present extraordinary justification for their choice" (Reinharz & Rowles cited in Guba & Lincoln, 1989, p. 140). In both the research proposal, which went to the ethics committees, and this thesis, I have chosen **not** to justify the choice of qualitative approaches against quantitative approaches. I believe the issue is about demonstrating the "fit" between the research approach I have used and the research area of grandparent bereavement. The issue is not that one approach is "better" than another, it is that different approaches suit different research aims. I also believe that we are 10 years on from that quotation from Reinharz and Rowles and into the "*Fifth Moment – The Future of Qualitative Research*" (Lincoln & Denzin, 1994, p. 575), where we should accept that qualitative research does not need to be defined in relation to another research approach. In terms of proposing the "fit" between qualitative research and the area of grandparent bereavement in the family context I cited, in the research proposal, a quote from Daly (1992a). I believe this sums up the focus of the research aim in Chapter 2.

Qualitative methods are suited to understanding meanings, interpretations and subjective experience of family members .... With qualitative methods the focus is not on identifying structural or demographic trends in families, but rather on the process by which families create, sustain and discuss their own family realities. (p. 3-4)

Having decided to use qualitative research, the next question was, which particular qualitative research approach?

## ➤ The choice of case study

I chose case study because, as I explained in the research proposal approved by the ethics committees,

*The ... rationale for the choice of collective case study as the chosen qualitative method [strategy] for the research is outlined below. Case study places emphasis on the opportunity to gain depth and insight from focused, detailed attention on a case (or more than one). From this, detailed, holistic description can be developed to enable the researcher and the reader of the final report to raise their level of understanding about the issue studied (Lincoln & Guba, 1985). This is particularly facilitated by the simultaneous process of data collection and analysis, proposed by Stake (1995), which means that data collected are guided by lines of thought and inquiry which develop during analysis, rather than completing these as separate phases of the research. ... Within the data collection and analysis, the researcher is a tool and part of the process, as Stake (1995) noted, "a case study is both the process of learning the case and the product of our [the researcher] learning" (p. 33). (Research Proposal, 1995, p. 18)*

Recognising the debates about "What is a case?" (e.g., Orum, Feagin & Sjöberg, 1991; Merriam, 1988; Ragin & Becker, 1992; Yin, 1994) I defined case study using the view of Stake (1995) who noted that instrumental case study is an appropriate choice for a situation "where we will have a research question, a puzzlement, a need for general understanding, and a feel that we may get insight into the question by studying a particular case [or more than one as a collective case study]" (p. 3). It was congruent with the idea of case study used in family research to explore realities within families (Handel, 1991) and in psychology to focus on a critical event which is part of a person's life (Bromley, 1986). Case study fitted with the premises of naturalistic inquiry (Lincoln & Guba, 1985) in terms of research which is in the natural setting, using the human instrument<sup>1</sup> and valuing tacit knowledge to explore individuals' constructions.

*The focus of the study is on developing understanding of grandparent bereavement from differing perspectives (not just one individual's experience) which means this is a collective case study where, "Each case study is instrumental to learning ... [about the issue studied] but there will be important coordination between the studies." (Stake, 1995, p. 3). My decision to use a collective case study to explore the different "faces" of grandparent bereavement, as it appears to different stakeholders in the experience (grandparents, parents and health workers, is based on clinical experience and consultation with bereavement groups. (Research Proposal, 1995, pp. 18-19)*

<sup>1</sup> I am not keen on this mechanistic term but have used this since it is one of the four entry conditions in constructivist inquiry (see Figure 3.1, p. 62).



### ➤ The shift to constructivist inquiry

At the end of 1995 I read Guba and Lincoln's (1989) book "*Fourth Generation Evaluation*". This extended their earlier work (Lincoln & Guba, 1985), which I had used to underpin the research proposal, and now presented the constructivist paradigm underpinning the methodology of constructivist inquiry. It was a critical turning point in the research journey. The reason constructivist inquiry "clicked" for my thinking was because the process of hermeneutic dialectic circles offered a means of working beyond the constructions within the three participant groups, which I had called the "faces" of grandparent bereavement in the proposal. The circles enabled dialogue **across** the three groups commenting on the constructions of other groups. It moved the idea of multiple constructions one step further than the proposed collective case-study which had three separate groups, and it offered the potential to reach a consensus construction made from the three groups together. From my perspective this was an advantage since I wanted to explore constructions of grandparent bereavement within the family context and this process provided a way to have dialogue within that context. In effect, this was a shift in the naming of the research approach to call it "constructivist inquiry", since the focus of constructivist inquiry is the case study (Guba & Lincoln, 1989 p. 133) where case is the topic researched and the end "product" is a case-report (p. 223). The beliefs underpinning the constructivist paradigm are the same as those I had used in the research proposal; namely, the existence of multiple constructions of reality, and the nature/outcome of the research being determined by the interaction between participants and researcher. In terms of methodology I had sought approval from the ethics committee for three interviews and member checking of material such as interpretations and final drafts, which is what happened during this research. What changed was my thinking about the process of analysis. I had planned "*that data collected [in interviews with all the participants (cases)] is guided by lines of thoughts and inquiry which develop [simultaneous with data collection] during analysis*" (Research Proposal, 1995, p. 18). However, what my thinking did not have was a named process for taking "*lines of thought and inquiry*" across the three groups of grandparents, parents, and health/bereavement professionals. This process was that of the hermeneutic dialectic circles proposed by Guba and Lincoln (1989).

### ➤ What is constructivist inquiry?

Before exploring the detail of this inquiry approach I believe it is useful to outline the context, as I interpret it, of Guba and Lincoln's ideas. This appears appropriate given the belief that constructions, such as the constructivist paradigm, are located in particular beliefs and contexts. This theoretical outline sets the scene for the debates in the second part of this chapter. The early work of Guba and Lincoln "Effective Evaluation" (1981) and "Naturalistic Inquiry" (1985) was situated in what Lincoln and Guba (1985) called the "postpositivist era" (p. 28) alongside the work of Rom Harré (1981) and John Heron (1981), amongst many others, where positivist assumptions were challenged. The arguments for the shift to alternative, or emergent, paradigms included issues such as: researching with, not on, people (Heron, 1981; Rowan, 1981a); the reactive nature of participants which affects the data (Heron, 1981); the value-ladenness of facts (Lincoln & Guba, 1985); and the underdetermination of theory with different ways of accounting for a set of findings depending on the perspective taken (Lincoln & Guba, 1985).

The title of the book which details the constructivist paradigm and constructivist inquiry, "*Fourth Generation Evaluation*", represents Guba and Lincoln's (1989, pp. 21-31) view that constructivist inquiry succeeds three preceding eras [generations] of evaluation; measurement oriented, description oriented, and judgement oriented, and that this new era is negotiation oriented. Whilst the example which Guba and Lincoln presented is that of education evaluation, they stated that the process of constructivist inquiry "is basic to all of naturalistic inquiry, whether research, evaluation, or policy analyses" (p. 155). It has not been widely used in published health research. Koch (1994) described her doctoral work using Guba and Lincoln's ideas, informed by existential phenomenology, to explore the experiences of older patients admitted to acute care settings. Streubert and Carpenter (1995) included it as one of the new generation methodologies in their book on "*Qualitative Research Approaches in Nursing*". Jane Appleton and Lindy King (1997) suggested that it has an increasing role to play in nursing inquiry. I would agree because the beliefs of constructivist inquiry, such as multiple constructions of reality and a process

which is cooperative and empowering, offer potential for a wide range of nursing and health research in the future.

So, turning to constructivist inquiry in detail - what are the underpinning beliefs? It is positioned as a methodology, or inquiry approach, within the constructivist paradigm. "Paradigm" is used here in the sense of one research approach, not at a meta-paradigmatic level (Hammersley, 1992) where it is an umbrella for a range of research approaches. I have taken it to mean a "basic set of beliefs which guide action" (Guba, 1990, p. 17), where the beliefs form a worldview which offers a way of looking at the world (Patton, 1975). To explore the constructivist paradigm I have used the three level structure, albeit an artificial division, of ontology, epistemology and methodology. In discussing this I have used the definitions from Guba's (1990) writing in "Paradigm Dialog", which are a briefer presentation of those presented in "Fourth Generation Evaluation" (Guba & Lincoln, 1989).

Ontology: What is the nature of reality?

Guba (1990) proposed that the ontology of the constructivist paradigm is "Relativist - realities exist in the form of multiple, mental constructions, socially and experientially based, local and specific, dependent for their form and content on the persons who hold them" (p. 27). The key point is that a single constructed reality of the world does not exist. For me, the appeal of this perspective is that it offers a way to see how and why individuals hold differing views of the same event or object, where for example, a conversation between two people is constructed differently by each person in terms of how they describe it afterwards. The metaphor implicit in the term "constructivism" is the idea of people piecing together and building constructions of what they experience - a process which Guba and Lincoln (1989) described as,

Events, persons, objects are indeed tangible entities. The meanings and wholeness derived from or ascribed to these tangible phenomena in order to make sense of them, organise them, or reorganise a belief system, however, are constructed realities. (p. 84)

Hence, the same event of having a grandchild die is constructed differently by grandparents in their stories in Part 2 because of all the different things which go to make up how individuals look at the world. Yet, given the diversity, it does not

mean that all constructions are totally different, because there are many aspects of life where shared definitions are held. Hence, whilst there is diversity amongst the stories in Part 2, there are shared definitions in the joint construction about ways of being a bereaved grandparent.

Having a relativist ontology means that no one person's construction is "better" or "truer" than another person's because we cannot assess it in terms of being nearer to the "correct" construction of reality. This is a consequence of the ontological position that one "correct" construction of reality does not exist. Therefore, all constructions are meaningful to the people who hold them and, therefore, meaningful to researchers. However, Guba and Lincoln (1989, p. 143) argued that whilst all constructions are equally meaningful, this does not preclude the existence of malconstructions, which are incomplete or inconsistent constructions. However, determining that a construction is a "malconstruction" requires an assessment of the construction in relation to the belief system that supports it. For example, a construction of the world as created in 7 days may be congruent with particular religious beliefs but is not congruent with Darwinian beliefs. Hence the context in which constructions are located and created is crucial to appreciating constructions. I believe this view may potentially preclude being able to assess someone's construction as a malconstruction, precisely because constructions are located in contexts which include much more than beliefs. If constructions are grounded in the constructor's previous experience, values, events and social expectations then how could I "know" about these in order to determine whether their construction is a "malconstruction"? So I decided that, in this research, I would work from the premise that all constructions were meaningful and I did not use any process to consider whether they were malconstructions.

As social worlds are not static with new experiences and information potentially always occurring, the relativist view of reality allows for constructions to change as new experiences are considered in relation to existing constructions. However, constructions are generally stable and, at times, may even avoid incorporating new information which might require a construction to change (Guba & Lincoln, 1989, p. 145). From a non-realist perspective this means that the nearest thing to "truth" is the "best informed" and "most sophisticated"

construction (Guba & Lincoln, 1989, p. 84). Such a construction includes known information with the best explanation, whether developed by individuals or by consensus from a group in a research study. Accepting that constructions are able to change illustrates the importance of considering time as a context to constructions. It means recognising that people may not hold the same construction for long periods of time and, indeed, during this research my initial construction of grandparent bereavement changed quite considerably by the time I completed writing this thesis.

*Epistemology: What is the nature of the relationship between the knower and the known?*

Guba (1990) described the constructivist epistemology as “*Subjectivist – inquirer and inquired into are fused into a single (monistic) entity. Findings are literally the creation of the process of interaction between the two*” (p. 27). Hence the research findings are constructed in the relationship between researcher and participants to which each brings their constructions of the world. It is a place where **new** constructions can occur, and others can alter, as comments from one person spark ideas for the other person. Consequently, the research is subjective, because there is no possibility of the researcher standing outside the research. In contrast to an objectivist stance in positivism, which seeks to minimize researcher bias, the researcher in constructivist inquiry takes an active part in constructing the research findings. The issue is, then, to ensure that the researcher’s etic construction is not favoured over the emic constructions of participants to influence the direction of the research (see p. 103). I particularly favoured the emphasis on relationship as the place of creating new understandings because of my experiences in nursing practice where the relationship is therapeutic, not research based, but the process of new insights within the interaction is the same.

*Methodology: How should the inquirer go about finding knowledge?*

Guba (1990) proposed that methodology in constructivist inquiry is, “Hermeneutic, dialectic – individual constructions are elicited and refined hermeneutically, and compared and contrasted dialectically, with the aim of generation one (or a few) constructions on which there is substantial consensus” (p. 27). As a process of inquiry Guba and Lincoln (1989, p. 174) emphasised

emergent design and developed the diagrammatic representation which is reproduced in Figure 3.1. I have outlined the process of constructivist inquiry briefly, because this relates to further discussion in this chapter about adapting constructivist inquiry. However, the detail of the methodology in practice is discussed in Chapter 4.

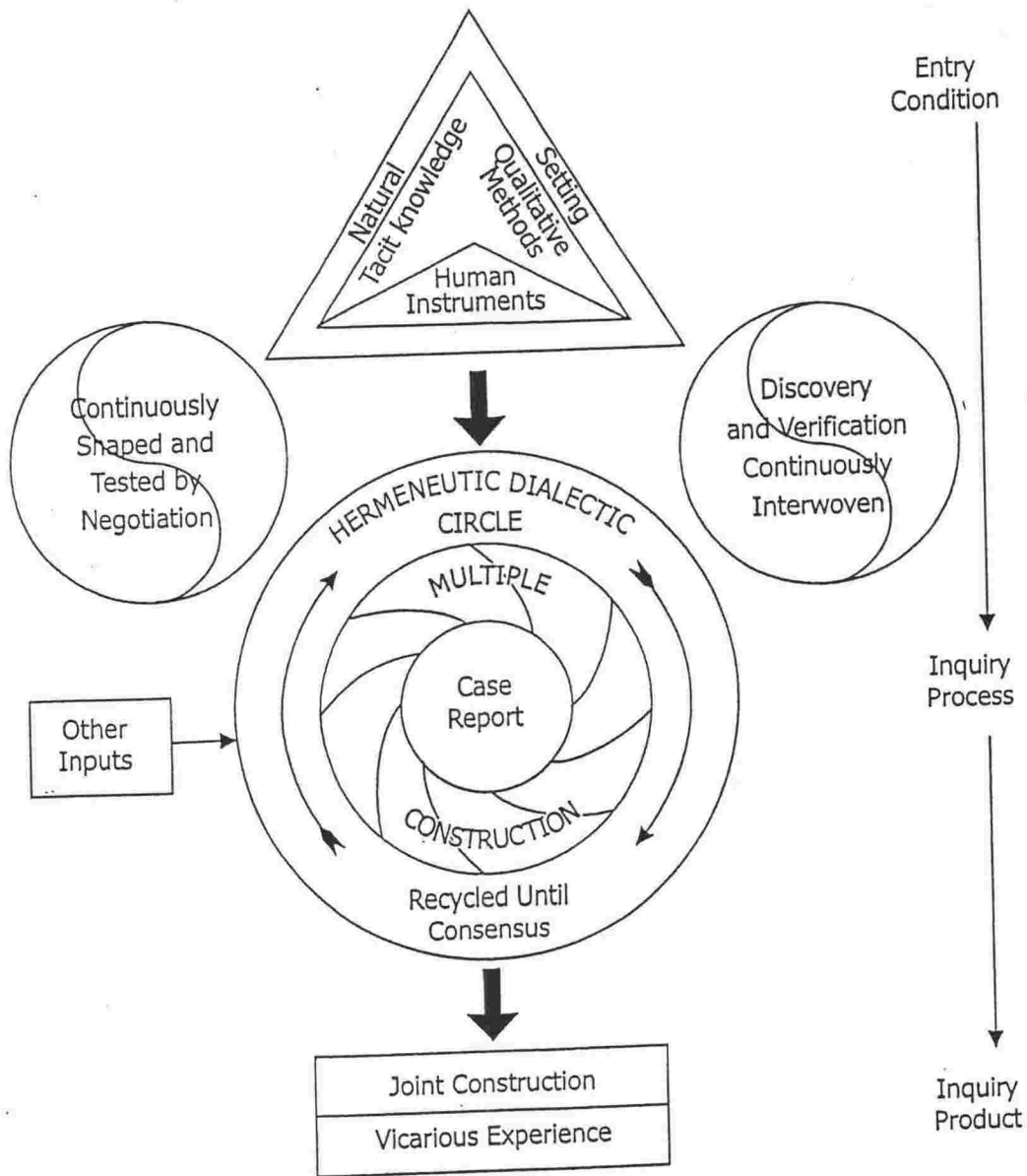


Figure 3.1

The methodology of constructivist inquiry

From: E. Guba & Y. Lincoln, Fourth Generation Evaluation, p.174, copyright 1989 by Sage Publications, Inc. Reprinted by permission of Sage Publications, Inc.<sup>2</sup>

<sup>2</sup> Copyright permission letters for Figures 3.1 & 3.2 in Appendix 1.

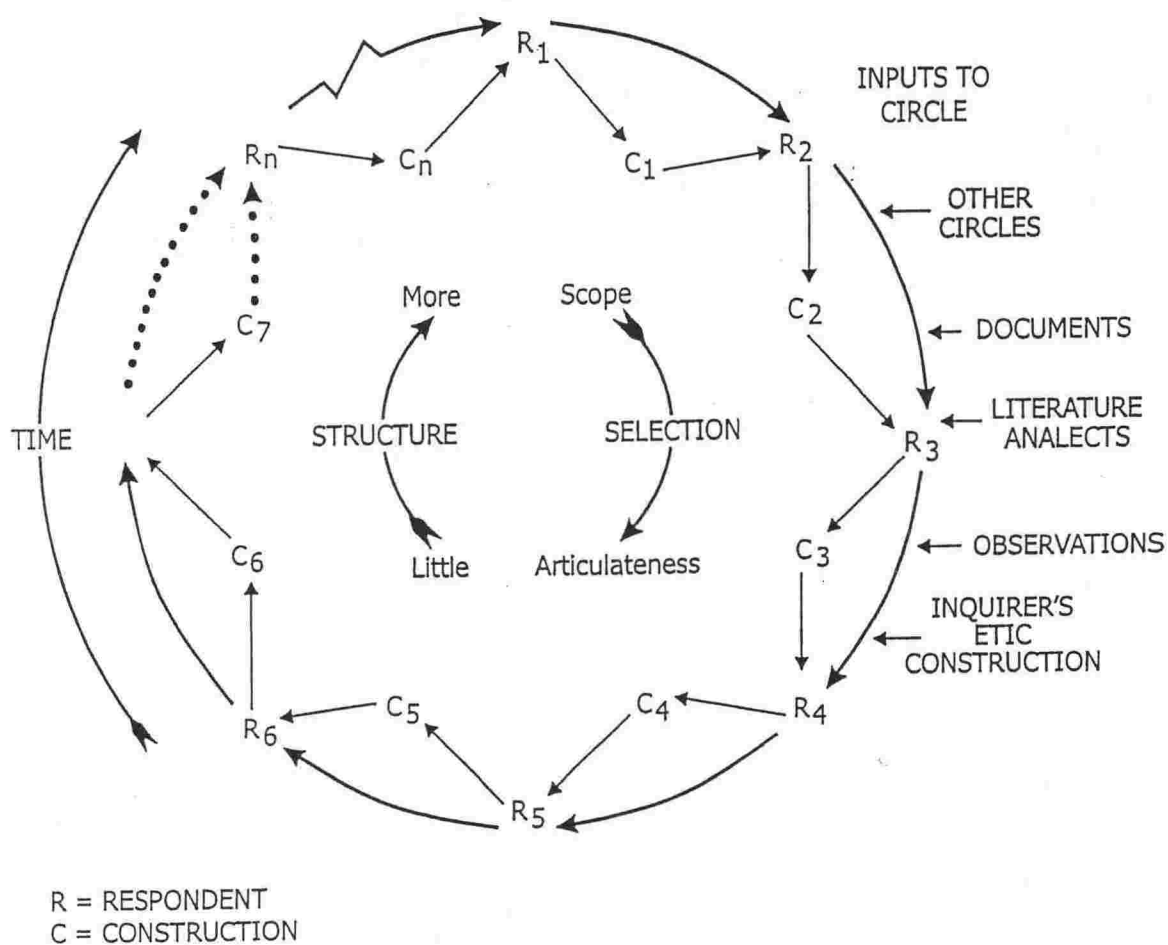


Using emergent design means not determining in advance exactly what the study will study. Instead the field of inquiry is made clear - grandparent bereavement in this instance. Particular questions are identified which are then refined according to what emerges during data gathering. The process of inquiry rests on four entry conditions (represented in the triangle in Figure 3.1, p. 62) of: natural setting; tacit knowledge; qualitative methods and human instrument. These entry conditions enable the researcher to explore in the natural setting and identify issues that were not known previously to be important. The interplay between discovery and verification, shaping and negotiation during data gathering, analysis and discussion of analysis with participants is represented in the two circles on the left and right of Figure 3.1. The process of discussion uses the hermeneutic dialectic circles represented in the centre of Figure 3.1 (see also Figure 3.2, p. 64) to explore individuals' constructions, develop group (multiple) constructions and to potentially reach a joint construction across participant groups. This is presented in a way to enable the reader to access and understand, for example, aiding vicarious experience with the use of description and quotations.

#### *Hermeneutic dialectic circles*

Guba and Lincoln (1989) proposed a number of hermeneutic dialectic circles with different groups of "stakeholders" (p. 149), as they termed participants who have a "stake" in the evaluation outcome. In this research there were three participant groups (grandparents, parents and health/bereavement professionals) with three circles simultaneously in existence, as Chapter 4 explains. It is worth noting that the three groups of participants are not a form of triangulation, with the intent to pinpoint grandparent bereavement from three sightings. Instead, each group brings different perspectives and, therefore, constructions which contribute to the picture of grandparent bereavement. The process of the circles is the continuous interaction between data collection and analysis with serial sampling. Guba and Lincoln (1989) proposed a diagrammatic representation of this process which is reproduced in Figure 3.2.





**Figure 3.2**

### **The hermeneutic dialectic circle - within circle process**

From: E. Guba & Y. Lincoln, *Fourth Generation Evaluation*, p.152, copyright 1989 by Sage Publications, Inc. Reprinted by permission of Sage Publications, Inc.<sup>3</sup>

Within the circle of participants from one group, such as grandparents, the first construction ("C1") from the first respondent ("R1") can inform discussion with the second respondent ("R2") and so on. This means that the researcher's discussion with participants can explore both individual's constructions and also debate and refine ideas across individuals in the group to eventually develop a

<sup>3</sup> Copyright permission letters for Figures 3.1 & 3.2 in Appendix 1.

group construction. Material from other circles of participants can then be discussed within circle, which builds up the dialogue of a construction across the participant groups. I perceived this was the strength of the circling process, as an extension of the collective case study that I had planned, and which Guba & Lincoln (1989) described as:

The object of a naturalistic inquiry is to identify and describe various *emic* constructions and place those constructions in touch - with the intent of evolving a more informed and sophisticated construction than any single one of the *emic* constructions or, the researcher's or evaluator's *etic* construction, represents. The outcome is a joint, or collaborative, construction (or, more appropriately, a reconstruction of formerly held constructions). (p. 138)

This describes a process which fitted well with the research aim *"to describe the different perspectives [of grandparents, parents, health professionals] of the bereavement which NZ grandparents experience when a young grandchild dies suddenly"* (Research Proposal, 1995, p. 4).

In this section I have explained why I believed that constructivist inquiry suited the aims and questions of the research. However, by adopting a constructivist approach, I believe that there are multiple constructions of ways in which research can be undertaken, so I am not presenting this framework as the right, or only, way (Guba, 1990, p. 17) to explore grandparent bereavement. Instead, I am suggesting that you view these beliefs, and the ones in the section below, as the context in which I have made decisions in Chapters 4 and 5.

In my initial use of constructivist inquiry I have to acknowledge holding on to a framework, outside the marshmallow. I liked "Naturalistic Inquiry" and "*Fourth Generation Evaluation*", not just because the ideas made sense to my vision of this research. I also liked the content where the authors teased out the philosophical flaws in positivism as evidence for the credibility of these emergent research approaches; this material provided the security blanket that I wanted at the beginning of the research. This only became clear to me when I read Joyce Walker's (1996) view of her experience undertaking qualitative research. She wrote, "Fundamentally, the successes and struggles I experienced around my dissertation research became an adventure, once I confronted my own demon, the closet positivist" (p. 227). That summed me up at the beginning of this

research. Some of the movement out of the closet into the marshmallow began when I questioned the extensive detail in "Naturalistic Inquiry" and how congruent this was with an emergent approach. Then there were other influences from nursing practice and readings which shifted me further into the marshmallow.

## **IDEAS WHICH SHAPED THE FORM OF CONSTRUCTIVIST INQUIRY**

I began this research with some beliefs which both informed and influenced how I used constructivist inquiry methodology. The beliefs come from my practice as a nurse, from my experience as a researcher over the years and from my beliefs as a person; they have influenced the study at both an epistemological and methodological level. The beliefs are explored in more detail in Chapters 4 and 5 in relation to practices, processes and decisions. At an epistemological level the beliefs are centred on the nature of the relationship as a conversation between myself, the researcher (Self), and the participants (Other); and the use of stories as a way of knowing about, and re-presenting constructions.

### **Relationship as conversation**

The epistemological position of the constructivist paradigm emphasises the research relationship as the arena for debate and development of constructions. It is central to what the research uncovers. This position had several implications for this research. I was aware that the nature of the relationship would affect both what participants were prepared to share with a family outsider (see pp. 127-128) and their willingness to critique and debate ideas. This would then determine what could be known of grandparent bereavement in this study. Equally, because the research is created within the relationship, I have written Part 1 of this thesis as a reflexive account to uncover my construction of the context that shaped the research. In envisaging the nature of the research relationship was, I drew on Steinar Kvale's (1996) work, in relation to dialogue as "*InterViews*", and then extended this to conceptualise conversation as a form of relationship in this research which offered a means to explore constructions. Kvale proposed the idea of interview as formal conversation at an

epistemological level<sup>4</sup> of a relationship of "*InterView*", this being the view between two or more people, which is the place where knowledge is explored and created. To illustrate this Kvale (1996) used the visual Gestalt figure and ground picture, with which all psychology students are familiar, and wrote,

We can focus on the two faces of the ambiguous figure, see them as the interviewer and the interviewee, and conceive of the interview as the interaction between the two persons. Or we can focus on the vase between the two faces and see it as containing the knowledge constructed inter the views of the interviewer and interviewee. There is an alternation between the knowers and the known, between the constructions of knowledge and the knowledge constructed. (p. 15)

The idea of alternation, where we can see either the two faces of the people in the conversation or the vase between the two faces, is somewhat different to the words which Guba and Lincoln (1989) used where the "inquired and inquired into" were "interlocked" (p. 84). It also differs from the view of Guba (1990) who described the relationship as "fused into a single (monistic) entity" (p. 27). These words emphasise the importance of the relationship and its subjectivity, although from my perspective, I remain unconvinced about "fusion" and "interlocked". I believe participants and I have remained separate, but jointly focused, during the research, more in the manner which Kvale described.

Kvale (1996) used "conversation" to cover a range of relationships with verbal dialogue, from everyday conversation to the formal conversation of a research interview. I have used "conversation" to include both spoken conversation and the written conversation of letters. I believe, that in this research, the intent of both has been the same, in that the conversation in both forms has been about dialogue and reflection. Support for this definition of conversation comes from the context of its origin, as a word derived from Latin to Middle English "in the sense 'living among, familiarity, intimacy'" (New Oxford Dictionary of English, 1998, p. 401), which describes the relationship participants and I shared through interviews and letters. Clandinin and Connelly (1994) also viewed conversation as relationship and placed letter writing as a "kind of written conversation" (p. 422). As a concept, conversation "fits" well with constructivist inquiry for, as Thomas Schwandt (1996) noted, social inquiry can be seen as dialogical with

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<sup>4</sup> Interview /conversation are also discussed in terms of practicalities as part of method in Chapter 4.

"inquiry as conversation" (p. 64). In addition John Shotter's (1993) view of knowledge was of conversational realities, an idea which resonates with this research. The strength of viewing relationship as conversation is that it reflects aspects of **how** I believed the research relationship should be. It involves turn-taking of listening and talking and, most importantly, it is something we do **with** people, so it is cooperative. Whereas if I use the word "talk" it means I could talk **to** people, and it does not always imply talking with them. However, to hold a conversation with someone requires careful positioning of the relationship between Self and Other.

### **Positioning the relationship**

Writing about research relationships between Self and Other, Michelle Fine (1994) proposed that, "*researchers probe how we are in relation with the contexts we study and with our informants, understanding that we are all multiple in those relations*" (p. 72). The beliefs that guide how I have been in the research relationship come from my own worldview which includes my nursing practice. I have seen the research relationship as a partnership with participants, to which they bring their expertise, and ownership, of their individual experiences; and to which I bring expertise to undertake this research in a way to make it living inquiry that is of use (Reason, 1996; Sandelowski, 1997). Within that partnership I have seen the stories and ideas, which participants have willingly shared with me, as a "gift", a point also made by Brigid Limerick, Tracey Burgess-Limerick and Margaret Grace (1996). I viewed the gift in this research, as one which was on loan. At different points I decided I needed to discuss the gift with the permanent owners, the participants, as to how it was located and shared in the public view. This belief has created a number of debates in relation to ethics, ownership and editing (see pp. 171-175).

Seeking to position the research relationship as a cooperative partnership fits with negotiation oriented inquiry (Guba & Lincoln, 1989). Partnership has weighty precedents such as the intent of the Treaty of Waitangi, as a living document for NZ society. The question for me has been, where does power sit in a partnership relationship? After all partnership is about sharing and, yet, as the instigator of this research who was motivated to finish it, I hold considerable power in this

relationship. There are several examples in the NZ context which illuminate the position of power in partnership. The Treaty of Waitangi can be seen as an example of the abuse of power by one partner to marginalise and disadvantage the other partner. "The Nursing Partnership", proposed by Judith Christensen (1990), makes no mention of power, yet it appears to implicitly remain with the nurse since it is the patient who makes the changes in role at stages such as "revealing self" and "recovering control" (p. 35). In the model of midwifery partnership developed by Karen Guilliland and Sally Pairman (1995), and adopted by the New Zealand College of Midwives as the statement of their underpinning philosophy, the role of power in the partnership is clearly recognised. The authors used the definition of "a relationship of 'sharing' between the woman and the midwife, involving trust, shared control and responsibility and shared meaning through mutual understanding" (p. 7).

Similarly, Guba and Lincoln (1989, p.150) identified that the willingness to share power is a necessary part of the hermeneutic dialectic circle for participants to be able to share and critique constructions. Clearly, if the power is unequal in the research relationship, such as taking the "view from above" (Mies, 1993, p. 68) of the research "subject", then the relationship moves to a situation of "Othering" (Fine, 1994, p. 70) where researchers are writing **about**, as opposed to **with** participants. Irihapeti Ramsden (1996), when writing about research with Maori, concluded, "Researchers should develop insight into the issues of power relations in research and ensure that the research participants are left better off in terms of information, skill and management of their own issues" (p. 32). I believe her comment applies to all research, including this study, not just to research around Maori health issues. This is a perspective which resonates with Guba and Lincoln's (1989) view of constructivist inquiry being both "empowering" and "educative" (p. 224 ).

### ➤ Sharing power?

The previous discussion indicates that other writers place ideas of "sharing" and "power" into the arena of partnership. Yet, what does it mean to **share** power? Does it have to be a conscious structuring of the power relations? Lous [sic] Heshusius (1994) seems to suggest not. He proposed that, in the act of



participatory consciousness, "there is an affirmative quality of kinship that no longer allows for privileged status" (p. 19). Thus it is about removing the distance between Self and Other, reflected in the positioning of the relationship for the "InterViews" of Kvale's (1996) book, and is represented textually by the linking of the hyphen between "Self-Other" (Fine 1994, p. 70) or merging the words "SelfOther" (Heshusius, 1994, p. 19). The next question, in a partnership, is whether participants want to share power? Do they construct the relationship in this form? Not everyone in this research wanted to take up the full role of active partner and the leadership of the research remained with me. I have worked with the perspective of partnership as a dynamic one, where the roles of partners change. During this research participants were the active partners in the sharing of their stories and I was the active partner in the analyses, then the ideas from these analyses were returned to participants to discuss. This reflected the cyclical nature of partnership which exists in the world outside of research studies, where partnership is never squarely 50:50 on every aspect of the relationship. During the course of the research I came to realise that what mattered was that there was the opportunity for participants to choose to be active partners if they wanted to. Similarly, I found envisaging a cooperative partnership researching **with**, not **on**, people, set the stage for power to be shared. I have also learned that such a partnership creates ethical situations with decisions which are grounded in the relationship, not in codes and rules of ethical research practice (see Chapter 5).

### **Self and Other(s) as individuals**

The other important aspect of the research relationship is individuality. Whilst partnership is a concept at a generic level, the partnership I had with each participant developed according to how we were as individuals. This meant that I believed that the relationship had to be positioned to be respectful and regardful of difference. Nursing practice and writings contribute to an understanding of what this means. In NZ, the positioning of the Treaty of Waitangi as a living document for both government agencies, and the wider society (Treaty of Waitangi Act 1975, amendment 1985) contributed to the cultural safety debate within nursing education in New Zealand (Papps & Ramsden, 1996). Where culture is defined by the Nursing Council of New Zealand (1996) as being far



more extensive than ethnicity to include "those [Other] who differ from them [Self], for example, by: age or generation; gender; sexual orientation; occupation and socioeconomic status; ethnic origin or migrant experience; religious or spiritual belief; disability" (p. 11). So, how do nurses "safely" care for clients of different cultures? Whereas cultural awareness and sensitivity focus on learning and practising in ways which see the Other [patient/ participant] as **different** from Self [nurse/researcher] and tend to involve learning about groups, stereotypes and ritual practices, cultural safety turns the Self-Other relationship around. It is "focused on the self-knowledge of the nurse or midwife rather than on attempts to learn accessible aspects of other groups. A nurse or midwife who understands his or her own culture and the theory of power relations can be culturally safe in any human context" (Nursing Council of New Zealand, 1996, p. 10).

Knowing who I was in this research included a number of voices, and cultures; as nurse, researcher, English born and now a New Zealand citizen. All of which contributed to make me aware not only of my cultural locations, but also that these defining categories do not describe the multidimensionality of me, my nursing practice, and my worldviews. Consequently I was aware that the same is true for participants, and with that reflection I have viewed the importance, in the research relationship, of being respectful and aware that we are all different; which is why we can construct realities differently. Standing in this position then the issue in this research is about being "regardful" of all that makes people unique (Nursing Council of New Zealand, 1996, p. 10)

The art of nursing assists in being "regardful" and valuing the individual in the research. Part of that "art", which I claim after 20 years of practice, is what Patricia Munhall (1993) described as the "art of unknowing" (p. 125). It is an idea which has been valuable in this research. It involves taking a position of "unknowing", a position which, paradoxically, facilitates knowing about patients (or participants). It means, "To engage in an authentic encounter, one must stand in one's own socially constructed world and unearth the other's world by admitting, I don't know you, I do not know your subjective world" (Munhall, 1993, p. 125). Recognising that we do not know other's worlds which are

different to our own, means that to be able to gain an insight requires a relationship where people will allow us entry to their views of those worlds. In both nursing and research this means having a "quality" relationship. "Quality" is about being in the relationship with mind, spirit and body. We can all think of conversations where the person is there physically and even asks questions or talks, but there is something missing. I believe this is what Munhall described as part of "good" nursing practice where one is "authentically present" (p. 125) in order to be able to be unknowing which then facilitates an "Inter View" between researcher and participant. It is, in part, the state of participatory consciousness, described by Heshusius (1994), in the research relationship which "results from the ability to temporarily let go of all preoccupation with self and move into a state of complete attention" (p. 17) in the encounter.

Whether I managed to position the research relationships using these beliefs in practice is commented on by the participants in Chapter 4 (see p. 122 and p. 165). Moving from the nature of the relationship, the other areas that informed and altered my construction of the research were ideas of stories and storying.

### **Stories as a way of exploring and re-presenting constructions**

Whilst not stated as part of constructivist inquiry, the idea of stories as a means to share ideas, debate constructions, and to re-present research material in a case report, is congruent with the beliefs of the constructivist paradigm. It also resonates with the ideas of partnership and conversations where people share, and listen to, stories. I appreciate the words "stories" and "narratives" are often used interchangeably. Norman Denzin (1989) defined "narrative as a story" and "story as a fiction, narrative" (p. 48) where story can be about personal experience. In this research I have chosen to use the word "stories" because it is part of our everyday language in a way that narrative is not. The other decision I made was to use the verb "storying" for this research as opposed to "storytelling" which indicates the oral tradition of telling and creating stories for face-to-face audiences (Livo & Rietz 1986), whereas I felt "storying" could encompass the way the participants shared their stories in both interviews and letters.

### ➤ **Stories as a means to share constructions and gain new insights**

Stories are part of our lives. We tell stories to ourselves in our heads, and to other people, about many aspects of our lives. In 1991, Margaret Sandelowski echoed, and cited, the work of Denzin and Mishler when she made a plea for nursing research to consider that, "The interview and the research report need to be rescued from efforts to standardise and scientise them, and be reclaimed as occasions for storytelling" (p. 162). The concept of stories as reflections of individuals' experiences resonates with nursing practice which focuses on the individual. In the time-period since Sandelowski's plea, stories have been widely used in nursing research. Areas of research using stories include: healing (Baker & Diekelmann, 1994); the links between practice, ontology and epistemology (Boykin & Schoenhofer, 1991); the nature of nursing practice (Bowles, 1995; Geanellos, 1995); and critical case-study in the NZ context (Dixon, 1996). The use of stories to share individual constructions of reality where meaning-making can take place has been discussed in a range of writings (e.g., Brody 1987; Frank, 1995; Polkinghorne, 1988). It is the power of this meaning-making which has potential for not just research, but also as a healing tool (White & Epston, 1990). Whilst this was not the initial focus of this research, it was one of the outcomes for a number of participants (see p. 161 and pp. 165-167). From my perspective, stories reflect a partnership in this research with opportunities for meaning-making for the person sharing the story and for the listener to gain new insights and access tacit knowledge which, for me, was of great value. I was struck by the work of Michael McCall (1989) who used stories of life events to share in a group. He found that "they [participants] learned other people's interpretations of common experiences and tested their own, thus developing shared understandings of problems and possibilities people in their position in history have in common" (p. 43). In this respect I viewed stories as a means with which participants were familiar from everyday life, to talk in conversations about their experiences. Participants' stories held their constructions of grandparent bereavement alongside other constructions of other related realities, such as Ailsa and Elwyn's discussion of their experiences of being widowed. The stories were a way for me, to explore new insights about grandparent bereavement, and then for other participants to read each others' stories for a final dialogue about grandparent bereavement across the groups' hermeneutic dialectic circles.

### ➤ **Stories as a re-presentation of constructions**

Having used stories as part of conversation during the research means that they are a logical choice for the re-presentation of constructions. It is the potential for stories to aid understanding (Reason & Hawkins, 1988) which led to my decision to make them a central part of this thesis, as both stories of individuals and of the research. I believe stories offer the readers of this thesis the opportunity to hear, and to have their tacit knowledge touched, by some of the situations, struggles, choices and beliefs within the stories. In particular, stories offer a place for each participant to have their own voice within the research, which keeps their voices clear (Cortazzi, 1993) within the text and provides the opportunity to be heard in public (Lincoln, 1997). The process of creating the stories is described in Chapter 4 (see pp. 112-115). It was a process which, I believe, was about working the hyphen between "Self-Other" as opposed to "Othering" participants (Fine, 1994, p. 70) and contributed to the decision to include all 26 stories in this thesis. The other belief contributing to this decision was the relationship as partnership where we all have an equal place in the research. So, all the stories belong in the thesis. No one story is "better" than another; the relativist view of constructions. And, the stories are all different which is their beauty and strength.

As the discussion in the previous pages explains, both my nursing practice and other writings have shaped constructivist inquiry to adapt it as a framework for this piece of nursing research. This has brought some interesting consequences such as nurse-researcher roles (see pp. 115-121) and emerging ethics (see Chapter 5). This was the beginning of the shift inside the marshmallow, leaving behind a firm shape and structure for the research. The other element of the shift was stepping into the philosophical debates surrounding constructivism.

## **OUT OF THE CLOSET AND INTO THE MARSHMALLOW**

For a few months the structure and form of the research was clear in my mind. Then I began to have questions and debates about the constructivist paradigm and rigor with the role of criteria. I began edging into the marshmallow. First, I need to acknowledge that other people's thinking, too, changes over time and what an author writes at one point in time does not represent their position months or years later. For example, Lincoln was writing in 1997, 8 years after

"Fourth Generation Evaluation" was published, presenting a postmodern perspective in terms of representational issues, which extends, and differs from, her earlier writings. So, I acknowledge that my comments on constructivist inquiry have the vantagepoint of further writings which did not exist when "Fourth Generation Evaluation" was published, and also the experience of using constructivist inquiry in practice. Second, I recognise that being constructivists Guba and Lincoln (1989, p. 17) would never claim to provide **the** answer to research. However, I felt there were a few areas where answers would help. The areas I particularly struggled with were the philosophical underpinnings of some of the terms used in "Fourth Generation Evaluation". From here it was a short step into the debates about relativism and the congruence of criteria for rigor with constructivist inquiry.

### **What about the philosophical underpinnings of the constructivist paradigm?**

One of the issues that bewildered me over several years was what "exactly" (yet can one ever be exact in constructivism if there are multiple constructions?) was the context in which Guba and Lincoln were using the terms "constructivist paradigm" and "hermeneutic dialectic circle" (Guba, 1990; Guba & Lincoln, 1989; Guba & Lincoln, 1994)? There is a clear account of the terms in "*Fourth Generation Evaluation*" which draws on an extensive range of literature justifying the constructivist paradigm in relation to conventional inquiry and preceding measurement eras, but there is no reference to other writings on constructivism.

### **➤ Where does the paradigm fit in the wider context of constructivism?**

The short answer to this question comes from Schwandt (1994, pp. 125-130). He believed that the "constructivist paradigm" is one of six "persuasions", as he called them, of constructivism in the social sciences. The other five he identified were; Nelson Goodman's work, radical constructivism, social constructionism, feminist standpoint epistemologies and Elliot Eisner's work on educational connoisseurship. From Schwandt's perspective, all "persuasions" share the belief that knowledge is constructed not discovered, hence it is an anti-essentialist perspective. However, each "persuasion" focuses on different aspects of the world of meaning for the individual. Much of the work of other "persuasions"

preceded that of Guba and Lincoln's (1989) constructivist paradigm and has potential relevance for constructivist inquiry, although not referred to in their text. In particular, Nelson Goodman (1978, 1984) offered ways to understand the formation and development of constructions. Whilst Guba and Lincoln (1989, pp. 145-147) offered a model for the process of construction change it was not linked to other work such as the thinking of Goodman. Another "persuasion", social constructionism, shares a similar view of the construction of knowledge, but shifts the primary emphasis to the role of social interaction and language in shaping how experiences are constructed (Gergen, 1985). Whilst social interaction underpins the constructivist paradigm epistemology, language does not hold the same precedence at an ontological level, which some social constructionists argue does not exist. Similarly, feminist standpoint epistemologies such as the ideas of Ann Oakley (1981) focus on the social construction of knowledge, particularly in relation to gender and issues of power in the research relationship. Power was identified by Guba and Lincoln (1989, p. 148) as a pre-requisite for the hermeneutic dialectic process, but the debates from feminist writing were not explored.

Why, when Guba and Lincoln (1989) used extensive evidence and references to track their thinking, is there no mention of where the constructivist paradigm "fits" in the wider field of constructivism? The answer, which took me over a year to find, lies in a footnote to the foreword of *Fourth Generation Evaluation* (p. 19) and in an article by Jo Michelle Beld (1994) entitled "Constructing a collaboration: a conversation with Egon G. Guba and Yvonna S. Lincoln". Asked by Jo, "How do you see the relationship between naturalistic inquiry and constructivism?", Guba replied,

They're the same thing, just renamed. It was simply a matter of getting away from some of the implications of the word 'naturalism<sup>5</sup>'. Some people would get confused and say things like 'Is this like eighteenth-century British naturalism?'.... Thinking we needed another name, the word *constructivism*, came to mind because we kept talking about constructions. (p. 100)

My interpretation of this has been that Guba and Lincoln's focus for the constructivist paradigm, and constructivist inquiry, is about **researching** constructions as they exist in the everyday worlds of individuals. It is not about a



theory addressing the social or psychological processes by which constructions develop and re-construct. So, within this research, I have used constructivist inquiry and paradigm to refer to the perspective of Guba and Lincoln, and where I have drawn on other ideas related to constructivism I have indicated this.

### ➤ What about the hermeneutic dialectic circle?

The next thing I worried away at, like a dog with a bone, was the "hermeneutic dialectic" process. Guba and Lincoln (1989) offered this definition,

The process is hermeneutic in that it is aimed toward developing improved (joint) constructions, a meaning closely associated with the more traditional use of the term to denote the process of evolving successively more sophisticated interpretations of historical or sacred writings. It is dialectic in that it involves the juxtaposition of conflicting ideas, forcing reconsideration of previous positions. (p. 90)

Hence, the emphasis is on methodology. In the sense that hermeneutics is the theory, practice or science of interpretation (Thompson, 1990) then this is consistent with Guba and Lincoln's process of developing constructions. However, there is no mention in "Fourth Generation Evaluation" of any writings about philosophical hermeneutics such as Hans Georg Gadamer (1975, 1976) and how these writings fit with the "hermeneutic dialectic circle" proposed by Guba and Lincoln. Intriguingly John Smith (1990) argued, without reference to Guba and Lincoln specifically, that constructivists use a philosophical version of hermeneutics, "with a collapse of the distinction between understanding and interpretation" (p. 176). Citing Gadamer's work, Smith presented the view of constructivism as a situated understanding of meaning resulting from dialogue "just as the interpreter questions the work, the work questions the interpreter" (p. 176) - a comment which reflects the cycling of the circle proposed by Guba and Lincoln. In the sense that interpretivists and constructivists are united in focusing on the world of meaning for individuals, which is then interpreted or constructed by the research (Schwandt, 1994) it is, perhaps, to be expected that there is overlap in the use of terminology. Such a perspective fits with Schwandt's (1994) comment where he described the constructivist paradigm, of Guba and Lincoln 1989), as a "wide-ranging eclectic framework" (p. 128). Tom O'Neill (1995), when reflecting on his experience of using the constructivist

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<sup>5</sup> Used in the book "Naturalistic Inquiry" (Lincoln & Guba, 1985).



paradigm supported this view, in an article entitled "Implementation Frailties of the Fourth Generation Evaluation Approach". O'Neill proposed that hermeneutic dialectic circles are a "process: building up a consensual portrayal of a certain entity by circling within a group of people .... Thus their circle means something similar enough [to philosophical writings] to be confusing but yet quite different" (p. 19). So, in this research I have seen the circles as the process of a series of conversations; between myself and the participants, between participants and myself, and between the texts and myself with emphasis on making explicit the situated context of knowledge (Allen, 1995; Rowan, 1981b). I had similar debates about dialectics to those about hermeneutics, but I merely note here that I have retained the same approach of dialectics as part of the process for debate, critique and synthesis of differing or opposing views into developing constructions.

As I write this thesis I wonder if my desire for "clear terms" and context is unimportant in a postmodern world of uncertainty and paradox. Guba (1992) alluded to this when writing a paper on relativism, "I do not intend to define what I mean by relativism. I believe that key terms ought to be kept problematic, inviting reconstruction and redefinition as knowledge and sophistication grow" (p. 17). So, is my struggle to place the "constructivist paradigm" within the context of constructivism about locating the context-situated nature of knowledge? Or is it about trying to impose rationality and structure? Features, which Jean Watson (1995) proposed, belonged with modernism - not postmodernism.

### **And now to the quicksands of relativism**

Relativism as a concept has provoked considerable debate about constructivism (Gergen 1994; Guba, 1990; Hammersley, 1992; Smith 1990). For most of the time the debates have felt like being on shifting sands in terms of "*How do I respond to these arguments?*" I have come to appreciate Sam Banks' (1982) statement about researchers. "They must be secure enough, confident enough, to *live with*, rather than *escape*, the anxiety consequent to the creative task" (p. 26). I, too, have learnt to live with these complex questions and not expect that I will have an answer for them all. Rather, the importance is to acknowledge them.

If I believe that realities are constructed, then, one of the critiques of this position is the question, "*Does the world exist?*". Guba (1990) wrote "Constructivism thus intends neither to predict and control the 'real' world nor to transform it but to reconstruct the 'worlds' at the only point at which it exists; in the minds of the constructors" (p. 4). Taking this quotation at face value – does the world exist at all? Or are we all parts of other people's constructions? In "The Lewis Carroll Book" (Herrick, 1931), Tweedledee makes this point to Alice when he tells her that the Red King is dreaming about her and then asks Alice,

"And if he left off dreaming about you, where do you suppose you'd be?"

"Where I am now, of course," said Alice.

"Not you!" Tweedledee retorted contemptuously. "You'd be nowhere.

Why, you're only a sort of thing in his dream!" (p. 215).

Tweedledee's view of the Red King is that he holds the power to construct reality and, literally, to create Alice. Is this true of the constructivist paradigm? LaRossa and Reitzes (1993) criticised symbolic interactionism suggesting that "it overestimates the power of individuals to create their own realities, ignoring the extent to which humans inhabit a world not of their own making" (p. 154). The same criticism could be levelled at the constructivist paradigm. So, how do I respond? I believe that the world we live in is tangible, it is not a figment of someone else's construction, but my nursing practice convinces me that from the same event people do perceive, interpret and construct different meanings. Similarly, in their work in 1989, Guba and Lincoln referred to "tangible entities" (see full excerpt on p. 59) around which constructions are formed. So, leaving Alice to her travels "*Through the Looking Glass*", what are the other consequences of relativism?

Another consequence of believing that all realities are equally meaningful because they cannot be assessed against one "true" reality is, as Martyn Hammersley (1992) pointed out, the denial of a social research perspective where any one account is more valid than another. Such a perspective negates exploration of power relations where topdogs and underdogs would all have equal weight placed on their constructions. The logical consequence is that researchers using the constructivist paradigm become "folklorists, devoted to the collection of stories" (LeCompte, 1990 p. 252). My response to this is that I do believe this is a potential weakness of constructivist inquiry. However, I do not

believe that one research approach can suit all research questions and in this study, power issues have not been an immediate concern of the study topic. I do acknowledge the potential limitations of constructivist inquiry in exploring the power structure of family relations in grandparent bereavement.

The third issue within relativism is the idea that "anything goes", a view which can lead into cultural and moral debates such as moral relativism (Gergen, 1994; Guba, 1992). This follows the idea that if no one view of reality is privileged then antisocial constructions have to be accepted as equally meaningful as socially orientated constructions. At the extreme this could mean that someone's view that women should be abused and shot is acceptable as their construction. However, from my perspective this is a circular debate because anti-social views and behaviour will occur regardless of the philosophical view of reality we adopt as individuals, or even as a society, and taking a constructivist view does not legitimate the behaviour. A point which Nancy Moules (1998) made when she wrote, "realities may have equal legitimacy but not desirability" (p. 149). I believe that relativism can, at best, provide one explanation of how individuals hold different constructions. Of more importance is whether "anything goes" methodologically. This has been the criticism levelled against qualitative research methods on the basis of small samples and processes for interpretation of data, with resultant questions about "How useful is such knowledge?"

The term "anything goes" comes from Paul Feyerabend (1975) who wrote,

... the idea of a fixed method, or of a fixed theory of rationality, rests on too naive a view of man and his social surroundings.... it will become clear that there is only one principle that can be defended under all circumstances and in all stages of human development. It is the principle: anything goes. (p. 28)

Given the context surrounding the phrase "anything goes" I would not interpret this as meaning that qualitative research can do anything. Instead I would support Guba's (1992) view when he interpreted it as evidence "that there is no single right methodology which suits for doing inquiry" (p. 19). It is, in part, the over-reaction in response to the criticism that "anything goes" which has resulted in the excessive development of criteria to demonstrate that not anything has been allowed to go on in constructivist or qualitative research. Schwandt (1996) wrote about such adherence to criteria arising from the quest to legitimate

qualitative research as “criteriology” (p. 58). So, what about rigor and criteria in this research?

### **The debate about rigor and criteria**

The debate is about how to assess or “know” if both this research and thesis, which are different things, are good or not. It is about the quality of the work. My thinking on this issue traces a debate which starts with the criteria proposed by Guba and Lincoln (1989), moves to the question of whether criteria are congruent or needed in this research, and ends at a place of compromise.

#### **➤ Criteria proposed by Guba and Lincoln**

Guba and Lincoln (1989) devoted an entire chapter to quality issues in “*Fourth Generation Evaluation*”. It developed, and extended, their earlier work in “*Naturalistic Inquiry*” (Lincoln & Guba, 1985), which at that time period was a seminal piece of thinking when it was published. Carolyn Emden and Margaret Sandelowski (1998) commented, when looking back at the work of Guba and Lincoln from the position of the 1990s, that Guba and Lincoln’s ideas were the work of “giants” (p. 208). Lincoln and Guba (1985) proposed trustworthiness as being the issue of concern in naturalistic inquiry, which is “How can the inquirer persuade his, or her, audiences (including self) that the findings of an inquiry are worth paying attention to, worth taking account of?” (p. 290). To establish trustworthiness they proposed criteria parallel to those used in positivist studies, which reflected the ontological and epistemological differences between the inquiry approaches. The trustworthiness criteria are credibility, transferability, confirmability and dependability<sup>6</sup>. Some of the techniques that Lincoln and Guba (1985) proposed had been developed and used for decades, for example, “thick description” described by Clifford Geertz (1973, p. 3) and the ideas relating to credibility and confirmability developed by Glaser and Strauss (1967) in the context of grounded theory. However, the contribution which Lincoln and Guba (1985) made was to present the criteria in detail and packaged as “trustworthiness” (p. 289). This could then be used to strengthen the claims of naturalistic inquiry as being different from, but of the same potential use and

<sup>6</sup> Explanation and comments about use of criteria in Table A2.2 in Appendix 2.

quality as studies using conventional inquiry. The criteria have been used widely ever since in a wide range of studies under the naturalistic inquiry umbrella. In proposing the criteria Lincoln & Guba (1985, pp. 382-384) cited the work of Edward Halpern, who emphasised the role of the audit trail in tracking decisions, organising research texts, evidencing that criteria have been met and being open to audit by an external auditor. As a closet positivist in 1996 I was a convert to this way of thinking. I established a system for managing and tracking the trail (see Table A2.1 in Appendix 2, p. 449) and even debated having an external auditor. However, actually undertaking this process contributed to starting a shift in my thinking about rigor.

In addition to the parallel criteria, Guba and Lincoln (1989) proposed two further ways to establish the quality of constructivist inquiry studies. They noted that the hermeneutic dialectic process provides a means of quality control where, "The primacy of verification procedures is eliminated since there is nothing to verify" (p. 138). I would agree that, by making several circles around the same participants, there are opportunities for people to check, debate and alter developing constructions – all of which contributes to the credibility. Whilst the hermeneutic dialectic circles may enhance the credibility aspect of the trustworthiness criteria, Guba and Lincoln also proposed a further set of criteria called authenticity criteria. These "spring directly from constructivism's own basic assumptions" (p. 245) as opposed to the trustworthiness criteria which are at a methodological level and which parallel the criteria of reliability and validity in conventional inquiry. These criteria have been less widely debated by qualitative researchers; which is perhaps surprising since some aspects of the criteria are relevant to consider in relation to other forms of naturalistic inquiry. Guba and Lincoln (1989, pp. 245-50) identified five areas within the authenticity criteria, which I have summarised as follows. "Fairness" which is about reflecting the inclusion, and valuing, different constructions in the research. "Ontological authenticity" which is the degree of change, maturation, sophistication in individuals' emic constructions. "Educative authenticity" which reflects the degree to which participants have increased their understanding of the constructions of others outside of their participant/ stakeholder group. "Catalytic authenticity" which reflects the impact of the research in promoting subsequent

action, and "tactical authenticity" which is the extent to which participants are empowered to act by the research. When reflecting on these criteria in 1996 I felt that they were framed from the context of education evaluation. I believe this is reflected in the educative and catalytic criteria, which present the view that evaluation research, will result in change. These criteria spoke to me of a shift, in Guba and Lincoln's thinking, towards a more ideological research focus of empowerment, change and action. As time went on I began to wonder whether I wanted to evidence these criteria in this study. On the one hand, I could provide some relevant evidence (see Table A2.2, Appendix 2, p.452). On the other hand, I questioned whether the expectations of the criteria, such as participants becoming active and empowered, were congruent with the view I held of the relationship in this research where participants had offered a gift. I was certain they had not constructed their participation with these expectations so, should I? I concluded that this was potentially where constructivist inquiry for nursing research and constructivist inquiry for evaluation might have differing emphases.

However, to continue there are further criteria to consider before beginning the wider debate. Guba and Lincoln (1989, p. 224) also proposed four groups of criteria for the "good" case report, as distinct from "good" research. They are:

- axiomatic criteria where the study and report must fit with underlying beliefs such as multiple not single realities;
- rhetorical criteria which are about the style and form of the report;
- action criteria which reflect the effect of the report on the reader to facilitate action;
- application and transferability criteria which reflect whether the case report enables the reader to identify aspects which are relevant to their own context.

Added to the earlier criteria there were, in total, nine criteria proposed by Guba and Lincoln relating to the study, and four groups of criteria relating to the research report. The comment I wrote in June 1996, having listed all the criteria was, *"Will I ever achieve this? This is far more rigorous than any piece of research than I have done previously using the conventional inquiry approach"* (Journal 2:50).

One of the questions I asked myself in late 1996 was whether it was achievable. I was, at that point, still convinced of the need for criteria. I wondered whether I would become more concerned with the criteria than with why I was doing this



research. I noted my thoughts about criteria in Table A2.2 (see p. 452) and debated this material at a PhD school in 1997. One example I pondered about was the group of rhetorical criteria for the research report, which Lincoln described (1990) as demonstrating “power, elegance, creativity, openness, problematic qualities, independence, the writer’s emotional and intellectual commitment to the case itself, social courage and egalitarianism” (p. 74). I wondered whether I could demonstrate, or achieve, these characteristics in this thesis. A turning point in my thinking came when I read Carol Berkenkotter’s (1993) article. She reported a conversation with Egon Guba at a conference where she asked him how he, as a journal reviewer, assessed articles for the rhetorical criteria such as power and elegance. She wrote, “I will never forget his answer. Guba turned to me and said, quite without pause or hesitation, ‘When I’m reviewing I wear my Catholic hat; when I’m writing [about methodology] I wear by [sic] Martin Luther hat’” (p. 299). It could be an ironic comment but it flags the gap, or chasm, between scholarly debate and the practice of research. So, I continued to wonder about these constructions of criteria. How did such detailed techniques and, in effect, requirements fit with the ontological position of relativism in the constructivist paradigm? This leads to the question of whether I need, or should have, criteria in this research.

### ➤ Do I need criteria at all?

I have wondered, during this research, whether it is appropriate to use the term “criteria”? It is a term extensively used by Guba and Lincoln and it fits well with their context in the field of education inquiry. The definition of “criterion” is “a principle or standard by which something may be judged or decided” (New Oxford English Dictionary 1998, p. 435). So, are criteria consistent with a relativist ontology? Can a judgement or decision be made that measures work against a principle or standard, when an absolute, “true” construction of the principle or standard does not exist? And, how will the context, beliefs, previous experiences of the assessors influence how criteria are constructed? Kvale (1996) tackled this from another approach and cited Rorty to support the position of rejecting the view that knowledge is re-presenting an objective world where, “If we regard knowing not as having an essence but as a right to believe” (p. 37). So, if I, the participants, and perhaps the readers of the thesis, *believe* in the



research then does it constitute successful or good research? If this was not a thesis for examination this is the position which I would want to debate and claim. However, it is a thesis, so we will return to the debates about criteria.

Debates about criteria in relation to qualitative research have been widespread and ongoing. One interesting debate at the Alternative Paradigms Conference, San Francisco in 1989 was summarised by Heshusius (1990, pp. 198-200). He noted that there were three positions which people took in relation to criteria.

- a) "Criteria are not needed" – based on "you know if something is good", which links back to Kvale's (1996) view about the right to believe in the work.
- b) "Criteria are OK but can never be fixed or descriptive" based on the idea that criteria need to emerge in context and are always linked to the construction that we hold of them.
- c) "We must have criteria" – based on three reasons of: (i) researchers retaining power by defining the criteria; (ii) the use of criteria in reviewing proposals; and (iii) in making a distinction between research and literature.

All three perspectives relating to criteria have some interesting consequences. The first perspective ostensibly rejects criteria and yet uses "good" which is a construction that can vary, according to who defines it, and is still a criterion of assessment. The second and third perspectives accept that criteria are needed to suit various agendas, but the difference between these two positions is the extent to which criteria are pre-defined for a study. If pre-defined, then there can be some universal or widely used criteria, as opposed to criteria emerging in the context of each particular study. This position, then, raises the question of who defines these criteria? Is it the researcher, other "experts" in the field, or the reader of the research report? Schwandt (1996) argued that the whole concept of criteria is grounded in the foundational epistemology of objectivity which belongs in positivism. He proposed instead that we say "farewell to *criteriology* [which] means that we have not resolved this quest for criteria but that we have gotten over it or gone beyond it" (p. 70). He suggested that we focus on the practical philosophy of social inquiry **with** participants, not **on** participants. For me, this creates the question of whether the only "thing", I hesitate to use the word "criterion", that matters in research which claims to be grounded on partnership is the ethical aspects of the research. Lincoln (1997) made this point

in her discussion regarding how researchers are **with** participants. The intriguing challenge is whether, in moving away from concepts of truth and certainty which from Schwandt's perspective enable us to say farewell, we can actually let go of the notion of criteria. Three years after Schwandt's article was published, Emden and Sandelowski (1999) wrote a detailed critique of the issues surrounding data quality where they suggested that in the postmodern world of research there should be a criterion of "uncertainty". So, even in the uncertain, postmodern world there remains something to be evidenced and assessed.

As I explored further debates about criteria my conception of quality in this research moved from the checklist of criteria to a more holistic view of the interrelated "crises of representation and legitimation. These two crises speak respectively, to the Other and its representation in our texts and to the authority we claim for our texts" (Lincoln & Denzin, 1994, p. 576). This, I believe, offered a place of compromise for this research in relation to an assessment of the "quality" of the research and of this thesis.

### ➤ **To a place of compromise regarding the issue of quality**

In writing this text in 1999 I have focused on the two crises of legitimation and representation (Lincoln & Denzin, 1994), rather than my earlier flurry of activity relating to the criteria discussed previously. I believe my response to these crises, which I began discussing in Chapter 1 when I positioned the research and the text, forms part of the assessment of this work. Such an assessment could consider the claims that I have made for the place which participants have within the research and this text; an assessment could also take into account whether I have "signposted" the decisions and dilemmas through the research. The latter being a strategy, which Tina Koch and Ann Harrington (1998) proposed in order that, "the reader will be able to travel easily through the worlds of the participants and makers of the text (the researchers) and decide for themselves whether the text is believable or plausible (our terms for rigour)" (p. 882). It is interesting that this quotation returns to Kvale's (1996) use of Rorty's ideas about the right to believe in a piece of work. I appreciated Koch and Harrington's perspective because the concept of signposting the research journey is congruent with the belief that constructions are context bound and therefore any

assessment of this research requires knowledge of the context in which the research was constructed. Part of the context of this research has been the following quotation from Lincoln and Denzin (1994) relating to the crisis of legitimation, which has been my personal reference point, not a criterion, for my work. "Does the text have the right to assert that it is a report to the larger world that addresses not only the researcher's interests, but also the interest of those studied?" (p. 578). One response to this reference point was to develop this thesis as a reflexive text, with a separate chapter on the ethical issues in the research to explore whose interests have been met by the research.

## **SETTLED IN THE MARSHMALLOW**

This chapter has explored the shifts in my thinking about the theoretical framework for this research. I started wanting clarity and structure in my doctoral work with a secure framework which would hold a space around me whilst I undertook the research. The blending of beliefs and ideas from other parts of my life, from readings and from some of the dilemmas that arose in the life of the research (see Chapters 4 and 5,) meant that the framework soon "caved in". As constructivist inquiry was informed, and adapted, by other ideas, approaches and challenges, so I took up living in a pink marshmallow. Everything was sticky and clung together; the issue of relativism was tangled up in the crises of representation and legitimacy (Lincoln & Denzin, 1994, p.576), which led into the ideology of doubt (Tierney, 1997), the debates about writing styles (Richardson, 1990, 1994) and the congruency of criteria in a constructivist approach. The ending of the story is that I quite like being in the marshmallow – it is satisfying in that it reflects the interrelated aspects of bereavement research, which has a family and a nursing focus. The marshmallow has become, for me, more akin to the view of Watson (1995), a nurse-scholar, who wrote about the theoretical possibilities of postmodern ontology and epistemology as "invites and works with context, connections, relations, multiplicity, ambiguity, openness, indeterminacy, patterning, paradox, process, transcendence and mysteries of the human experience of being-in-the-world" (p. 61). The experiences described in Chapters 4 and 5 are about the opportunities, the contrast and the complexity

which Watson described. In this research the opportunities and complexities included the ways in which people joined the research from two separate countries, the differing voices of nurse and researcher, and managing the participation of multiple family members when participants wanted different outcomes at different times. These are aspects of the research which I discuss in the next chapter by exploring, in detail, how this research was constructed in practice.

## CHAPTER 4

### A STORY OF PRACTICES, PROCESSES AND CHOICES

#### BEING A BRICOLEUR

This is a story of becoming a bricoleur in response to the emergent nature of constructivist inquiry where things happened which could not be anticipated in advance. Denzin and Lincoln (1994) quoted Levi-Strauss when describing the role of researcher as bricoleur as “a ‘Jack of all trades or a kind of professional do-it-yourself person’” (p. 2). The work of the bricoleur produces a bricolage, that is, a “close-knit set of practices that provide solutions to a problem in a concrete situation” (p. 2). This described my role as the researcher working through a series of decisions and choices to reach a point that could be called the end of this research study. A large part of the bricolage was the use of constructivist inquiry in nursing research and I believe the material in this chapter contributes to the debate of the potential that this research approach has for both nursing and health (Appleton & King, 1997). I found that being a bricoleur required an appreciation of contexts, power relationships and underpinning belief systems to sort through which practices were congruent with each of these. Hence, the assessment of these bricoleur activities in relation to the beliefs I stated in the previous chapter is an important part of considering the quality of this research.

In the following sections of this chapter I explore the plans, decisions and changes involved in working through this research with participants. One area, ethics, is written as a separate story (see Chapter 5). The bricolage described in this current chapter is about the interrelated aspects of the research in practice. The interrelationships mean that there is not an obvious starting point, therefore the chapter starts with the most important aspect of the research; the participants. This is followed by an exploration of the hermeneutic dialectic circles and the processes of the inquiry that underpin the circles.

## **THE STARTING POINT OF THE STUDY – WHO TOOK PART**

Ethics approval for the research proposal was received from the, then, Southern Regional Health Authority (SRHA) Ethics Committees of Otago and Canterbury<sup>1</sup> (see Appendix 3, p. 457). Two further ethics committees noted that the study had received approval from accredited ethics committees; that of my employer (Otago Polytechnic) and that of Victoria University, Wellington, as the institution through which this doctorate is conducted.

I initially planned to seek participants in the Otago and Canterbury areas because the areas were accessible for me to meet with, and revisit, participants. In addition, the two areas combined provided a large target group of bereaved grandparents from whom, given the nature of the topic, it was likely that only a few would respond. I hoped that 10 grandparents, 2 parents and 2 health professionals would take part in the study. We finished as a study with 16 grandparents, 6 parents and 3 health/bereavement professionals. How people joined the study involved a series of interlinked decisions that first began with how participants found out about the study.

### **Contacting grandparents and parents**

My original plan included two strategies to contact people who might be interested in the study. The first strategy was to approach the local parent bereavement self help groups in Otago. I was known to members of the self-help groups – they had provided support and advice when I had discussed the study with them during the development of the proposal. I spoke at the monthly meeting of two self-help groups, this included explaining the study, answering questions and handing out information sheets and consent forms<sup>2</sup> to parents. I asked parents who took these materials to either pass the grandparents' version on to their parents, if the grandparents lived in the geographical areas of Otago and Canterbury, or to read the parents' version themselves (see Appendix 4, p.460). One self-help group passed on the information at a monthly meeting to anyone who was interested. Clearly, the strategy of passing written information

<sup>1</sup> Ethics committees accredited in New Zealand by the Director-General of Ministry of Health or the Health Research Council Ethics Committee.

<sup>2</sup> The process of consent for each interview /contact is discussed in Chapter 5.

to people at self-help groups had two limitations. First, it excluded people unable or unwilling to read what was a lengthy explanation of the research. The written information was deliberately lengthy to try and answer questions people might have in a friendly way. Second, it approached members of families who favoured the use of support (self-help) groups and my own personal experience tells me that groups do not appeal to everyone who would be eligible to join them. However, in terms of this research, it was parents who went to self-help groups who then passed information to grandparents who generally did not go to groups. Of the 16 grandparents only 2 had been to group meetings and 5 were contacted by word of mouth not via parents attending groups. Of the 6 parents, 3 regularly went to a group.

The second strategy I had intended to use to contact potential participants was to advertise in two of the main papers in the NZ South Island. The purpose was two-fold. First, to contact people whose experiences did not necessarily include self-help groups within the family who might have other constructions of grandparent bereavement. Second, to offset the possibility of few people contacting me via the self-help groups because, in 1996, the number of regular members attending meetings was low (5-15 average). I planned to advertise when there had been no further phone calls from interested people. However, by the end of August 1996, I decided not to advertise because, with 23 participants taking part, I found that whilst there was an extensive range of issues and experiences, salient issues were recurring.

### ➤ **Three grandmothers from the UK**

One of the reasons there were 16 grandparents participating by August 1996 was that in July 1996 I received approval (see Appendix 5, p. 465) from SRHA Ethics Committee (Otago) to include three grandmothers from the UK, who had written to me sharing their stories of their grandchildren who had died. Jenny, Colston and Elisabeth came to join the study because of what appears, with hindsight, to be a fortuitous twist of fate. It resulted from a misunderstanding by the Stillbirth and Neonatal Death Society (SANDS) in the UK. In June 1995 I had written to various baby bereavement support organisations worldwide. I was seeking information about resources available to grandparents such as booklets or support groups. SANDS (UK) interpreted this as a request for personal contact from grandparents



in their organisation and put the request in the "Information Wanted Column" of the Autumn 1995 newsletter. Colston, Elisabeth and Jenny wrote, sharing some of their stories and expressing a hope that the information would be useful to me. The dilemma this created for me was huge. Here were grandparents who had willingly shared a personal and painful part of their lives in the hope that it would be of use. However, I could not value their gift by including it in the study because I had no original intention, or plan, to invite grandparents into the study from outside Otago and Canterbury - areas where I could visit. So did I "reject" their letters of sharing? Or did I place their letters as personal communications or background information? Of equal concern was the fact that if I tried to find a way to include them in the study, their participation might create a "risk" for them in terms of sharing personal and painful information in letters. The time delay between posting their letters, arrival of the letters with me and my return reply meant there was no immediate or direct support that I could put in place for them if they were upset.

After discussion with my supervisors I wrote back to Elisabeth, Jenny and Colston outlining these issues, explaining the study (with sample information sheet and consent form) and stating that I would approach the SRHA ethics committee (Otago) for advice about the possibility of their participation. In particular I asked them to consider how they would feel writing and answering questions in letters at a distance. In some respects this was shutting the stable door after the horse had bolted because they had already chosen to write down and reflect on what had happened when their grandchildren died. In July 1996, with ethics committee approval, I formally invited Colston, Elisabeth and Jenny to join the study and I sent them an adapted consent form (see Appendix 5, p. 465). All three decided to participate and continued to write regularly and indepth about their experiences.

Having Jenny, Colston and Elisabeth join the study was a bonus for this study for several reasons. This was an exploratory study of constructions of grandparent bereavement. The intent is not about generalisation, it is about an **understanding** of grandparent bereavement, which is time and context bound and is presented as one joint construction. There could be other joint constructions generated by different research groups, but this one is grounded in the experiences and constructions of 26 participants and myself from NZ and the UK. It does not claim

to represent perspectives of NZ or the UK. Hence, when the ethics committee asked about my plans to actively include Maori participants as part of a NZ view of grandparent bereavement. I explained that I was actively seeking people willing to take part whether Maori or non-Maori, as opposed to targeting the inclusion of worldviews identified with any particular culture. Further, the emphasis in constructivist inquiry is on gaining a range of individual constructions which inform a developing joint construction. To achieve this Guba and Lincoln (1989, p. 178) proposed maximum variety sampling. I have some reservations about the word "sampling" since it has connotations of sampling a meal or an experience with the intention to assess, or represent, the whole on the basis of the sample. Clearly, such a process of generalisation was not the intent of this research. However, I accept that "sample" is the research term used in research writings to represent the group of participants in the study.

A range of individual constructions is reflected as **scope** in the hermeneutic dialectic circle (see Figure 3.2, p. 64 ). At the point I received Colston, Elisabeth and Jenny's first letters, their constructions extended the scope of the existing discussion and constructions in the grandparents' circle. For example, their ideas explored views such as legitimacy of grandparent role continuing when a grandchild dies and putting oneself on hold to support the parents at the time that the grandchild died. These were perspectives I wanted to acknowledge and include in the construction. By the time all three had consented to join the study they complemented other participants, in that everyone **articulated**<sup>3</sup> different aspects of the joint construction. So, the constructions of Colston, Elisabeth and Jenny enabled us to refine the construction further and, as their individual stories illustrate, the socio-cultural context in the UK has similarities to NZ in terms of maternity practices and community views of infant death. From a "sampling" perspective I believed it was appropriate to include Colston, Elisabeth and Jenny in the research because I was making no claim to undertake a study that was representative of any particular group of people. This was not a study about NZ bereaved grandparents, or UK bereaved grandparents or, as mentioned earlier, about bereaved grandparents in general. Instead it was a study based in NZ where I was looking for some people who were willing and able to debate and

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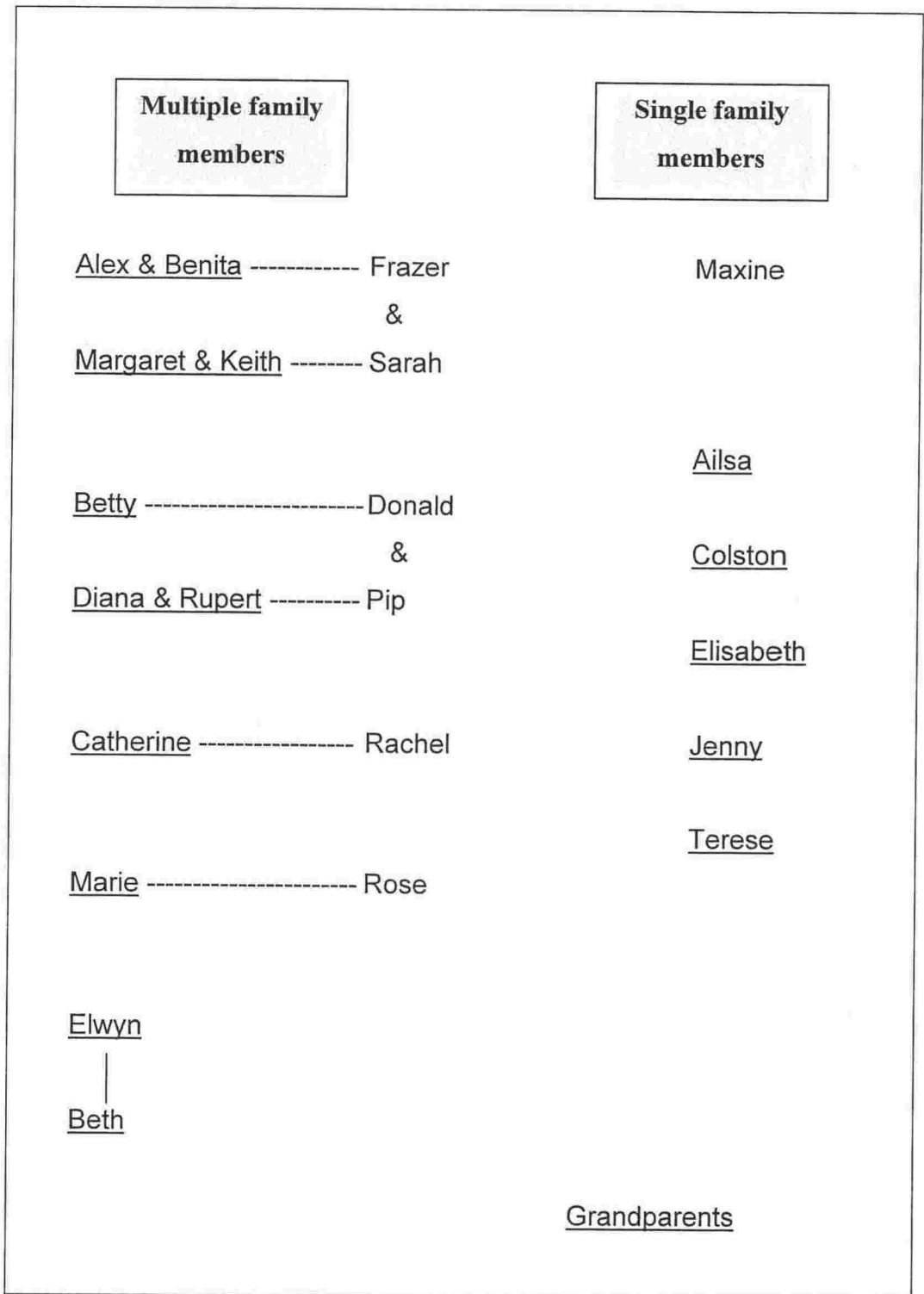
<sup>3</sup> This is the other feature which complements "scope" in the hermeneutic dialectic circle (Figure 3.2, p. 64).

discuss their experiences and ideas. The three UK grandmothers have fulfilled this role.

### **Multiple family members and some detail about participants**

The other serendipitous feature of the research was where more than one family member joined the research. This moved the study towards the idea of a "whole-family" methodology (Handel, 1996, p. 335). The combination of circumstances with the need for scope to include a range of individuals and the wish to include multiple family members when the opportunity arose, meant that the study extended from the proposed 10 grandparents to 16 and 3 parents to 6. The grandparents and parents are from 11 families which form 5 family clusters and 6 individual perspectives (see Figure 4.1, p. 95). During the study the complexity of differing constructions of the same event held by parents and grandparents, in the same families, highlighted the value and the unexpected insights of having these two perspectives of grandparent bereavement.

It is impossible to do justice to a summary of the diversity of participants in terms of their bereavement, life experiences and worldviews. Nor would I want to put the participants into "boxes" which create expectations of their experiences of bereavement. However, the following, with the participants' agreement, provides a quick sketch of some of this diversity. The introduction to participants in Chapter 1 offered a more individual perspective for each participant. Grandparents and parents experienced having a grandchild/child die aged from stillbirth to 9 months of age. The reasons for their deaths included: stillbirth unknown cause, problems with which the baby was born (such as congenital capillary alveolar dysplasia, or left hypoplastic heart); problems which developed after birth (such as bronchopulmonary dysplasia); and SIDS. At the time of writing this in 1999, which is 2-3 years after participants joined the research, the parents are aged 33 to 44 years and grandparents are aged 57 to 79 years. In terms of other family bereavements, five grandmothers have been widowed prior to the death of their grandchild and three grandmothers have had children of their own die. Of the 23 NZ participants, 3 self-identify as part Maori, 3 are grandfathers and 2 are fathers. Grandparents and parents live and work in a range of settings. These include offering urban pastoral care as a minister, practising as a registered nurse, farming in isolated geographical locations and holding roles in the community activities.



**Figure 4.1**

**Family clusters amongst grandparents and parents taking part in the research**

## Health/bereavement professionals

I directly contacted the three participants in the field of health/bereavement practice and sent them the relevant professional version of the information sheet (see Appendix 4, p. 460). I chose two of these participants because of their different areas of practice with families where children die; as a paediatrician and a paediatric nurse. As a result of hearing several grandparents talk about funerals, I decided to contact a local funeral director to see if their bereavement support coordinator, who followed up families after the funeral would be willing to take part. This was not part of the original proposal and required additional ethics committee approval (see Appendix 3, p. 457). Health/bereavement professionals' perspectives offered valuable insights about the context of health care and support for families where a child and grandchild has died.

## A note on who takes part and when

Guba and Lincoln (1989, p.173) proposed that maximum variety sampling underpinning constructivist inquiry has two characteristics: serial and contingent. I have adapted these concepts in relation to this study because of the ways in which the study unfolded. Participants from NZ joined the study sequentially, one after another, and I took ideas from one person's construction to discuss with the next participant. This moved the developing group constructions around members within each of the three participant groups (grandparents, parents, health/bereavement professionals). Jenny, Colston and Elisabeth, the grandmothers from the UK, were on a separate time frame since they all joined the study at the same time.

Contingent sampling refers to each person being "selected" to be: a) different to the preceding person; and/or b) to suit the needs or focus of the inquiry at that point in time. Within the idea of "selecting" participants (Guba & Lincoln, p. 177) is an implicit assumption that some people might be "rejected" or not "included" in the study; which is about the power sitting with the researcher. I fully accept the idea of selecting participants **in principle**, since a joint construction rests on the scope of the individual's constructions. However, I felt **in practice** that when grandparents or parents offered to take part in the study they were generously offering a "gift" to explore personal and private areas of their lives. I wondered "Do I have a "right" to refuse that gift?" and then, "Do I want to refuse that gift if they did

not "fit" with the sampling plan?" The answer was "No, I do not want to reject the gift that was offered when a keen and willing person contacted me to find out about joining the research". I believe this position can be justified in the context of small-scale research such as this, where extensive selective sampling may be unnecessary if the goal of the inquiry is "reasonable scope" with the inclusion of a range of individuals' constructions. This belief rests on my observation that, even with this small, self-selected group of 26 people, all the stories and constructions differed to varying extents and provided extensive scope in relation to grandparent bereavement. Consider for example, Colston and Terese's grandchildren were stillborn, but their constructions of the experience are different in their stories (see p. 189 and p. 199). Similarly, the co-constructions in the stories of Margaret & Keith and Alex & Benita, about their grandson, Matthew's, death, are very different (see p. 240 and p. 246). The events and the people are the same but the constructions are individual. Therefore, I believe that without selective sampling, this small-scale research study met the goal of constructivist inquiry, which is to explore differing constructions and provide extensive material for critique, contrast and development of joint construction(s).

Having decided that I was happy with the scope of the range of constructions that emerged in the discussions, I accepted people's offers to join the research without a "selection process". The only inclusion criterion I originally had in the proposal was that at least 12 months should have elapsed since the death of a child/grandchild. However, as I explore in the next chapter, when Marie and Rose offered to take part only 5 months after Ruby's death, I left aside the criterion with the agreement of the ethics committee administrator. Instead, I worked from the premise that if people made the effort to contact me and wanted to take part then I would accept their offer. I do fully accept that this research claims to offer some constructions of grandparent bereavement but, in not pursuing a "selection" process, there are many perspectives which are not included in the development of the joint construction. In the end, the only "selection" that took place was to regretfully refuse the offers of eight further potential participants who contacted me at the time when I was feeling there was sufficient information for debate with the existing 26 participants.



## OF HERMENEUTIC DIALECTIC CIRCLES

There were three group circles; grandparents, parents and health workers, which followed the process of making the circle round successive participants (see Figure 3.2, p. 64). The actual sequence of the contact with participants is illustrated in Figure 4.2 (p. 101). I briefly explained this process in Chapter 3 (see pp. 63-65) and will recap before exploring this study in detail. The process was initially a **within** participant group circle and focused on developing a group construction formed from the emic constructions of the participants in the group, where the three groups were grandparents, parents and health/bereavement professionals. Discussions were then held **across** groups with participants commenting on other groups' constructions, for example, with grandparents commenting on parents views of grandparent bereavement. My hope was that "at the end all the groups would concur in a common description" (Guba & Lincoln, 1989 p. 212) of grandparent bereavement. This "*description*" would be a joint construction from all the participants which had developed through discussions of etic constructions into group constructions and then finally into the joint construction. The beginning point of this process was the first hermeneutic dialectic circle.

### Making the first hermeneutic dialectic circle

There were three simultaneous circles, one for each participant group. It took between February and October 1996 to meet with, or write to, all the 26 participants in the first circle (see Figure 4.2, p. 101). My goals for the first circles were to establish a relationship with participants which could be developed in further conversations, and to listen to their experiences of grandparent bereavement. In my meetings with grandparents and parents this generally meant listening to a story of what happened.

By focusing on the activity within the grandparents' circle (see Figure 4.2, p. 101) this process will become clear. I met with Terese, the first grandparent to take part, in early February 1996. As I listened she shared her story of what had happened when her grandchild, Bernadette, died. This included a description of what it had been like for herself and her family since the time of Bernadette's death. Sometimes I asked questions for clarification or to explore an area



further. I summarised as we talked to check with her how I was interpreting what she said. After our first meeting I wrote my fieldwork notes which described my immediate thoughts of things which stood out clearly from the discussion. In the notes I identified issues to explore further in our next interview, if Terese was willing, and issues to explore with the next participant.

Fieldwork notes, transcribed interviews and letters became the texts that I used in constant comparative analysis. I undertook analysis alongside the conversations with participants to identify issues and questions to discuss with the next participant. Whilst Glaser and Strauss (1967) proposed constant comparison as a means to generate theory, I have used it in this research, as Lincoln and Guba (1985, p. 339) suggested, as a technique to explore and synthesise information to develop the joint construction - not to develop theory. After meeting with Terese, I took the transcription and identified the smallest meaningful pieces of information which provided a perspective on the research topic. The pieces or units of text ranged in size from a sentence to a page. Guba and Lincoln (1989) described what were, in effect, the units in this research, as "central themes, concepts, ideas, values, concerns and issues proposed by respondent, R1 are analysed by the inquirer into an initial formulation of R1's construction, designated as C1" (p. 151), where "R1" is respondent one and so on, and "C1" is construction one and so on, as illustrated in Figure 3.2 (p. 64). Analysing the units into a very "initial" view of Terese's construction was a process of sorting units into provisional categories where units appeared to have the same content - a judgement partly made using tacit knowledge on a look-alike, feel-alike basis. From reading Terese's story in Part 2, it is possible to identify some of the key issues that I heard in our first conversation. I recorded these in my analyses<sup>4</sup> journal, an excerpt of which follows.

- a) *The shock that it had happened when all had been fine.*
- b) *The pain Terese holds from having only 1 memory of Bernadette, that of briefly holding her.*
- c) *The support which Terese gave to Donna both by being there for her and in practical terms.*

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<sup>4</sup> I have used plural "analyses" to represent the series of analyses that I undertook during this research, with analysis of existing and additional material after each conversation with each participant.

- d) *The importance for Terese of links with Bernadette- she was born on Terese's birthday, she is buried at the bottom of Terese's grandparents' grave, she had the same dimple as Terese's husband. (p. 6)*

From this sorting process I took questions and ideas from my interpretation of Terese's initial construction to discuss with the next participants, Alex & Benita. These included the following.

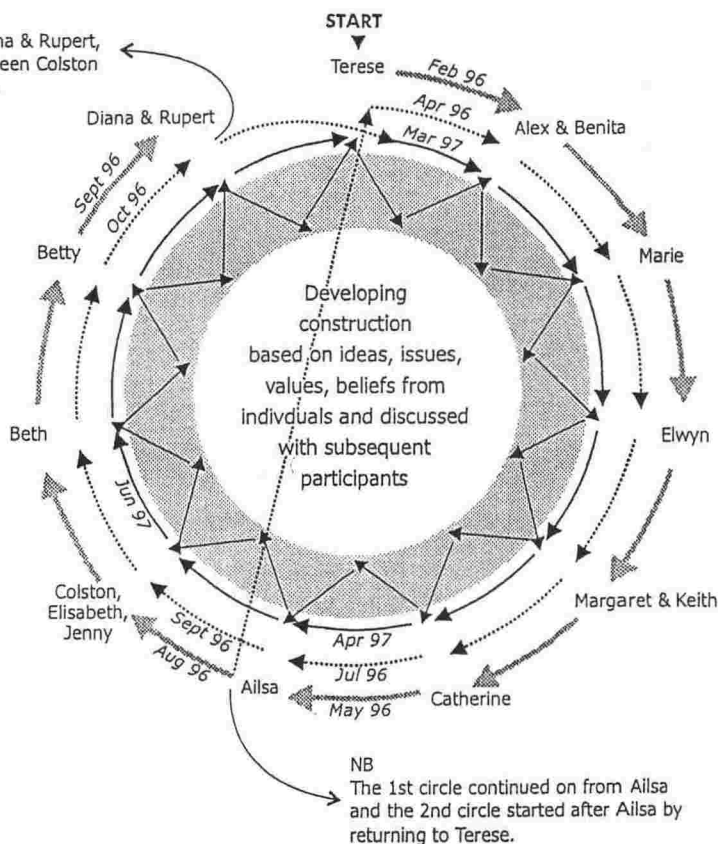
- a) *Was it always a shock? Did anyone ever anticipate death might happen to their grandchild given that people know about the cot death rate and that children do die?*
- b) *What was the similarity /difference, in terms of feelings and pain, if grandparents had more time with their grandchild?*
- c) *Is there an association between few memories and the importance of links*
- d) *Are these 'links' symbols?*
- e) *What are the elements of 'support' which grandparents offer, and why, to parents of their grandchild? (Analyses Journal p. 8)*

In many respects Alex & Benita's experience was very different to that of Terese, for example, they had the opportunity to spend time with Matthew whilst he was alive and were very involved with Sarah & Frazer in caring for him in the short time that he was home. When I met with Alex & Benita, they told their story of Matthew's death and then we shifted into a conversation which clarified aspects of their experience and discussed ideas from my interpretation of Terese's conversation. Their perspectives opened up new areas to consider in a developing construction, such as, part of their shared construction of Matthew's death included the "fact" that he was their third grandchild and only grandson. This perspective raised questions to explore with subsequent participants about the importance of birth order and gender and the meaning that these can hold for different grandparents. From the meeting with Alex & Benita, who were "R2" – the second respondents in the circle (see Figure 3.2, p. 64) I developed further questions and with constant comparative analysis identified areas in what became "C2, a now more informed and sophisticated construction based on the two sources R1 and R2. This is the beginning of the ultimate joint construction sought" (Guba & Lincoln, 1989, p. 152). In this research "C2" was still a very long distance from the final group construction from the grandparents' circle and an even longer distance from the joint construction presented in Chapter 6. In developing "C2" I sorted units from the texts of the meetings with Alex & Benita and with Terese into provisional categories. From this sorting process I took questions and ideas to discuss with Marie who was the next participant ("R3").

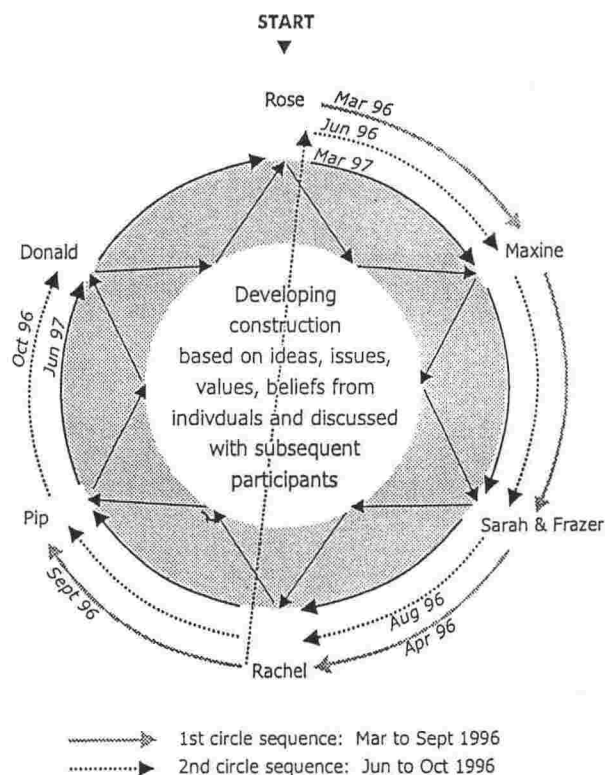
NB

The 1st and 2nd circles stopped with Diana & Rupert, in the 3rd circle all of the discussion between Colston onwards returned to Terese for comment.

- 1st circle sequence: Feb to Sept 1996
- 2nd circle sequence: Apr to Oct 1996
- 3rd circle sequence: Mar to Jun 1997



## PARENTS



## HEALTH / BEREAVEMENT PROFESSIONALS

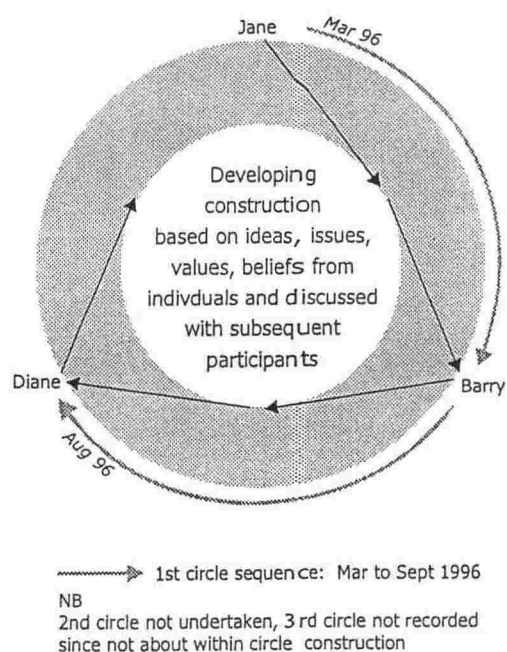


Figure 4.2

The simultaneous three participant group circles illustrating the sequence of my conversations with participants within circles

As Jenny, Colston and Elisabeth all joined the research at the same time, they are positioned as a cluster on the grandparents' circle (see Figure 4.2, p. 101). This position represents my conversations with Jenny, Colston and Elisabeth occurring at the same point in time when I wrote letters to all of them which contained specific questions about their individual experiences and also some general questions framed from the earlier discussions with other grandparents in the circle.

### ➤ **A comment on the parents' circle**

The parents' circle followed the same process as I have outlined for the grandparents' circle. During the first meetings with parents my focus was framed by the following "broad" questions. First, parents' perceptions of the experience and meaning of the bereavement for grandparent(s) in their family, with questions such as *"What do you remember about how it was for grandparent(s) at the time your child died? And since that time?" "Did they talk about their feelings? Seek any support?" "How do you think it was for them as people and as grandparents?"* Second, the family context of bereavement, such as *"What effect has the bereavement had on grandparents and their role and relationships in the family?"* However, before we explored these areas, I asked parents to tell me their story of when their child died. In sharing this, parents gave me an insight into their experiences, their perspectives and construction of their child's death, which forms the family context of grandparent bereavement.

### ➤ **Discussions with parents and grandparents in the separate first circles**

In some interviews with parents and grandparents I listened to their story and asked only a few questions based on analysis of discussions with previous participants. In these instances a full discussion of developing ideas as proposed by Guba and Lincoln (1989, p. 152 ) did not happen, because it felt "inappropriate". I felt that the pain and emotion, which some participants re-lived in telling their story, meant that we needed to return to less painful areas in slowing and closing the conversation. In these cases I noted the issues that I still wanted to ask their thoughts on and held them until our next meeting. In talking with three groups of participants in the first circles I was concerned to clarify

provisional categories and to try and identify properties - the features of the categories; and establish why units did, or did not, belong together in a category. This meant I asked many questions, if it was appropriate, over a wide range of issues since I believed it was like getting the detail on a piece of jigsaw. If I could see the piece more clearly then, in the future, I would be able to see where it fitted with the next piece.

I had planned not to discuss parts of my own etic construction in the first circle, but many of these issues emerged because they were part of participants' emic constructions. I had a view, from my clinical experience, that some grandparents wanted support for themselves, whether from family, friends or health professionals. I had not planned to ask about the issue of support early in the study. However, Terese confirmed that she had wanted to talk to a colleague who had not given her the chance to talk. In the next research conversation, and then Alex & Benita described the mutual support they give, and receive from, Sarah & Frazer. So, I went on to ask everyone in the first circle about "support". The two examples that follow illustrate the reason I had to abandon my original ideas and explore support much further using questions such as "*What does it mean to you?*" and "*When might grandparents want it?*" if indeed they do. When I talked with Marie we had already talked about the parent support group to which Rose, her daughter goes, and which Marie perceived as being very "helpful" for Rose to have a chance to talk about Ruby's death. So, I asked her,

*Alison:*     *Would you have liked to have had the chance to talk to other [bereaved] grandparents?*

*Marie:*     Not really, I don't think. We have all got to handle things in our own way. Everyone's different, it might have upset me more. (Marie 1:10)

She returned to this later when she explained, "Some people are good about talking about her [Ruby], but I don't always want to. And I think I should be able to pick my times of talking about it" (Marie 1:13). I interpreted this position as Marie valuing the idea of support, by managing opportunities that she wants with friends, whereas the idea of support from "strangers" who are bereaved grandparents was not perceived as helpful. Ailsa, too, appeared to value talking about her feelings with friends and family.

I've talked to friends and relations - one sister-in-law, she doesn't mind me talking, I've found that people are quite happy for me to talk about it. I don't

sit and dwell on it at all. I try not to. I don't think I do. But if it comes up in conversation I certainly don't push it away. I think all that helps. (Ailsa 1:20)

It took further discussions with other participants round the second and third circles to begin to disentangle different perspectives about where "support" fits into a construction of grandparent bereavement.

### ➤ **Health/bereavement professionals' first circle**

Within the health/bereavement professionals' first circle the focus of discussion was on the experience, and constructions, of grandparent bereavement which Barry, Jane and Diane held from their different areas of practice as paediatrician, paediatric nurse specialist and bereavement support co-ordinator. I was interested in their views of grandparent bereavement within the family. As their stories, in Part 2, show, they all valued the idea of available, accessible information and support for bereaved grandparents. However, the health and funeral services where they practice, are focused on supporting the parents of the child who dies. This meant that all three had few opportunities to directly contact, meet or offer information or support to grandparents. We explored these areas in the first interviews and, because there were no further issues within the group to explore at the time of starting the second circles, we did not undertake a second circle of discussions. Instead, I asked Barry, Jane and Diane to join the third and fourth circles. In these circles they commented across the circles on the group constructions emerging within the parents' and grandparents' groups.

### ➤ **Different constructions within and across groups at the start**

One of the struggles I did experience, whilst talking in interviews and writing letters, was the complexity of holding a sense of the whole research in my head because, at the outset, there were very differing perspectives of grandparent bereavement both within and across the three participant groups. At one point, within the first parent circle, there were two differing constructions of grandparent bereavement relating to grandparents as supporters for the parents. There was Maxine who was concerned to support and protect her mother, Matthew's grandmother. Then there were Sarah & Frazer, Rachel, and Rose who all received extensive, and varying types of support from their parents. As time went on, the diversity between participants in the same group and across the



three groups became clearer and reduced as more detail from the conversations clarified categories.

### **Making the second circles**

In late April 1996, 2 months after the first circle started, I decided to start the second circles of the parents' and grandparents' groups because so many things had happened in the conversations as I talked with the participants in the circles. I wanted to go back and discuss with people like Terese, the ideas and developing constructions which had not existed when I first met them. The second circles took until October 1996 to complete which meant that for every participant there was approximately 2 months between our first and second meetings. Starting to make the second circle before the first had ended was an adaptation, since Guba and Lincoln (1989) proposed completing the first circle before "making the circle again" (p. 153). However, at that point I did not know where the end of the grandparents' first circle would be since I was waiting for the ethics committee decision on whether Colston, Jenny and Elisabeth could join the study. Meanwhile I wanted to meet again with participants to maintain and develop the relationship which we had started to form in the first meeting. Based on clinical nursing practice, I felt that if I left it too long, the rapport needed to feel safe to explore and critique ideas about painful and private aspects of life would be lost. The second circles followed the same sequence of participants in the first circles. So, in the grandparents' circle I first went to see Terese, and then to see Alex & Benita. In Figure 4.2 (p. 101) I have drawn the first grandparents' circle as continuing beyond Ailsa to the other seven grandparents, whilst also returning to Terese to begin the second circle. This represents that the first interviews with the grandparents participating after Ailsa, followed the form of first interviews as a telling of their story, rather than second interviews which were about clarification and debate. Having seven more grandparents join the circle after Ailsa was a result of the ethics committee approval for Colston, Elisabeth and Jenny to join the study. In addition, opportunities arose for multiple family members of existing and new families to join. This extended both the grandparents' and parents' numbers beyond my original plans but strengthened the research in terms of having multiple family members.



In the parents' group circle, represented in Figure 4.2, the first circle continued beyond Rachel when Pip joined. However, Figure 4.2 does not represent Donald as part of the first circle, because the conversation that I had with him involved a discussion and debate as part of the second circle. Donald did not tell a story of Gracie (as part of being in the first circle) because he felt that Pip had told it from their joint perspective, as Gracie's parents.

The second circles were, from my perspective, very valuable in terms of the new insights that I gained through discussions about where units and categories existed and related. The conversations with participants making the second circle involved developing a dialogue which critiqued, negotiated and reconstructed aspects of individual's constructions in the light of the debate. During the second circles I increasingly talked with participants to explore material from "outside" the group circle (see Figure 3.2, p. 64). This included what Guba and Lincoln (1989) called "literature analects" (p. 211), which is the term they used to refer to "snippets" from the professional literature. In doing this I was mindful of Guba and Lincoln's comment that participants might be unwilling to critique professional literature presented as such. Therefore, when asking for ideas about analects I kept the discussion with participants at the level of a general conversation. In this excerpt I wanted to hear what Elwyn thought about stage/phase theories of bereavement.

*Alison: Some people talk about grief that one can get over, or that it resolves - what do you think?*

*Elwyn: Well, there have been times in the last few years... They [people in general] used to talk about working through your grief. And there have been times when I wondered if I actually worked through my grief when Lindsay died [her husband] (Elwyn 2:34)*

Elwyn went on to explore her ideas of two concepts of bereavement; "working through" and "accepting". She concluded by wondering if one ever gets over it because "if wishing they were here is still part of grieving" (p. 35) then she still feels that for Lindsay, who died 20 years ago.

As part of exploring how grandparents viewed other people's constructions of grandparent bereavement I asked if they would be willing to comment on two booklets specifically written for bereaved grandparents by Margaret Gerner (1990) and Lori Leininger and Sherokee Ilse (1985). These booklets are not

stories – rather they are a guide about grandparent bereavement with sections that include: grief; grandparents and holidays; and tips on coping. I posted the booklets to grandparents either after the first interview if they were later in the circle or after our second meeting for participants like Terese, Alex & Benita who were at the beginning of the circle. I chose the timing of the posting to be after our first meeting because I wanted us to have a chance to talk through individual's stories before reading the booklet. A strategy that Rupert decided, from his perspective, was the right thing to do. "It's a good thing we didn't read those books before you came [for the first interview] because otherwise we would have had preconceived ideas" (Rupert & Diana 2:2). The booklets helped to explore constructions of grandparent bereavement as people made comments in the next interview or letters about them. Some participants made comments, after reading the booklets, which re-emphasised the individuality of bereavement, for example, Diana perceived that the value of such a resource was limited because "I thought to myself that each experience [of grandparent bereavement] was such a totally different experience" (Rupert & Diana 2:2). In this sense, the construction of grandparent bereavement presented in the two booklets did not fit with the personal experiences of bereavement that Diana had in her own life, whereas Marie felt the construction of grandparent bereavement presented in the booklet by Gerner would be valuable for other bereaved grandparents. She made this comment because she could identify with material from the booklet.

Yes, I found it [Margaret Gerner's booklet] very easy to read, and I think the way she expressed her feelings made the book and the information in it able to be absorbed with no difficulty. I think others in my situation would find it most helpful and I would suggest that it should be essential reading for anyone similarly bereaved. Reading the book helped me to sort out many of my muddled emotions and my reactions to the recent death of my youngest granddaughter. I am sure that it is usual to look forward to a new birth with happy confidence, if there had been no indications of problems during the pregnancy. So when my thirteenth grandchild was born, I expected that, as usual, it was the beginning of a happy new life. Therefore, I was not prepared that this time it was going to be different. (Marie Comment: 1)

Similarly, Beth wrote that, after reading the booklet, she had decided to remember Daniel at Christmas with a tree decoration, which indicates that the booklets had informational value for some participants. An extension of this was when some participants asked if they could pass the booklets on to other

families. Elisabeth wrote, "Lorna [my daughter] saw them [the booklets] and asked if I would pass them on for the SANDS book-box as they are short of material for grandparents. She read them and thought they were well written and could be very useful" (Elisabeth 5:1).

During the second circles of the grandparents and parents' groups I continued the category sorting of new units and re-sorting of existing units in the light of subsequent discussion. Some categories had identifiable properties and rules that I could use to check units for inclusion within the category, (Lincoln & Guba, 1985, p.348) whereas other categories remained provisional as I tried to identify why units seemed to belong together in that group and where subcategories would "fit". At completion of the second circles with parents and grandparents I could clearly identify issues and categories which were frequently mentioned or stood out as being "rare". We debated these issues and categories in much more detail during the third circles.

### **Making the third circles**

The third circles took place between March and May 1997 in a series of interviews and letters going round the same sequence of participants within the three groups (see Figure 4.2, p. 101). Before I went to see participants I wrote two "Overviews to-date", one for each of the grandparents' and parents' groups (see Appendix 6, p. 470). The overviews were a description of the analyses, with category headings and examples of units. I chose to write the material in a rather "jelly-like" state because I did not want to present it as structured "findings" which people might not be willing to critique and challenge with me. The purpose of the overviews was to give participants a sense of things that we had discussed, which formed a developing construction. I then asked their help to check, critique and clarify the categories. Copies of both parents' and grandparents' overviews went to the health/bereavement professionals inviting their comment across the participant group circles. This was the first step towards integrating the constructions of the three groups into one joint construction. Comments from all the grandparents and parents confirmed that these overviews contained a range of issues which "fitted" with both their experience and understanding of grandparent bereavement. Several people commented that, whilst they could

appreciate some areas applied to other people, some comments were not relevant to their own experience. As Sandelowski (1993, p. 5) pointed out the investment which participants have in their own experiences can make analytical abstractions appear some distance from their own, individual, experience. The strength of the hermeneutic dialectic circle process was that we could have further discussion about why particular categories did not seem to be part of an individual participant's experience.

The third circle was the turning point from my perspective because I clarified issues and categories within circles and across the three groups' circles. Within the grandparents' circle, Catherine was one of several grandparents who helped me disentangle why grandparents said they felt helpless around the time that their grandchild died.

I think some of it is not knowing- not knowing what is right and what needs to be done and it is like feeling your way and everybody communicating, talking and finding. I remember Rachel saying "We have to get an undertaker - I wonder who to get?" and I didn't really know. (Catherine 3:4-5)

Taking issues from one group's circle and asking participants about it in another group's circle uncovered new perspectives on the within circle constructions and the framework for a developing joint construction across the three groups. Several parents felt strongly about grandparents counting their grandchild as an acknowledgement of the child's existence, so I asked grandparents what they did when asked "*How many grandchildren do you have?*" This opened up a whole new category of how, when and why grandparents "choose" to count their grandchild (see p. 367). Similarly, I asked parents about their thoughts and feelings on being "protected", "supported" and "parented" by their parents in an effort to unravel how parents perceived, as the recipients, the role that grandparents constructed for themselves as a "*parent of the adult parents*". I also asked both generations of parents about actual and desired services offered by health/bereavement professionals and into this dialogue came comments from Barry, Jane and Diane which confirmed the complexity and diversity of experiences in families.

By the end of the third circle of the parent group a group construction was clearly developed which centred around categories of grandparents as supporters and

helpers. This “fitted” with the perspective that grandparents held of themselves, as “*parents of adult parents*”, a category which included features of “*helping out, but not taking over*” from the parents of their grandchild. My focus, at this point, was on confirming a group construction of the grandparents’ circle before moving to a joint construction from the three groups. To do this I reviewed all the units from all the grandparents’ texts to date, checking whether they “fitted” the properties of the categories or whether they needed to move or to create a new category or subcategory.

### **Making the fourth circles**

The fourth circles with grandparents, parents and health/bereavement professionals debated the grandparent group construction that I proposed as a re-construction of all the conversations which had taken place in the grandparents’ group. In November 1997 I wrote the second overview of the grandparents’ developing construction (see Appendix 7, p. 475). In this re-construction I proposed a framework which used the concepts of change and challenge to underpin three time-periods in the bereavement. These were: “*When the world turns upside down*”; “*Riding it out*”; and “*As time moves on*”. Within each time period there were categories and subcategories: “*When the world turns upside down*” included facing, feeling and responding to the challenge; “*Riding it out*” encompassed challenge and change as a family; and “*As time moves on*” focused on accommodating and managing challenge with a variety of strategies such as symbols, mementos and reflection. The presentation of the overview was a shift from the very detailed outline of March 1997, to minimal use of headings and I did not include all the detail of properties and inclusion rules that I had in my analyses journal. Understanding the overview relied on all the previous discussions I had had with participants so, without that context, it may seem “thin” but the category labels were all areas which we had discussed and had developed over time. My interest was whether participants thought this overview, had the “flavour” of, and the “fit” with, the previous conversations we had had.

I posted this overview to participants in all three participant groups for comment. I have called this process “making a circle”, as opposed to member checking, because there was extensive dialogue between participants and myself which

went round the circles again as I checked comments from one participant with the next participant. The comments that came back were "positive". From 26 participants there were 19 replies. Some were excited and enthusiastic; Jenny wrote, "I like the title "Challenge and Change" (Jenny 4:2). Other comments were a confirmation that this "looked fine". For those participants who did not reply, it did not seem to be because of lack of interest or disagreement; several mentioned later, when we were developing their stories, that the non-reply was a confirmation by default of "nothing further to add". All the comments that came back from the fourth circles became the final texts from which units entered the category set.

### **Moving to the final circle – joint negotiation**

Whilst I was pleased participants confirmed that the content of the overview "fitted" with our discussions, I was still not convinced about the structure of the overview in terms of where categories were placed. I had doubts about using the three distinct time-periods and about placing the circle of the family in "*Riding it out*" when I felt that the family circle framed the whole experience. During the next few months I re-read all the units and re-viewed how they fitted into categories and subcategories. For the first time I worked through units within families; previously I had been working with units within the three circle groups. This time, I worked through the units in two families, where there were several family members, starting first with grandparents and then I extended out to include all the other participants to develop a joint construction across the three groups, which was predominantly underpinned by the grandparents' group construction. This process allowed me to make explicit, and potentially account for, some of the differing perspectives between grandparents and parents. The other process which helped this re-construction was working with each participant to develop their story, which gave me a perspective back to the "whole" of the experience as opposed to units of analysis. By the end of 1998 I had re-positioned some categories; for example now the "*Circle of the family*" category surrounded the whole experience (see Figure 6.1, p. 377). I felt the categories were saturated and that the construction felt "solid" by which I mean categories were confirmed, and relationships between categories were integrated and no longer felt ambivalent.



I posted this joint participant construction, written as a case-report, to participants in 1999. This final circle was not a circling round participants. Instead, this was a conversation back and forth between individual participants and myself. In this circle I was asking participants to member check the reconstruction of individual and group constructions and also to read for understanding across the three groups' constructions now integrated into one



on the informational content of data. In addition, the stories enable a reader of this thesis to assess the "quality" of the research by tracing the shift from the individual, emic constructions (in Part 2) to the joint construction (see Chapter 6).

I worked with each parent and grandparent to construct their stories using the information that they had shared with me across several interviews or letters. My contribution to those stories was the narrative sequence and the subheadings which frame different sections of the stories. I developed the sequence from the structure of stories told in first interviews and letters. This tended to follow through: all was well; when things went wrong and the grandchild or child was born and died; the associated events (such as the funeral); what happened afterwards; issues in the family; and reflections looking back from now. Where people had taken part in conjoint interviews I decided that we would create conjoint stories of their co-construction of the experience. However, we did keep the voices within the stories distinct (such as Alex & Benita, see p. 251). The debate that I had all the way through this process was how to have these stories told in the voices of participants; not my voice re-telling their stories. This was the reason I chose to construct the stories using the words participants wrote, or spoke, in our conversations with only the occasional word added to clarify meaning. This meant that the expression, the nuances, and the style was each person's, and was as near as possible to the conversation in which the story was shared. The comment which confirmed for me that this strategy did offer participants a voice came from Catherine, who wrote "You have condensed this very well - this is my story" (Catherine Story Draft: 1).

The stories involved us going round family circles. First, participants commented on their draft story, with minimal changes of clarifying words or names. Only two participants chose to re-write their story; not changing the intent but altering the structure of material and the wording. Then we had to decide on names in the stories. The research started with the premise that we would use pseudonyms but, as I explain in Chapter 5, we shifted, with ethics committee approval (see Appendix 8, p. 478), to using either real family names or pseudonyms. Both options involved participants confirming with family members, whether

participants in the study or not, that they were happy with the final naming decisions. The next stage was a draft volume of all 23 grandparents' and parents' stories posted to all participants as a final member check of their story now seen in the final context amongst other stories. Many participants shared with me their excitement and pleasure at seeing their story with those of other participants. For some people, as I explore in Chapter 5, this was one of the benefits of taking part in the research. Diane expressed not only her own feelings, but those of several other participants when she wrote, "The stories are beautiful and inspirational and very sad too. It is good that they are being recorded. The human spirit is strong and the love and the care that comes through gives great hope for the future of our world" (Diane Letter January 1999).

Once the family stories were developed I started working with health/bereavement professionals to develop their stories, since Barry and Jane's experience in the context of the health system offers an important perspective on grandparent bereavement. As for Diane, she agreed to share not only her professional perspective, but also her personal perspective of having her son die 30 years ago, which influences her practice now.

Whilst developing the stories with the participants, I was acutely aware that participants did not focus solely on the death of a grandchild as an isolated event in their lives. Instead, they wove the event of "When a grandchild dies" into the fabric of their existing, and then changing, lives. This meant that their stories provided a picture, or context, where grandparent bereavement was in the foreground, accompanied by considerable detail in the background. Working with stories which include both background and foreground material is, I believe, congruent with constructivist inquiry, which rests on the belief that constructions are context bound. It is also congruent with my nursing practice where I seek to work with the issues that individuals believe are important or relevant. Holding this belief, I did not edit or constrain stories to contain **only** material about grandparent bereavement. Instead, we included material if it contributed to an understanding of the context of grandparent bereavement. This is most apparent in the stories of parents where they have shared their experiences of being bereaved parents, into which they have woven constructions about grandparent

bereavement. I believe that the importance of the parents' stories is most apparent after reading the stories of parents and grandparents in a family cluster. My sense is, that the juxtaposition of parents' with grandparents' stories illuminates the extent to which grandparents construct their bereavement, and their grief, in relation to the bereaved parents.

## **THE PROCESSES OF THE INQUIRY**

Having explored two important areas of the study on which the research rests - who took part and the circling process; the next section reviews the particular processes that enabled the functioning of the hermeneutic dialectic circles. These were; natural setting of the study, me as the researcher (the human instrument), and the qualitative methods used to generate and analyse texts. These three aspects constitute three of the four "entry conditions" of constructivist inquiry (Guba & Lincoln, 1989) represented in the triangle in Figure 3.1 (p. 62). The fourth entry condition was tacit knowledge. This was an aspect of the research which was woven through the decisions and analyses and which I have referred to in this text at relevant points.

### **Natural Setting**

The focus of the research has been grandparent bereavement in the time and context where it is lived – the natural setting. This meant discussions, meetings and the whole range of contributions which people have made during the research have all been centred in their homes and families. What has this meant for the research? It has affected how people have been, what has been near to them and what I have seen and experienced through the research. During one conversation Alex & Benita commented on the physical location of Matthew's photograph. At the end of that interview I was offered the opportunity to go and see Matthew's photograph, which is placed on the stairway wall between the photographs of his three sisters. It was an important point for me to recognise the importance of physical links with grandchildren and their continuing place in the family. By the completion of the research, nearly all the participants had shared with me, photographs and mementos of the child/ grandchild who had died and of other dead family members. Having interviews in homes meant that conversations with most parents were interspersed with interruptions by young

children. It brought clearly to the forefront of my mind the life and activity of these children contrasting with the death and absence of the child about whom we were talking. Going to people's homes to talk with them has provided the chance to share moments and interests outside of the research, which then offered a common ground and bond which extended into the research conversations. This included discussing ideas of house building and garden development with Catherine, helping Rose to get the washing when it started raining, and most importantly the social sharing of cups of tea and meals which people offered me. The three grandmothers, who wrote letters from the UK, and I, worked hard to share our natural setting. We sent photographs of whatever was important at the time and shared considerable amounts of news about family, home, gardens, the weather and health. Parts of the letters reflected the content of the general chatting that occurred at the beginning and end of interviews. This sharing of self enriched my understanding of the context from which the data came.

Research in the natural setting also meant conjoint interviewing. There are five couples who took part in this study and I followed their choice of separate or joint interviews. Eight participants chose joint interviews. For Pip and Donald, the fifth couple, joint interviews were not an option given Donald's commitments the first time that I went to meet Pip, so we had separate interviews. The advantage that I perceived in joint interviews was that it was a conversation in the natural setting where participants jointly hold their roles as parents or grandparents which, Daly (1992b) argued, are a construction created and shared by the couple of that self identity. Joint interviews enabled me to explore ideas simultaneously with two participants, which brought double the energy and insights to bear on developing constructions. An example, is where Frazer developed upon Sarah's comment reflecting on my role in this research (see p. 122). Daly (1992b) noted that the disadvantage of conjoint interviews could be a situation where couples will not share private or conflicting views. I did not have the sense that this happened. Instead, I was appreciatively aware that, at different points, participants shared individual views, which were not always in accord with each other. This was a reminder that, whilst couples may hold shared constructions, they also hold individual constructions, for example, when I asked Diana & Rupert if there was a difference between their roles when Gracie died this was the reply.

- Rupert: There is probably a difference  
 Diana: What [ would be the difference]?  
 Rupert: Doesn't the maternal thing come through probably stronger on the grandmother's side?  
 Diana: We talked about everything together didn't we? I mean, I didn't rush off and do anything. .... I don't know that there is anything special. I don't think there was for me anyhow, we did it together as far as I was concerned. (Diana & Rupert 2:23)

However, I was mindful in joint interviews of being alert to the well-being of both participants since, whilst listening to one person talk, it is possible not to be attentive to the feelings, or potential distress, of the other person who is not talking.

### **Me as researcher – the human instrument**

One of the advantages of research in the natural setting is the opportunities it has brought to see things which, at the outset, I did not know that I needed to know - like the positioning of Matthew's photograph on the wall between his sisters. This is the reason Guba and Lincoln (1989) proposed that only the human instrument is able to adapt, respond and shape the study according to what happens. Examples in this research included responding in a conversation to follow up an idea which someone suggested, or sorting units of analysis using tacit knowledge into look-alike and feel-alike groups. The particular features I have brought to this research, as a human instrument, are the voices of two roles, which I hold – as nurse and as researcher. Both have guided decisions, in particular the ethical choices discussed in Chapter 5, and the nature of how I, the instrument, have positioned myself in the research relationship. These two roles have, I believe, strengthened the research and illuminate the contribution that nursing can make to the use of constructivist inquiry in health research.

### **➤ The duet of researcher and of nurse- discord or descant?**

As I discussed in Chapter 3, I entered the study with two roles, as nurse and researcher, because I undertook research in an area of my nursing practice. As a nurse I work in practice with bereaved families and as a nurse educator, the role as nurse is generally focused on health, well-being and care of the client – in effect a therapeutic role with the emphasis on healing. As a researcher my role was focused on completing this study to advance understanding of

grandparent bereavement. Exploring the consequences of having two roles, and two voices, as a human instrument is an important part of this research. Each role has a particular perspective with consequent responsibilities and actions which could create tensions regarding how to be as a researcher and what to do in the research relationship. Munhall (1988) distinguished between the two different imperatives of nursing research and proposed that where conflict arose the "therapeutic imperative of nursing (advocacy) takes precedence over the research imperative (advancing knowledge) if conflict occurs" (p. 151).

Munhall's perspective differs from Streubert and Carpenter's (1995) view of the role of nurse-researcher as "... the intertwining role of caring professional and the scholarly researcher. Neither role can, nor should be, suspended in the conduct of nursing inquiry" (p. 310). My own experience of the two roles in this research has not been one of conflict, and has been more akin to Streubert and Carpenter's perspective that the roles are intertwined.

I believe that the two roles can co-exist and that, within this study, I moved to have one role, as a human instrument, which had two voices; each one providing a valuable and differing perspective on the decisions that I have made. The potential for the two roles co-existing occurred because this research was born from my nursing practice. My choice of constructivist inquiry, which emphasises aspects of research such as multiple constructions of realities and partnership with participants, was a considered decision to frame the research in a way which was congruent with my nursing practice. I still have roles within my work life which are "nurse" and "researcher" – it has only been in this one piece of research that the two have been integrated into one role "nurse-researcher" which has the guidance of two voices commenting from my nurse and researcher roles. The voices have enjoyed both duets and monologues as the study progressed regarding decisions about what I should do. The particular examples explored here are about the tension between the human instrument as an instrument solely for research purposes and the nurse researcher who takes on, at times, a predominantly therapeutic role, which is not about being a research instrument. I recognise, however, that the therapeutic role can benefit the research instrument with an increased understanding of emic constructions in the context of the research. In addition, Paul Rosenblatt (1995) proposed, and



I would agree from this research, that the boundaries of roles are artificial distinctions and at times almost any activity will, for a bereaved person, be therapeutic. Similarly, Sally Hutchinson and Holly Wilson (1994) argued that a perspective which holds interviews as having a core identity which is **either** research **or** therapeutic, is not substantiated. Whilst recognising that my roles were intertwined as nurse-researcher, there were specific situations which arose where the voices of nurse and researcher could be clearly distinguished. These included giving suggestions or information, and affirming choices or experiences.

*Should I give a suggestion?*

Colston wrote in her sixth letter that she had no photographs of her grandson, Christopher, although her daughter, Christine, does.

As much as I would love a photo I felt it an intrusion to ask for one, they are so precious to her. This I find a sadness, we have photos of Martin and Justin [Christine's other children] almost at birth. It was something as a mother I had to let Christine have for herself.... I feel the family record is incomplete without a photo, but even now I keep that feeling to myself.  
(Colston 6:6-7)

I could hear both voices when I read that letter from Colston. In my researcher voice this was information about the importance of memories and tangible links to Christopher. It illustrated that she put her wishes second to her perception of the rights of her daughter, Christine. In my nursing voice I heard this as an opportunity to explore whether Christine had ever indicated that she did not want Colston to have photographs. I was aware, from my nursing practice, of the emphasis which parents place on whether grandparents ask for, and display, photographs of their grandchild who died. Both actions are important acknowledgments of the existence of the child. I decided to write with comments from both nursing and researcher voices.

*Reading your comment about photos and not asking Christine for one. I wondered is it because you don't want to take a photo away from her? In which case could you colour laser copy, as we do for families in the photocopy shops here? Or is it because you feel that the photos should be something that only she has? I was interested because all the parents I have talked to are intensely aware of whether the grandparents have photos or asked for them and then whether they displayed the photos or just put them in a drawer. Anyway I did not mean to pursue something so private, but I did wonder. (Alison C5:2)*

Colston wrote back and described how she had the opportunity to talk with



Christine. She wrote,

Carefully, I mentioned the subject of photos of Christopher and my feelings, knowing that she had some photos but I couldn't ask for one as I felt they were so personal to her. I felt that was a border I could not cross. Her reaction was interesting, she had only been thinking recently that I hadn't got one and wanted me to have one. [excerpt from Colston's story see p. 192]

Colston explained, in her letter, that she now had photographs of Christopher. After reading her letter, I wrote in my journal *"I am glad that it has turned out to the end which Colston wanted and that chance stepped in with Christine having the time to talk with Colston"* (Journal 3:202). Re-reading those letters it is easy to hear my nursing voice wanting to intervene with a suggestion. Equally, given that the research was underpinned by partnership with participants, it can be argued that the researcher role can legitimately go beyond the data gathering remit and extend to making suggestions.

A similar situation to Colston's occurred when Betty asked what I thought she should do as it was coming up to the first anniversary of Gracie's death, "Well, I know that the anniversary is coming up and it is rather difficult to know how to approach it. I haven't discussed it lately with Donald and Pip. How do you think they are coping with it?" (Betty 2:4). At this point both voices had the same perspective; confidentiality was paramount. I could not discuss details with Betty, even though I had seen Pip and Donald the day before whilst Betty had not seen them for several months, so I kept to the truth without details.

Alison: *I think they are good, Betty*

Betty: You see they are going to be up here just before that time. I don't know if I ring up on the day - it could be a bit harrowing perhaps to be dragged through it all again, isn't it? (Betty 2:6-7)

At this point my nursing voice was dominant because I have often listened to parents talk about their pain, and sometimes anger, when family members have either forgotten or chosen not to acknowledge the anniversary. So, I actively encouraged Betty to contact Pip and Donald. Such encouragement was still consistent with my researcher voice which emphasised that I was not trying to take "data" from participants without making some return as part of the reciprocity of the relationships. The distinction for me in both my working roles (nurse and researcher) is that I would never "tell" someone to do something like this, to do so would not be a partnership and would not be "right".

- Alison:* Yes, on the other hand it can be nice that grandparents remember even if it is just to say "I am thinking of you".
- Betty:* That's right. And of course it is Jessie's birthday so I could make a phone call to her in a way and she is a great chatterer on the phone.
- Alison:* So, yes, that might be a good way. ( Betty 2:6-7)

### Should I give information?

I also offered information outside the taped interview or the loan of resources when it seemed useful. On the first visit to Pip, one of the things we talked about was that Jessie and Lachie [her other children] did not know that Gracie had been cremated and that Pip and Donald had her ashes. I suggested that sometimes the opportunity arises which makes it easy to explain. I posted some books for children about death, which I use in my practice with families, for Pip to read with the children (Althea, 1982; Varley, 1992; Wilhelm, 1985). At the second interview, Pip told me that she had told the children about Gracie.

But I did tell the kids about her being cremated ... we were having a fire and Donald was having his pyromania phase. The dog dug up a nest of rabbits and they were quite little so we have the idea that we don't keep them if they are too little because they are not going to survive and the kids are quite good about. So Donald tapped them on the head and burnt them. And I thought, "Ah yes, this is the opportunity that Alison was talking about" and I went through that with the kids and told them about it and I don't know if they listened or not but I did tell them. And I said that we have got Gracie's ashes and then they haven't said anything more about it. (Pip 2:7)

The beliefs that have guided my actions to provide information or material have sought to maintain the intent of partnership within the relationship. It was about reciprocity (Oakley, 1981), which is discussed further in the next section on qualitative methods. In return participants have not only shared their stories with me but lent me material which they felt might be relevant, such as Ailsa, who lent me the book "Widowed" by Beryl Te Wiata (1987) because,

I found that very, very good to read that and it can fit into any sort of bereavement really. Hers was definitely for a partner but a lot of the situations could come in too and you are sitting reading, you think "That is exactly how it was, that's how I felt at that particular time". (Ailsa 1:22)

### Giving affirmation

Most of the interviews, and some of the letters, had points where people asked me for confirmation about their thoughts. Sometimes this was in the context of normalising grief to check out that what had happened to them was similar for

other people. Betty was reflecting on how she and the family had coped with Gracie dying.

Betty: Do you think some people take it harder than we [our family] have?

Alison: *I think some people are not so accepting, Betty. They seem to struggle more with the meaning of it and the anger of it and then you can't put it in your life and keep going every day.*

Betty: Yes, I guess it is temperament isn't it? I have never suffered with blood pressure in my life- I take things very calmly on the whole. But it is to do with how your make-up is?

Alison: *Which is why it is so individual. ( Betty 2:16)*

My nursing voice felt it was important that I provided the affirmation and support that Betty was seeking; my researcher voice felt discussions such as this were an important part of constructing grandparent bereavement.

### ➤ What do participants think about the human instrument?

Interestingly, when I asked some of the participants what it had been like talking with me, and whether it made any difference to the research that I was a nurse, their response was focused not on my clinical role or credentials but on the "nature" of the relationship. It confirmed the centrality of the relationship for the creation and development of ideas presented in this research. Catherine was very clear about this.

That [being a nurse /midwife] doesn't make any difference - it is you. You are very nice and easy to talk to - it is you. When you came in here tonight and started to talk to me I could just sort of feel myself go "Ahh" [relax] (Catherine 2 :16).

Where my professional role was perceived as important or relevant to the research it was because of the knowledge, skills or insights that participants felt I brought to the research as a nurse/midwife.

Alison: *Does it make any difference, knowing that I am a nurse and a midwife when you talk to me? ....*

Sarah: I suppose I see you as Alison, the person. But then you do have that knowledge that comes through in your questions that you do know about it [bereavement].

Frazer: As you say it is probably more the person than the job in this situation. However, with all your communication skills it would not be the same discussion without necessarily having that sort of background. (Sarah & Frazer 2:17)

Beth summed up how I, too, felt, that the role of my nursing voice was to

passionately believe in this research as having value.

*Alison: Lastly, does it make any difference knowing that I am a nurse or a midwife?*

*Beth: It probably does a little and I think that is probably because your interest is there. Something you are doing because you are caring [about bereaved grandparents]. (Beth 2:13-14)*

Whilst I have situated this discussion of roles and voices in relation to the human instrument it is clearly linked with the next section, on qualitative methods, which includes the nature of the conversation relationship in which constructions are debated.

### ➤ **The trade-off of the human instrument**

The adaptability and responsiveness of the human instrument has a trade-off in that I, as researcher, came with my own constructions of reality. My concern has been to ensure that it has not dominated the direction of the research and the development of group constructions. From the start I used reflexive journaling to explore my constructions of the research, the decisions I made, my experiences and my constructions of grandparent bereavement. This helped to track changes in my views which have then become integrated in this thesis, such as the excerpts in Chapter 2, which reflect my thinking in 1995 and the text in Chapter 7, which reflects my thoughts in 1999. One area that I re-visited several times to reflect about was the role of gender in this research. I was conscious that the majority of participants were women, a feature of qualitative family research where fewer men seem to take part (Daly, 1992b). I was also aware that within the texts, features of the category "*parent of adult parents*" included the support which grandmothers provided to newly bereaved parents. Whilst exploring this category I was challenged by Daly's (1992a) comment that researchers' gender "may affect their perceptions of how family members carry out roles" (p. 9). I spent some time critically reflecting on whether the roles I hold, and those I have experienced women having in my family, led me to construct grandmothers as nurturing or whether it was a constructed reality for individual participants. As discussed in Chapter 6, we reached a position where participants supported a view that both individual responses and gender differences shaped grandparents' constructions and activities.

The other strategy I have used to balance the power that I have as the researcher, was debriefing with supervisors. This offered a space to explore things which arose and to test out my proposed responses. Early in the research, I debated at length with one supervisor how I was going to manage the process of finding out whether a family member who was taking part, was willing for another family member to know that they, too, were taking part. I then debated my responses if they said "No", they did not want other members to know about their involvement. These debates became increasingly important as a whole range of ethical decisions emerged (see Chapter 5).

## Qualitative Methods

Qualitative methods offer the means for the "human instrument" to find out about the research issue. The following discussion of qualitative methods in this research is divided into conversations with interviews or letters, constructions of conversations as texts, constant comparison as a process for analyses, and issues of rigor.

### ➤ Of conversations seen as interviews and letters

The main source of information in this research has been gathered from both interviews with, and letters from, participants. As I proposed in Chapter 3, conversation as relationship has been a way of exploring constructions. In taking part in conversations I have seen them as dialogue **with** another person not **to** another person. We can all think of instances where someone talks **at** or **to** us, but to create new insights, share experiences and understandings the dialogue needs to be **with** each other; turn taking, clarifying and checking. As I explored in the previous section, the voices of nurse and researcher have guided how I have responded in conversations. However, by using the word "conversation" I am not implying that there was a lack of focus or direction to the research. I worked with the perspective that D. Jean Clandinin and F. Michael Connelly (1994) proposed where conversations include "in-depth probing, but it is done in a situation of mutual trust, listening and caring for the experience described by the other" (p. 422). Whilst the focus of the study was on in-depth exploration, the earlier examples from interviews and letters illustrate that there

was a blend of unstructured dialogue, listening and very structured question and answer discussions.

A considerable amount has been written about interviews for the purposes of in-depth, unstructured or structured discussion (e.g., Chirban, 1996; Finch, 1984; Fontana & Frey, 1994; Gordon, 1997/8; Kvale, 1996; Miller & Glassner, 1997; Mishler, 1986) but there is less writing on the use of letters. Clandinin and Connelly (1994) position letters amongst a range of personal experience methods, which include interviews. As they explained, there are similarities between interviews and letters as,

In letters we try to give an account of ourselves, make meaning of our experiences and attempt to establish and maintain relationships among ourselves, our experience and the experience of another....one of their merits [letters] is the equality established in the give and take of conversation (p. 421).

The issue of equality is an interesting one, given that the time delay between posting and receipt of letters does create a space where neither person can dominate the conversation, which is always in the balance within the spoken conversation of interviews. Was there a difference, from my perspective, having conversations with participants through interviews or letters? My sense is that letters can be, but are not always, more reflective and structured than interviews. However, letters do not share the joint excitement of new insights. Instead, the reader, or writer experiences these alone, and there is a delay until the next letter goes conveying news that the previous letter created this response. However, I believe the differences I perceived between conversation style in letters and interviews, were as much to do with the different relationships I had with individual participants as it was to do with different media of conversation. What did participants think about interviews and letters? As the first and second group circles used either interviews or letters for conversations I was interested to know whether participants favoured one or the other approach. So, I asked the question in the third circles framed around *"If you met me at interviews – would you have preferred to have written down your experiences in letters?"* and *"If you wrote your experiences by letter, would you prefer to have met me personally at interviews?"* Participants whom I met in interviews unanimously favoured interviews. Several pointed out that they were not letter writers and would not have taken part if the research had relied on letter writing. For Colston, Elisabeth



and Jenny, the reply was less definitive. All favoured the opportunity of writing but also valued the idea of meeting face-to-face which enables an immediate conversation as opposed to a postally distanced conversation. Colston explained this as,

Writing to you gives me a chance to think in depth, which I may not have done in an interview. I usually read your letters and put them away for a few days to let them stew before answering, this gives me time for reflection. Yet I would dearly love to have met you. (Colston 9:4)

It seemed that the premise on which everyone undertook to take part in the research, whether interviews or letters, appeared to be the one that they favoured for our conversations. Having considered letters and interviews as the methods of conversation in this research, there are three aspects to consider: how conversations were structured; how conversations from interviews became texts; and a note on analyses.

### *How conversations were structured*

Making the epistemological claim that conversation is the place in which ideas, emotions, reflections, experiences are shared, and the place where constructions are created, critiqued and developed means that I need to give some detail of how the conversations unfolded. For, as James Holstein and Jaber Gubrium (1997), writing from a social constructionist perspective, claimed the **how** of active interviewing, which in this research includes letter writing, is as important as **what** is asked. The “what” has been discussed in the earlier parts of this chapter. To explore the “how” I could give extensive excerpts from interviews and letters, but instead, I have chosen to offer my construction of the process, balanced with the constructions participants were willing to share. Within my construction of conversations as meaning-making social interactions I believe there are three key areas: reciprocity in practice, respecting family space; and time and energy.

### *Reciprocity in practice*

Viewing conversations as meaning-making interactions, means that the relationship on which conversations are grounded determines the possibilities of that meaning-making. Hence, the beliefs I discussed in Chapter 3 are the ones I have worked to uphold in interviews and letterwriting. In particular, these beliefs

have been about establishing a relationship with rapport (Fontana & Frey, 1994) which involves both trust and give-and-take. Oakley (1981) described this as “no intimacy without reciprocity” (p. 49). In response to this, when I planned the study I wrote,

*The study is about families and we all come from families so it may be important for participants, who are sharing about their families or their practice as health workers in families, to know where I come from in terms of the research and my family and practice. I will share this detail on both the information sheet and in the first meeting if this is appropriate. (Research Proposal, 1995, p. 3)*

Striving for rapport within research relationships has meant that participants have asked me lots of questions about my own experiences of family and bereavement. I have answered these honestly, without protecting what have been painful areas in my own life. The importance of “intimacy”, in the sense of trust and closeness, is in creating a space where both participants and I, felt safe to share ideas and feelings, which meant that unanticipated disclosures felt “safe” (see pp. 154-155). The importance of caring about participants and sustaining research relationships which we had developed together was the reason I felt passionately about keeping in touch with participants. Undertaking doctoral study part-time, in the context of commitments such as work and home, meant that there were active phases and slow phases. I was very conscious of keeping in touch with participants in between our interviews and letters in the group circles. So, in November 1996 after the second circles had been completed with the grandparent and parents groups, I started the first of a series of newsletters and phone calls about every 3-4 months from the last contact with participants. They were newsletters of progress in the study and of general conversation. From my perspective they represent reciprocity and sharing because I did not expect to be able to enter and leave people’s lives for short episodes of interviews and letters without making the effort to sustain an ongoing relationship.

### *Respecting family space*

Writing about families, Daly (1992a) noted, “they are typically thought of as being one of the most closed and private of all social groups. Family members coalesce in the processes of preserving and protecting their traditions, secrets and habits” (p. 4). The question then, is where do we, as researchers,

stand in relation to these places. From the start of the research I wanted to develop a relationship with participants where they could feel safe to explore personal and family experiences, as far as they wanted to. I had no wish to cross boundaries into the family space where participants might share information which they regretted with hindsight, since that was not about a safe, regardful and respectful relationship. As I explore in Chapter 5, there were unanticipated disclosures by both participants and myself, but the context of the relationship provided ways to acknowledge these safely. When writing the research proposal I wondered how "far" participants might trust me to explore some of the realities of family life, which include conflict and differing perspectives. Even at the first meeting some participants chose to explore differences in views and behaviours within the family with a candour that I found startling. However, such comments were firmly situated in a stated context of love and appreciation for family members, whilst at the same time "seeing" that everyone, self included, has their weaknesses or irritating habits. It is a view that is part of the joint construction where everyone is appreciated as trying to do their best even though it can result in differences and tensions.

During the third circles I asked grandparents and parents if they felt *"there is some information that is not shared with a 'family outsider' such as myself? Things which are too private?"* (March 1997 overview questions). The consensus was "No" people felt that they had talked freely about the things that were important about grandparent bereavement. Diana & Rupert said that, "As far as we were concerned 'all was revealed'" (Diana & Rupert 3:1). Colston wrote, "I don't consider you to be an 'Outsider', the purpose of all this is not intrusive" (Colston 9:4). These comments reflect the intent of the relationship where we all shared the same goal, to acknowledge grandparent bereavement. From one perspective it was an advantage that I was not a family member, because I was not part of the bereavement. As Ailsa explained,

Even people who were there at the time, they have all got the same feelings as you and you can talk about it, but it brings it all back. When you talk to someone else [not family] it is all the little finer points perhaps you forget about and it brings it all back and perhaps airs it and puts it away in a safer place, so that it is put to rest. (Ailsa 3:22)

There was a sense of relief described by several grandparents and parents in being able to share feelings with a "safe" non-family member, which was an opportunity that some grandparents had not had whilst they had maintained the role of supporting the parents. From another perspective, there will always be areas that I cannot share as a non-family member. As Terese explained, "there are some things that I could share with you and not share with the family, but there are some things that I could share with the family and not share with you" (Terese 3:20). Such "things" are about a shared understanding, based on intimacy, shared events and memories of being there at the time, which might be explained, but from Terese's perspective would not have the same meaning for a non-family member who is outside the family "culture".

### *Time and energy*

The length of interviews and letters varied hugely and duration gives no sense of the nature, the intensity or the new understandings which occurred in the dialogue of that space. However, to give the context; interviews ranged from 1-2 hours for the first interview, 30 minutes to 2 hours for the subsequent interviews and letters ranged from 3 to 12 sides of A5 or A4 paper. Of course, within that conversation space, we talked about other things like gardens, families, holidays, books, as well as about grandparent bereavement. My research journal entries reflect that conversations existed in different forms. Sometimes they were a very creative space where we "sparked" ideas, depth and insights. Sometimes our attention was focused but the conversation did not have a life of its own which, from my perspective, was why it was valuable to be able to re-read letters and transcripts to re-visit and gain new insights. The commitment to channelling energy into that interaction was, at times, draining for us all.

Ailsa said, looking back from our third meeting,

I found after the first one I felt completely washed out, completely drained. Not after the other ones but the first one I found that. Perhaps it was bringing everything to the surface gain and in another way that is probably a help. It is probably another part of healing and it is probably very good for everyone to do that. (Ailsa 3:22)

Similarly, I learned to transcribe and work with texts for analysis or stories in short sessions of 1-2 hours, then I needed to physically move for a few minutes

to release the pain and tension that I had absorbed as I tried to work with the meaning in the words. I also learned to allow plenty of time after interviews and reading letters to both reflect on what had happened, write my fieldwork notes, and to let go of some of the feelings and pain that I felt having listened to people's stories.

Before interviews and reading letters I took a few minutes to centre my attention on the forthcoming conversation. Sometimes it meant that I did not read letters on the day they arrived and I would wait for a time in the next day when I had the opportunity to re-enter the world of that relationship and attentively read what was written. Catherine noted the same point when she told me in our third meeting that she had kept the letter and copy of the March 1997 overview in a drawer for several weeks because she did not want to look at it immediately because it would bring back pain and memories. When she chose to read it, it was at a time when it felt "alright". These quotations illustrate the commitment that participants gave to this research by re-living their pain; it was a gift that was both a privilege and a weighty responsibility. It was a privilege because grandparents and parents unstintingly gave me their gift and talked about intimate and painful issues with insight and depth in a way I had not imagined possible. The gift was a weighty responsibility in terms of making choices and decisions to honour that gift, which are explored further in Chapter 5.

The reason that people took part in the research and gave such commitment was their valuing of grandparent bereavement as an important issue. Parents perceived that recognition and people outside the family gave support to them when their child died. In contrast their parents received nothing and part of the parents' commitment to the research was seeking to redress that injustice.

*Alison: [Was there] any reason why would we be happy to take part in the research and suggest it to your mother?*

*Rose: Just that I think it is very valuable because it is not something that we ever thought about before. But I see that there is a big gap in support. I mean it is there for us [parents] if we want it, but for people like grandparents [there is nothing]. It [the research] is so that they don't feel like they don't count, because they do. (Rose 2:24)*

From the perspective of grandparents their interest in the research was to help

others and to claim a place for grandparent bereavement. As Terese said,

I thought it was important as an issue.... When you think about it there is not much thought given to what grandparents feel like at all. They just carry on, they're not supposed to have feelings, they just carry on as normal. (Terese 2:16).

Terese described, in her story that few people wanted to hear how she felt, which contributed to her sense that people and society do not expect grandparents to have feelings. Elisabeth explained the importance of acknowledging feelings when she wrote, "I think the finished product will be of great use to bereaved grandparents who don't know what is expected or how to express the great sense of loss and sadness they feel" (Elisabeth 3:2). Margaret, too, was motivated for other grandparents, "Well, I just thought if it was going to help someone else - that is a good thing" (Margaret & Keith 2:24).

The extent to which the research was perceived as able to help other grandparents varied and was tempered for everyone by an appreciation of the individuality of bereavement. Whilst the event of having a grandchild die is shared, the experience and construction of it varies. As Beth said in her story, it is "individually different for everyone, with the common bond of emptiness and loss" (see p. 296).

### ➤ **Constructions of conversation as text**

I made a decision prior to starting the study that I would audiotape the interviews if people gave permission, whereas Lincoln and Guba (1985, p. 241) favoured the use of fieldwork notes wherever possible. I was aware, from my experience in both clinical practice and education, that the presence of tape recorders can be disconcerting at the beginning of a discussion and that this can continue if this tension does not fade like an habituation response. My decision was made on the basis of the following points from my practice with bereaved families that I discussed with supervisors and colleagues. I felt that people talking (even voluntarily) about such a personal and painful event as a grandchild/child dying needed support in terms of "quality listening". This meant focusing completely on what they said, maintaining eye-contact and being an active part of the relationship. I could not provide this while simultaneously jotting down points for research data. I wanted the process of moving from conversations to joint



construction(s) to be transparent and traceable to participants, so that they could go back to what they had said and see how this was related to the final joint construction. Finally, I wanted the voices of participants to have a place in the research text, not just as reported through my eyes, or with short quotations. This meant taping the actual words they used in interviews to then be able to develop their stories. I used two tape-recorders in each interview to ensure quality for transcription. This became particularly important where there were two participants and myself talking. So, did the arrival of two tape-recorders constrain participants willingness to talk? I did not have a sense that it limited the conversations and the perspective from participants was similar. Marie wrote after two interviews, "I initially found all the equipment a little daunting but realised afterwards that I had forgotten about it once we started talking" (Marie Letter:3).

### Constructing transcripts

Moving from audiotapes to transcription began a process of constructing conversations as written documents. The decisions were **who** was going to transcribe and then, **how** to transcribe. Advice from many of my colleagues was to have tapes transcribed by an "efficient typist". After the first interview with Terese I felt that I could not hand over the tape to a stranger. There were things that we had discussed which were a window into painful and personal areas. I felt that giving the tape to someone who had not been part of the discussion, and who had not sat in the context of that home and started building a relationship with Terese, would be putting something special and private on public view when it was not ready to go there. I added to these feelings the argument that, in transcribing the tapes, I would have the advantage of repeatedly hearing what participants said. I went on to transcribe 57 interviews. Looking back from now, it was the right decision, although it would not have been an option with a larger study. I did have comments from several participants that it was "good" to hear that I was the only one who heard the tapes. Two participants who regretted something that they had shared in a moment of intimacy knew it could be edited out and that I, alone, had heard it. Listening to the tapes three times (typing, checking and final checking of the

transcript content) meant that I developed a very clear view of who said what in which interview which was helpful during analyses.

The next question was, "How to transcribe?", because the transcriptions became the texts used in the analyses. As Kvale (1996) pointed out, "the question 'What is the correct transcription?' cannot be answered – there is no true, objective transformation from the oral to the written mode. A more constructive question is: 'What is a useful transcription for my research purposes?'" (p. 166). The answer I chose was to form a written document that used the actual words of participants. Editing during transcribing was confined to removing some of the unevenness of direct conversation such as omitting repeated "ums", since I decided these could be safely ignored. I also added punctuation to form speech into sentences whilst constantly being aware that in this process I was constructing, and potentially changing, the meaning (Sandelowski, 1994). I affirmed to everyone that the transcripts were the raw materials and that the version which would go on public view would be formed, smoothed and sculpted as a written communication. Transcripts were posted to participants to read, to alter and to return if any changes were needed. After these changes the agreement between participants and myself was that the transcript would be used within the analyses. From the transcript some excerpts would be used as quotations and they could edit and consent to the use of these, particularly in relation to the context in which any quotation was being used. In practice, participants' editing was minimal and it occurred in only eight transcripts. It was confined to correcting names I had misspelt or a change in punctuation to alter the meaning of the text.

I had not appreciated, until I met participants in second interviews, just how important each part of the research was for some participants as a validation and acknowledgement of their dead grandchild. Several grandparents noted that they were keeping their copy of the transcript in a "special place" or "in a memory box". Several commented that this material was for their child, the parent of the grandchild, to be able to read. This created for me an imperative to consider what purpose the "partners" in the research wanted the materials to serve. My purpose was clearly different from that of some of the participants and

yet the transcripts could be created to serve a dual purpose as a reference for the research and as a family resource. The change I made in response to the question "*What is a useful transcription for participants' purposes?*" was to consider the quality of the copy that participants held. When I knew that people, like Marie, read and re-read the transcript I printed it in 14 size font for easier reading and offered an extra copy for the memory box, whilst the other copy remained in everyday use. I also transcribed handwritten letters and sent a copy back with a photocopy of the original for participants to check the copy of the letter. After confirmation from participants, this became the "data" which I was using for analysis and participants could then refer back to the typed copies to see the source of my coding categories.

### Editing

Editing was a process that I actively encouraged participants to do throughout the research. Editing was minimal for all the items which participants checked; transcripts, stories quotations and the joint construction. From my perspective, the importance of editing as part of the process of member checking was that it upholds a relationship of partnership since this is a piece of research where participants and I have jointly shared and created the constructions - so we jointly own the material. As I described in the section "Respect for the Gift" in Chapter 5 (see p. 171), I believe editing has an ethical imperative. However, it is also congruent with the constructivist paradigm where multiple constructions can be seen as situation and context dependent. This means the story I share about Event A today, will differ in small or large ways from the story that I present about Event A tomorrow. The differences between the stories will be a result of circumstances such as how I feel, new insights I have had about the event, and who the audience is. All the stories and quotations are "true" to the participants as representations at the time they consented to their use. However, as time progresses these may not be the representations that participants now want to put forward in text. This meant that the opportunity for participants to edit until the final draft of this thesis was consistent with re-visiting, re-viewing, re-finishing their story to present to different audiences. At first they shared their ideas with me, then their stories with each other, and now their ideas are shared in final form with the unknown public as readers of this thesis.

Encouraging participants to re-view their materials would not be congruent with an exogenic view of knowledge where interviews or letters "capture" reality. However, I have viewed conversations in this research as media for constructing reality through the use of language which, given the differing interpretations (constructions) of words, both communicates and potentially obscures meaning,. As Jody Miller and Barry Glassner (1997, p. 105) debated, interviews (and I would add letters) provide only a small window "inside" the experience which exists "outside" of the interview. So, editing, in some senses, is like trying to polish the glass to give a clearer view through the window on to that experience.

### ➤ **Constant comparison as a process for analyses**

The continuous interaction between analyses and conversations meant that much of the detail of analyses has been explained in the cyclical process of the hermeneutic dialectic circles. The two aspects of the analyses that I want to note are the process by hand, and tracking decisions within the series of analyses.

#### *The process by hand.*

I undertook the process of constant comparison by hand, physically cutting up texts (letters, transcripts and fieldwork notes) into units of analysis that varied in size from a sentence to a page of text. I stapled units to index cards which were labelled with identifiers cross-referencing to both text sources and to the category to which I coded the unit. Whilst I sorted units across the participants within the three circle groups, I always filed the units within envelopes labelled with categories in a folder allocated for each participant. This meant easy access to source and re-sort material because, by the end of making the fourth circle, there were 1298 units relevant to developing constructions of grandparent bereavement. Analyses by hand had not been my original intention. I had planned to use NUD\*IST (Richards & Richards, 1994) as computer software to manage my coding of the large amount of information and to provide a trail of decisions on the coding process. The context of my life, which surrounds the research, changed that decision. First, there was no quiet space by the computer as we lived on the noisy building site of our new house. Second, I badly damaged one of my hands which meant that typing was no longer an option. The consequence of changing to the pen and paper process meant that I

needed to establish strategies to track decisions relating to analyses in the way I had planned to use the option which NUD\*IST offers of printing successive drafts of coding text to nodes and developing analysis trees.

### *Tracking decisions within the series of analyses*

From the outset of the research, I used the analyses journal to record everything from thoughts on what to follow up in the next interview, to memos, provisional categories, and coding decisions. As an auditing process early in the research I took four transcripts on which I marked the units of analysis and comments about possible categories. I made three copies and sent these to my two supervisors and a critical friend for their comments on this coding process. I was not asking for confirmation that my coding was correct, since clearly that would be inconsistent with believing that we all construct the world and will have differing constructions. I was asking for feedback on whether my comments were: comprehensive (was I missing issues of relevance/ importance?); and extensive (was I viewing the interviews through a sufficiently "wide lens" in terms of memos and linking ideas laterally?). The feedback was valuable as confirmation of my comments, of the powerful emotions within the interviews and offered several other perspectives to consider in relation to the roles which family members took in the texts. Coding changed over time, particularly as more units were added during the first and second circles with grandparents and parents. I gradually created a series of documents which recorded how the units from each participant's text were coded to categories. On the document I made notes of ambiguous categories and inconsistencies which led me to change coding. The example in Appendix 9 (see p. 483) records the units used in analyses of participant 13's texts coded into categories developed in the November 1997 overview. As one of my struggles was holding in my head the issues and categories across the three participant groups, I worked with mind maps to explore possible relationships of categories to each other.

### ➤ **Issues of rigor in practice**

Whilst the wider debate about rigor was part of Chapter 3 (see p. 81), there were three sources of rigor in practice; the pilot study, the audit trail, and member checking.

### The pilot study

The piloting work that I undertook at the beginning of this research was conducted with the belief that I was working with conversations to explore constructions. It was for the purposes of trialling my skills, equipment and decisions in the context of exploring constructions. I did not complete this pilot work with a grandparent or parent whose grandchild or child had died. I made that decision for two reasons. First, talking with a parent or grandparent about grandparent bereavement would have meant that the study started, since what they said would inform and guide what I talked about with the next participant, so, in effect I would be starting into a hermeneutic dialectic circle. Second, I would feel uncomfortable with "excluding" their story from the research report, which would be the practice of survey or experimental work, since the conversation would have been a gift given to the research. My concerns, relevant to pilot work, were about decisions made during interviews and transcribing. Therefore, those were the skills that I piloted by practising conjoint interviewing with two colleagues, which alerted me to a range of practical issues around tape-recording and transcribing.

### The audit trail

The audit trail, which I started to establish from early 1996, was a process of indexing and locating research materials using the categories proposed by Halpern (cited in Lincoln & Guba, 1985). I found there were materials which I felt did not fit into Halpern's categories and ended up noting this separately (see Table A2.1 in Appendix 2, p. 449). I believe that the most valuable aspect of using Halpern's categorisation of materials has been the indexing system which enabled me to rapidly find materials. Kathleen Rodgers and Beth Cowles (1993) made a similar point when they suggested that whilst Halpern's system is complex, what is crucial for all qualitative researchers is having a process to find and track information. As I explained in Chapter 3, the process of identifying criteria and establishing processes, texts and materials as evidence relevant to the criteria contributed to my questions about the congruence of criteria in a constructivist study. As a consequence I shifted my focus to maintain a "trail" of reflections and decision points through my journals, not with the intention to undertake an audit but to enable writing a reflexive account of the research. In



writing this thesis as such an account, I have drawn on the ideas from Koch (1994) and Koch and Harrington (1998). As part of that story one of the aspects of audit and criteria is, of course, member checking.

### *Constructions of member checking*

During my debates about the role of criteria in this research I became caught up in member checking as a technique which is the mainstay of credibility. Clearly, the hermeneutic dialectic circles described earlier, provide a continuous member checking of my interpretations of dialogue around the participants. At this methodological level, member checking makes sense because who else but members can confirm if the researcher has appreciated the issues which members perceive as important. However, there were a number of problems which I experienced in relation to the complexity of a technique which enters the theoretical, ethical and representational aspects of the work (Sandelowski, 1993, p. 1).

At a theoretical level, member checking presumes that members are commenting on the developing joint construction from the position of a stable construction. Yet the ontological assumption of the constructivist paradigm is that constructions change, and they did during this research. Stories and constructions altered with time and new ideas, a notable example was the issue of whether grandparents wanted resources or outside family support for themselves. Early in the research, many participants, clearly did not perceive a need for such resources, as Marie explained (see p.103). However, by the end of the last circle a number of people commented that perhaps, in hindsight, they would have liked to talk to someone. The shift in views about support illustrates the point, which Charles Bloor (1983) noted from his own experience, that participants' views can be "provisional, contingent and subject to change over time" (p. 164). Sandelowski (1993, p. 4) suggested that the revisionist nature of narratives, and I would add ideas and constructions, is one of the problems of going back and checking with members. I fully support Sandelowski's point that the process of member checking results in change and revision, however, I believe that has been a strength of this research, to allow everyone time to reflect on, and re-view, their experiences and ideas - because at an ethical level

member checking relates to fairness. Member checking also extends to the ways in which the views, quotations and stories are represented in the text (see pp. 171-173).

I came to realise that, regardless of purpose, member checking is not a stand alone technique; it is situated in the research relationship described earlier, which, in turn, constructs what happens during the process of member checking. Many participants took an active role in this process, making exhaustive notes on anything I asked them to look at, and spending time discussing ideas with me during our meetings. Other people were more factual and less likely to debate issues at length. This seemed to me partly how people we as individuals and also about learning a role. Some participants made more comments as time went on and some participants made comments some times and not at other times. This suggests that time and energy are important parts of the context of the checking. There was another context that I did not immediately appreciate until one participant explained to me that this research was "different", with a positive connotation. I had talked with participants about the process of this research and the idea of working together in partnership to discuss and debate ideas. For some participants this experience was "different", to their previous experiences of research where they had provided data, such as blood samples and activity diaries with no further contact with the researchers. This highlights the importance of knowing how participants construct the concept of member checking since it determines what happens in the process. As Bloor (1983) wrote, the responses of members are not "*immaculately produced but rather are shaped and constrained by the circumstances of their production*" (p. 171) – a view which, as Sandelowski (1993) suggested, means that member checking itself is a social process which should be open for analysis. So, where does member checking fit in this research? It has been part of the research but, given the earlier points, I do not claim it as a technique to establish trustworthiness. Instead, it has been a process about checking that participants (Other) are happy with their place in the text and with the claims that the text makes about grandparent bereavement.

## **SOME THOUGHTS TO CLOSE**

This chapter has unravelled the bricolage of this research with the expectation that, in making the reasoning behind the practices transparent, it is possible to understand the context in which this research was created. There are many decision points, in a study such as this, where different researchers might make different choices and, in most situations, there is not an absolute "right" decision. What I have tried to demonstrate in this chapter is that the choices I have made in this study are grounded on the beliefs discussed in Chapter 3, and the research aim presented in Chapter 2.

The key aspects of this research explored through this chapter, are the process of hermeneutic dialectic circles which were used to develop the joint construction and the individual stories. Underpinning the circles were the nuts and bolts of the research which included: the form of the research shaped through conversations, transcriptions and analyses; the duet of nurse and researcher; and practices of audit and member checking within the debate about rigor. The research relationship has remained central throughout every aspect of the research; from the hermeneutic dialectic circles, to how conversations developed, to decisions about transcribing and member checking. It has been the reference point in decisions to consider what choices there could be, if I wanted to uphold a respectful partnership. The positioning of this study within the arenas of qualitative, family and thanatological research meant that there were a range of situations and choices that emerged in the context of "What was the right thing to do?" This is the story, which unfolds in the next chapter, where I explore the context of dealing with the anticipated and unexpected ethical issues that emerged during the study.

## CHAPTER FIVE

### A STORY OF EMERGING ETHICS

#### THE DEVELOPING PICTURE

The story in the previous chapter explored many of the choices and decisions in the research process. This chapter continues in the same vein, exploring the emerging ethics of the situations and choices which arose as the study changed from a sketched outline of ethical considerations at the beginning, to a fully painted picture at the end. The positioning of this study is at the point where three areas of research intersect; qualitative, thanatological and family research. These areas of research bring particular ethical issues, which have been a significant part of this research in terms of my own learning. In turn, I believe the story in this chapter makes a contribution to the debate surrounding research ethics. The particular issues arising in family research mean that the following discussion is predominantly focused around participants who were grandparents or parents, not health/bereavement professionals.

Lincoln and Guba (1985) noted that design “means planning for certain broad contingencies without, however, indicating exactly what will be done in relation to each” (p. 226). For the purposes of gaining ethics committee approval I had to provide some detail around the “broad contingencies”. However, that approval was like a licence to drive. Only after gaining the licence was I able to experience the range of ethical<sup>1</sup> decisions needed, similar to being a newly qualified driver who is faced with fitting their car into a tight parking spot. As Denzin and Lincoln (1994) highlighted, the decisions can be challenging to resolve, as “researchers now struggle [my emphasis] to develop situational and transsituational ethics that apply to any given research act” (p. 12). Part of the struggle which I experienced, was working as researcher-bricoleur (see discussion of this role on p. 89) to find ways which “felt” right to respond to situations where statements in codes of ethical conduct (e.g., American Psychological Association, 1982;

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<sup>1</sup> “Ethical decisions” used to denote moral decision making where “moral” is about right and wrong and linked to the principles of beneficence and non-maleficence.

Nuremburg Code and Declaration of Helsinki referred to in Levine, 1986) did not provide direction for what was happening in the study.

## AT THE BEGINNING – THE CHALLENGES AND THE CONTEXT

When I first started planning the “broad contingencies” of this research, the comment from several research colleagues was, “*That sounds very interesting research... but you might stir things up for the people, you might make them cry*”. This comment constituted a challenge to me as a nurse-researcher because it implied that the research might be harmful and people would be better left “in peace” rather than being asked to revisit painful memories. At a philosophical level it raised for me the question “*What is the premise (or the evidence) underpinning the assumption that research exploring bereavement is likely to be harmful?*” It also raised the question “*Is it ‘better’ for bereaved people not to take part in research and therefore not talk about their experience and cry?*” in which case should they be protected from taking part? Parkes (1995) pointed out that this has happened in a number of bereavement studies where access to bereaved people has been denied by a range of gatekeepers. Yet, my own experience in practice and research gives me evidence that people do **want** to talk and, sometimes, to cry. In addition, there is a range of work using different research methods in very sensitive areas of bereavement which, in itself, is evidence that people have been willing to take part (Cook & Bosley, 1995; Klass, 1996; Rosenblatt, 1996; Stroebe & Stroebe, 1998-90; Stroebe, 1993). The **challenge** from these colleagues’ comments meant that I wanted to explore, with participants, their perceptions of taking part in the research and whether they constructed it as “harmful”? As Alice Skinner Cook and Geri Bosley (1995) questioned, when reflecting on their experiences of undertaking bereavement research, “*shouldn’t speculation about the consequences for research participants be replaced with the voices of the bereaved on the matter?*” (p. 158). Moving to the context of constructivist inquiry, Guba and Lincoln (1989) placed considerable emphasis on ethics, both as a requirement to plan a negotiation oriented inquiry that can reach consensus, and to avoid one construction being advantaged over another.

So, the research proposal, developed at the end of 1995, was written in the light of the discussion above and in the context of a high level of awareness surrounding NZ research ethics, resulting from the recent experience of "harmful" research at the National Women's Hospital (NWH), Auckland. The Cartwright Inquiry highlighted a number of serious issues that had occurred during the NWH study of cervical cancer. The resultant recommendations included requirements of institutional ethics committees to ensure standards of practice for ethical research (The Report of the Cervical Cancer Inquiry, 1988). This brought the associated expectation that subsequent research would be rigorously assessed in relation to ethics. Consequently, I could foresee the need for me to give sufficient detail in the proposal to ethics committees to provide evidence and reassurance that this study could be completed with sensitivity and without harm to participants.

### **The sketched outline - what I proposed at the start**

My original research proposal, written in November 1995, was guided by a number of considerations. Philosophical writings on ethical ways of knowing in relation to nursing (e.g., Johnstone, 1994; Thompson, Melia & Boyd 1994) provided a helpful background. The rights of clients (e.g., self determination; privacy; anonymity, confidentiality, fair treatment), documented in codes of ethics in relation to professional conduct (e.g., New Zealand Nurses Organisation, 1996) were also a relevant context. Specific ethical considerations in relation to the rights of research participants in the different areas of research, such as qualitative (e.g., Denzin & Lincoln, 1994; Hutchinson, Wilson & Wilson, 1994); nursing (e.g., Holloway & Wheeler, 1995; Robley, 1995) family (e.g., Daly, 1992a; LaRossa & Wolf, 1985) and thanatological (e.g., Cook, 1995; Rosenblatt, 1995) offered insights into the complexity of research ethics.

The proposal content was formatted to suit the requirements of the SRHA ethics committees. The following information is taken directly from the main proposal and indicates the proposed plan for the research. The ethics approval has been referred to in Chapter 4. I have included this entire section from the proposal to provide evidence of the detail in which I was planning the study<sup>2</sup>. This, in turn,

<sup>2</sup> As this excerpt is shorter than the literature review I have presented it in quotation format.



provides the context for the subsequent discussion of issues that I had not anticipated.

## Ethical considerations

### ➤ Consent

*The project will initially be explained to potential participants in the information sheet. If they are interested they are invited to ring and discuss it further to arrange for a meeting with myself to answer any question before signing the consent form. It will be stressed in this pre-consent meeting that confidentiality is maintained in the study and that the participant retains the choice as to whether to audiotape interviews and to turn the tape off at any point in the interview. Consent in this study is written, with both myself and the participant retaining copies of a signed form. To acknowledge the fact that many participants will have different views on aspects of this study such as having direct (unidentified) quotes used in publications, preferring a short summary to the whole thesis or wanting to only participate in one interview the consent form has a range of options which the participants can tick, amend and sign. Whilst the consent form is signed to signify willingness to participate in the research, I will also check verbally for continuing consent at the time of the second and third interviews.*

### ➤ Confidentiality

*Respect for the intimate stories from individuals about themselves and their families is fundamental to this research. All data obtained in this study will be confidential. Audiotapes will be numbered and not named and will be kept with transcripts in locked storage and data files will be on a password protected computer. During transcription of interviews all names and any identifying events will be altered to protect confidentiality of participants. The transcriber, apart from myself, will guarantee to respect the confidentiality of participants whose tapes she transcribes [In the event I transcribed all tapes myself]. Where discussion at the second or third interviews is based on interpretations of data from both the participants and other participants, no details will be shared about other participants' unique experiences. Discussion will be in the general form of clarification e.g. "Someone else has raised the issues of whether they felt they could claim to be a grandparent when their grandchild died. How did it feel for you?"*

### ➤ Access to Data

*During and after the study, access to data will be limited to myself and as noted above will be kept locked and password protected. For the purpose of discussing and verifying analysis where participants have consented, portions of the data (with pseudonyms) may be shown to PhD supervisors, consultant for the research and the members of my PhD peer supervision group for discussion.*

## ➤ Use of Data and Results

*At the end of the research participants will be offered the opportunity to have their tapes returned. Where tapes are not requested, they and the transcripts will be kept in locked storage for a period of 5 years as recommended by the Australian National Health and Medical Research Council (1990). Where any further analysis or presentations of this material in another form e.g. anthology of stories is proposed I will contact participants to negotiate consent or refusal for their story to be part of this.*

*Either a short summary of results or copy of the thesis will be given to participants – they will choose which they prefer to have. Participants when signing the consent form will be noting agreement that the research will be publicly available in the form of a PhD thesis and publications of this material may appear in academic journals- copies of which can be sent to them if they request. The thesis and publications will only contain direct quotes (which are not identifiable) where participants have given permission for these to be used.*

## ➤ Risks and Benefits of Interviews to Participants

*All in-depth interviews carry a risk-benefit ratio for participants. The research is not designed to cause emotional or physical distress and seeks to avoid this by: excluding newly bereaved participants; ensuring that there is careful discussion of what the research involved prior to consent and having an experienced interviewer. However, as a health professional I recognise that the sensitive nature of the research topic may provoke a variety of reactions for participants. The clinical experience that I have will be used to set boundaries and where necessary stop the interview and suggest appropriate referral to a GP, counsellor or self-help group (most of whom I have links with in the local area). If the research has obviously "triggered" issues which would benefit from counselling then costs of up to three sessions per participant will be provided from the research fund.*

*If the participants have any concerns about the research or myself, then they can contact my primary supervisor as noted on the information sheet. However, I would note that research interviews are not necessarily harmful to participants and may have therapeutic effects. First, because participants who choose to take part are able to assess themselves for potential harm arising from discussion with me before consenting to take part. As Pauline Boss (1987), a family researcher noted,*

*[participants] may be wiser than we think. Those families who agree to participate in sensitive research (e.g. family loss, incest, violence or chronic illness) may sense that they can handle the "stirring up" whereas those who refuse know (and often say) that they cannot. (p. 152)*

*Second, interviews offer the chance to talk and reflect, which can bring a therapeutic benefit to the participants. Sally Hutchinson, Margaret Wilson and Holly Skodal Wilson (1994) recently undertook an overview of research on a wide range of health related topics (including twin death) using in-depth spontaneous positive comments from participants about the outcomes from interviews. Comments included: selfacknowledgement, sense of purpose; self-*

awareness and healing. As the authors noted, this did not necessarily apply to all participants, but did apply to a reasonable proportion. This evidence combined with my clinical experience indicates that for some participants in this study the interviews may act as a benefit by providing the opportunity to reflect and talk.

### ➤ Risk of Research for Researcher

*Ethical issues for researchers in qualitative family research are a possible occurrence (Daly, 1992a), which is not surprising given the intimate area of study and strong feelings which family members have both for and against each other. I am therefore clear that I will discuss issues as they arise (maintaining confidentiality) with the appropriate resource person e.g. research consultant, PhD supervisors, peer supervision group.*

### ➤ Financial costs and participants

*It is anticipated that there will be no financial costs to participants as a result of involvement in the study. Where expenses are incurred by participants, such as travel, childcare or postage these will be reimbursed from my research funds. Where the study has triggered a reaction in a volunteer participant (as discussed above) which needs counselling, then the costs of up to three counselling sessions will be met from the research fund. In recognition of the time, expertise and effort that participants have made to the study a token (book or supermarket) will be given to all participants regardless of the extent of their involvement. This is not an advertised payment to induce participation. Instead it reflects the philosophies of both qualitative research and nursing, that the participant is the expert and that expertise is acknowledged and not taken for granted.*

### ➤ Researcher qualifications for this study

*I have experience in this type of research in terms of a) data collection and b) case study method. I have wide experience of undertaking, completing and publishing health research in the fields of child health, cot death and wound healing. I also have extensive clinical experience in the field of bereavement support to families. In the UK having worked as the Avon Infant Mortality Study Co-ordinator for 2 years seeing an average of 60 bereaved families per year and in NZ having established and supported, with the social worker from NICU, the Baby Bereavement Group in Dunedin. I have access to support during this study from several other experienced researchers in qualitative research methods/family research in terms of my PhD supervisors.  
(Research Proposal 1995, pp. 26-28)*

## THE COMPLETE PICTURE –WHAT EMERGED

The emergent ethical issues were a mixture of anticipated "broad contingencies" and totally unexpected situations. The question I repeatedly faced was "How to deal with the situational and transsituational ethics?" which predominantly arose

during interactions. Ethics are about views on what is right and wrong. The problem is that we have individual constructions of "fair", "wrong" and "right". Rather than stating I used my integrity as a basis for decision making, I want to make more overt the processes I used to make decisions. I acknowledge that decisions were grounded in my own constructions of what felt the "right" choice. In making this decision I drew on a combination of ethical principles of the rights of participants, discussion with my supervisors and the ethical principles which I believed were inherent in this research. I tested my thoughts against those of colleagues, supervisors and the local ethics committee administrator, all of whom contributed valuable perspectives for the final decisions. To make the ethical principles I hold transparent I journalled, a strategy proposed by Munhall (1988) and I re-read my thoughts at times when I was unsure of what to do. The beliefs I held were an ethical interpretation of the ideas explored in Chapter 3 and were the following.

- *The gift participants are sharing with me is both precious and private; I will treat it with the respect and care such a gift deserves.*
- *The research is a partnership where participants should be offered choices and rights over the direction of the research throughout the study and afterwards<sup>3</sup>.*
- *Bereavement is a normal part of life; it is not to be covered up or ignored, but is extremely painful, so this research needs to be sensitive to that pain when making decisions.*
- *The intent of the research is for a positive outcome by making explicit some of the experiences of grandparent bereavement to people outside that experience. But such an end does not justify any means<sup>4</sup> that have negative effects or outcomes of participants. (Journal 2:10)*

Most of the points that I identified in my journal reflect the intent of the statement in the book "Doing Naturalistic Inquiry".

It would be well for the researcher to remember that in a naturalistic study the respondent should be considered a full partner in the study. The researcher's goal is to get behind the data being collected and to see through them to the constructed realities of the respondent. After having been allowed into this very private world of the respondents, what possible right can the researcher claim to harm or destroy it? (Erlandson, Harris, Skipper & Allen, 1993, p. 89)

The discussion that follows uncovers the ways in which these beliefs guided my decisions. I have presented material in the following sections; consent, relationships, responding to distress, benefits of the research, and

<sup>3</sup> For discussion relating to after the study has formally ended refer to p. 174.

<sup>4</sup> "Ends do not justify means" rejects the view of utilitarian ethics.

consequences of respecting the gift. Clearly these sections are not mutually exclusive and many of the situations I have included overlap several sections.

### **The issue of consent**

Whilst consent is the theoretical premise underpinning people's participation in any research, in this study there are three specific areas to consider; ability of bereaved people to consent, the process of ongoing consent, and the need for additional consent as the research evolved.

#### **➤ Able to Consent?**

One of the thoughts in my mind when writing the proposal had been the challenge of whether potential participants (parents and grandparents whose child or grandchild had died) should be "protected" from participating. In the research proposal I used the argument from Boss (1987) that people were **able** to decide if they wished to take part. Experience in the study went on to bear out Boss' premise. I had three comments back from different people who chose not to take part in the research, each of whom commented that it "did not feel the right time to sit and talk about it". This is consistent with the comments of other qualitative researchers such as Hutchinson, Wilson and Wilson (1994).

In relation to inclusion criteria I set a minimum time period of 12 months since the child had died, for people to be eligible to participate. There is no clear evidence in the literature to support this cut-off point – it was to assure the ethics committees that I would not be approaching newly bereaved people who might be perceived as vulnerable. Four weeks after I started interviews Rose, who had heard me talk about the study, said that both she and her mother would be willing to talk about their experiences, however, it was only 5 months since Ruby died. I decided that if they wanted to participate and I had not actively tried to recruit them early in their bereavement, then it "felt alright" according to my guiding ethical beliefs. I went back to the ethics committee administrator with this rationale and confirmed that the selection criterion could be altered which enabled this family to take part. Subsequently, other grandparents who had heard about the study and had not been directly approached by me also took part before the first anniversary of their grandchild's death. In hindsight the entry



point of 12 months since death of the grandchild was about my response to the concerns I felt other people might have – not necessarily a correct perception. Being bereaved does not mean that people are unable to “competently” consent - they have to make many important decisions, such as funeral arrangements, around the time of death. Cook (1995) explored ethical issues in thanatology and concluded that, in the context of informed consent, rather than working with the idea of “the bereaved”, which implies homogeneity across bereaved people, it is more useful to work with a term such as “bereaved populations” (p. 110). Thus some populations (groups) will be able to freely consent and others may not be able to do so. The question becomes how to know which “populations” can, and which cannot, consent? In this research I relied heavily on the premise that if people were interested in the study and **they made the approach to me** then, regardless of how long they had been bereaved, it indicated that they were able to make an active decision to consent.

### ➤ Ongoing Consent

The idea of consent as a process, as opposed to a “one off consent” at the beginning of the study, has been written about and advocated by various researchers (e.g., Munhall, 1988, p.156; Ramos, 1989, p.61). It concerns the difference between consenting with the **information** of what is involved in joining a study, and consenting progressively based on the **experience** of actually taking part in it. As Streubert and Carpenter (1995) noted, “Research participants should be provided with opportunities to renegotiate their agreement should an experience be different than they initially perceived it to be” (p. 309). This was the approach I sought to follow. To facilitate Streubert and Carpenter’s (1995) idea of “opportunity” to negotiate I planned a pre-interview face-to-face meeting where each person interested in the study could meet me and ask questions. The idea of a pre-interview meeting comes from my nursing practice in which I urge families who want to go to a counsellor to meet with the person before finally making a final decision. At a less personal level it is a strategy that Barbara Paterson and Ina Bramadat (1992, p. 107) proposed in the context of oral histories. They used it as a means to prepare participants to meet the tape recorder, think about resources and memories they might want to talk about in the actual interview and, most importantly to discuss consent issues and the



credentials of the researcher. I anticipated that interested people could make an assessment after I had left our pre-interview meeting about whether they wanted to continue to a formal interview. In practice, many pre-interview meetings became full first interviews because people commented that they were "ready" and wanted to talk about what had happened. An excerpt from my journal noted,

*I posted information and heard nothing for 10 days and assumed she did not want to take part. Then she rang and we arranged for me to go for a chat – which she then decided became an interview.... The pre-interview was very much a social chat and not touching on the research until we started to talk about the consent. She then had no hesitation in wanting to go ahead with the interview [now]. My sense is that she is ready, waiting and has prepared [herself] to talk NOW. (Journal 3:3-8)*

Given the sensitive subject we were talking about, it was not surprising that many people had psychologically prepared themselves to revisit their memories and did not want to prepare again for a separate interview. Pre-interview discussions worked most effectively by telephone, when potential participants had read the information sheet and I could clarify information about the study. This meant that the pre-interview phase did not have the face-to-face contact that I had initially thought would be so important a part of the consent process. However, my perception is that not having this meeting did not significantly alter the consent process, since there was still time for people to think about joining the study, having talked with me on the telephone or received my first letter, before actually signing the consent form to take part.

Once people had chosen to take part, the first consent form (see Appendix 4, p.460) was structured to allow opportunities to re-negotiate consent to continue to further interviews or letters. The rationale for this was to avoid participants feeling committed to ongoing involvement when they did not know what was involved such as, what it was like to actually sit and talk to me about their child or grandchild's death. Nobody chose to withdraw at any point during the study, and as a partnership, the participants and I held copies of all the consent forms where participants agreed to their ongoing involvement in the research.

In asking participants to consent to further involvement I was very conscious of **how** I asked participants. I tended to use the question "Would you be willing to meet with me/ write about some further things to discuss?" Limerick et al. (1996)

explored the complexity of power relations in interviews from their own experiences as interviewers. They highlighted a crucial element of interviews, which is not addressed in many texts, that “the power of the interviewees in the giving of the interview and our own empowerment and indebtedness as the receivers of their gift is a contradiction.” (p. 449). I especially felt this when, early in the study, I felt a tension of not persuading or over-encouraging people to take part in a second interview and yet, really wanting to hear their perspective to explore developing constructions. It made me realise, afresh, the power we may use, as researchers, to try to ensure that participants continue in the study, by shrugging off the “indebtedness” to be honourable holders of the gift and thus advantage the research not the participants.

### ➤ **Additional consent**

I interpreted **ongoing** consent as being the continuing participation in the research as it was originally discussed and presented in the first information sheet. However, as things happened during the research, new directions or issues emerged which I did not feel were fully covered by the original consent form; then we needed **additional** consent processes for specific issues. These were; knowing other family members were involved in the study; shifting from pseudonyms to actual family names<sup>5</sup>, and preparing to publish the participants' stories as a book.

As I explained in the previous chapter, the study evolved, much to my surprise and delight, to have several members of families taking part in the research. My original assumption was that all family members would be “open” and would talk with each other about their participation in the study. This assumption was based on the first family where both mother and daughter took part and talked freely about the content of the conversations I had had with each of them. In the next family, not all the members were aware that other family members had chosen to take part in the research. I decided I needed to negotiate a further verbal consent for participants to allow me to tell members of their family that other family members were also taking part in the study. Clearly, until all the members of a family had consented, it was not possible to break confidentiality by saying “Can

<sup>5</sup> Refers to the real names as opposed to pseudonyms - subsequently called “real names”.

*I tell Lisa, you are taking part?*" when I had not yet had consent from Lisa to tell other family members that she was participating. I had to say something such as *"If any one else in your family chooses to take part, are you happy for me to tell them that you are taking part, too?"* To keep track of this "rolling" consent I documented when I had told other family members about each other's involvement. To everyone I reiterated the point that information we talked about in an interview remained confidential to the participant and myself and would not be shared with other family members.

As time and the research moved on I decided that we needed another consent form to take into account the decisions of finalising the content of participants' stories based on the interviews. This included giving consent for final drafts of stories to be circulated around all participants so that everyone, including other family members, had a chance to see the stories and edit them in the light of reading other stories. At this time, the choice between real names or pseudonyms in stories became important, as Rose wrote,

Dear Alison, Thank you for the opportunity to use a pseudonym in our story. John and I have discussed this and would prefer that all our names remain as they are. This is particularly important to us in Ruby's case, as her name means a lot to us. I hope this will not cause you any problems with the ethics committee. (Rose Story Draft 1)

I had assumed when I wrote the research proposal that we would have to use pseudonyms because that was the understanding I had from the current writing in qualitative research. Looking back now, how could I have been so naïve and unthinking not to appreciate the importance of names in this work? A second consent form and information letter covered the option for participants to use either real names or pseudonyms. The information letter and consent form was approved by the ethics committees (see Appendix 8, p. 478). Towards the end of the research the participants and I reached an agreement that their stories in the second part of this thesis should be offered for publication (see p.173). I developed a third consent form and information letter, which were approved by the ethics committees (see Appendix 10, p. 485). The form and letter sought to maintain the intent of partnership and yet deal with practicalities of possible royalties and a process for participants to participate in the process of publication.

## Relationships - the consequences

As I discussed in Chapters 3 and 4, this research relied on a trusting relationship between participants, and myself whether by interview or letter, so that we could together explore constructions of grandparent bereavement. There were a number of ethical consequences arising from this type of close and sharing relationship. These were respecting other issues, unanticipated disclosures, respecting individuals' choices, and managing boundaries.

### ➤ Respecting other issues

Unlike a neatly structured questionnaire the discussions we had in interviews and letters meant that we explored many ideas and issues which were totally, or partly, unrelated to the topic of grandparent bereavement. One of the early decisions I made was not to limit, or cut-off, these discussions to focus on the research topic. Instead, I wanted to respect the talking and the sharing about other experiences and constructions of realities. As Fontana and Frey, 1994) wrote "to learn about people we must remember to treat them as people and they will uncover their lives to us" (p. 374). Some of these discussions were part of the everyday conversation of getting to know each other - sharing ideas on garden design, the weather and differences between countries. Others were more complex. In these instances, from my perspective, the research interview or letter offered a chance for people to explore their ideas or give a narrative of events. Between the first and second interviews, Elwyn, who is in her 60s, decided to get a passport for a trip overseas and to do this she obtained her first ever full copy of her birth certificate. In so doing she discovered that she was adopted.

Elwyn: When it [the birth certificate] arrived and I opened it up I saw the name of my mother and I thought that's not right and it didn't indicate my father. I thought something is wrong - this is a mistake. So then I thought I had better ring Mum before I go ringing them [the birth certificate department] up. It turns out that I'm one of those ones that has found out through their birth certificate that they are not who they thought they were. I was absolutely devastated.

Alison: *I am sorry you found out that way*

Elwyn: Well, I thought how many more shocks do you have to have in life? Mum was very upset that I had found out she hoped that I never would but of course she wouldn't probably even realise that people had to have full birth certificates with all the details. But as I say she got very upset about it -

I had a job to hold the tears back. I let her know that I felt she couldn't have been any better mother because I really felt and still feel that she's really been like a mother.... I thought about it a lot for days. My youngest son I think he'd come in and say, "How are you?" and I'd say, "I'm fine" I've not forgotten about it but put it behind me - you can't change anything. (Elwyn 2:7-8)

As Elwyn talked, at no time did I think, "*This is not about grandparent bereavement*". Given the relationship we had developed it was important for me to sit, listen and offer my support. This was about a very important event in Elwyn's life so we talked further about how she and her family felt about it.

### ➤ **Unanticipated disclosures**

One of the most widely used quotations about interviewing has been Oakley's (1981) that "Interviewing is rather like a marriage: everybody knows what it is, an awful lot of people do it, and yet behind each closed front door there is a world of secrets" (p. 41). It was clear in some interviews that I had entered the "front door" and our discussions shared information that was not on public view. This was less apparent in the letters from Elisabeth, Colston and Jenny who had the opportunity to re-write their letters if they decided not to share the disclosure with me, whereas what was said in the interview could not be unsaid. Unanticipated disclosures in qualitative family research have been described as the "problem is the exposure of a family to itself" (LaRossa, Bennett & Gelles, 1981, p. 310).

The disclosures in this research generally involved comments about other family members such as how they had behaved or opinions about their intentions, none of which were harsh assessments, in my opinion. Some comments were marked clearly by participants **during** the interview as being "boundaried" by the interview and not for use as illustrative quotes. Examples of this were when people said, "I know this is just you I am talking to. I would not want this to go any further." Sometimes, comments were recognised as a disclosure **after** the interview, when participants read the transcript. The guiding principle for me was that people should feel safe; what they had said should not make them feel uncomfortable or vulnerable. This meant using strategies such as confirming to a participant that a comment they had made was for my ears only or editing out disclosures from the transcript, or final story, so that a permanent or public record did not exist. The option for participants of editing transcripts, which I

actively encouraged, was underpinned by the premise of cooperative research in partnership with participants. I also sought to avoid disclosures occurring which might make participants feel vulnerable. I used strategies, such as those from Daly (1992a, p.10), reminding people that there was the opportunity to turn the tape recorder off or to stop a moment before sharing their thoughts with me.

However, I would note that not all unanticipated disclosures were perceived as harmful and they could bring new insights, such as when Margaret learnt something about Keith, her husband.

Margaret: Do you not remember your grandparents? [turning to Keith]

Keith: They were dead by the time I was five

Margaret: Both of them? Your mother's and your fathers [parents]?

Keith: Yes

Margaret: Oh, yes. We've only been married 40 years or so and I missed this one [she had not realised this previously] (Margaret and Keith 1:38-39)

Just as participants made unanticipated disclosures during interviews, so did I. When Betty was talking about being an only child and learning that she had had a young uncle who had died in infancy, I found myself saying something which I had rarely shared with anyone. This was because I, too, was an only child.

Betty: I have only been the once [to the grave], but I would quite like to show it to some others in the family. But that would have been my uncle. I think you lack relations when your mother has been an only child and you are an only child and when you have a family crisis you are pretty much on your own.

Alison: *I can relate to what you are saying. I had always wanted brothers and sisters and I discovered when I was about 30 that my mother had had a miscarriage.*

Betty: Similar thing? She had never talked of it?

Alison: *No and I was quite upset because it was my chance to have had someone [a brother or sister].* (Betty 1:10)

From my perspective, the relationship discussed in Chapter 3, grounded on conversation, partnership and respect, meant that both participants, and myself, could feel safe if unanticipated disclosures occurred.

### ➤ Respect for individual choices

I felt the relationship between each individual participant and myself generally jogged along comfortably. However, the "pseudonyms versus real names in stories" situation brought me up with a jolt, I had to re-appraise how I held each relationship as equal, trying to favour none, when participants wanted different



things. As discussed earlier, in the process of reading drafts of their stories in May 1998 several participants asked to have real names in the stories. So, once the consent form was approved I posted it out and participants who were the only individual family members in the research made their choice. Where there was more than one family member in the study it was generally discussed and the decision made together. The consent forms started to return and all was going smoothly ... until members in two families favoured different naming approaches. Clearly a story cannot mix family names and pseudonyms because some people who did not wish to be identified would be identifiable through the other names. In one family, after I had talked with the different participants, the final decision was to go with the choice of the parents of the grandchild – a decision which is mirrored through the stories and the joint construction of grandparents putting the parents first. In the second family I talked with participants about their reasons for the decisions. One person was very keen to have family names, particularly of dead family members in order to see their memory living on in the story. Another person was keen not to be identifiable to people in the community who might hear of, or read, his/her story. None of the participants wanted to change their decision.

The nurse-researcher voice said, "So, what should I do now?" The tension I felt was enormous, trying to keep the wishes and relationships equally balanced without advantaging either. One thought I had was "*Should pseudonyms take precedence?*" because the original consent form with which all participants had joined the study, had stated we would use pseudonyms. The nurse-researcher voice said, "But each person had an equally important reason for their choices." Then I had fears that if we could not reach a resolution it would break up what was a grouping of stories in the same family which offered some fascinating insights into constructions of grandparent bereavement. The nurse-researcher voice said, "But the overall research should not be advantaged over participants' individual wishes." I explored the option of whether we could alter the stories so that each participant could have their wishes, by removing information which is common across the stories. The researcher voice said, "But then it would alter the context of the experience and that would be unethical since it would make one, or both, stories untrue to the original construction(s)?" So, what happened? It took us 6 months, over a series of phone calls and letters between myself and the

individual participants, to explore together the options and the consequences of each option. We eventually reached a compromise which was acceptable and which finalised the names in the stories. It reflects the participants' commitment to seeing the process through in the spirit of partnership and co-operation.

At the point, when all the decisions about names or pseudonyms were made, there was another important aspect to the naming in the stories. If real names were used in stories then I asked participants to follow up with any people named in the story to make sure they were happy with being identified in the public arena. This was a form of consent at a distance since I did not have contact with these people, but asked participants to verbally confirm the decisions with their families. If pseudonyms were chosen, then I asked participants to choose the names they wanted in their stories. If participants had no preference for names then I offered a range of names as a starting point to avoid us having recurrent names across all the stories. At the end of this process pseudonyms were used in 4 stories out of 20.

### ➤ **Boundaries**

A crucial aspect of relationships with participants was that of boundaries. I had to be very careful to maintain confidentiality, where two members (or more) from the same family joined the research. This meant keeping separate the knowledge that I had in one relationship from the knowledge that I had in another relationship. To achieve this I re-read previous transcripts and notes of all meetings with all family members, and I reminded myself of anything important that I should **not** "know" within this relationship before I went to an interview. This was rarely anything "major". Early in the research Marie talked about having an umbrella which symbolised her granddaughter Ruby, and when I first talked with Rose, Marie's daughter, I did not mention the umbrella because I did not know if Rose knew about it. Another aspect of the responsibility to maintain confidential boundaries within relationships with multiple family members was consciously not clarifying misperceptions. When Person A thought something about Person B, who was in the same family, which did not "fit" with the information I had directly from Person B, I had to sit tight and make no comment. Occasionally, at a later point, and **only** if it fitted in the flow of conversation, I would suggest to

Person A that it can sometimes be valuable to talk about feelings, or ideas, with other family members.

Boundaries in relationships meant maintaining confidentiality in settings outside the research where I knew participants. Some research participants were close family members of people with whom I worked in my nursing practice and other participants, I knew, in their role as members of the local self-help group. The issue of boundaries arose when a research participant, who had already met with me for two interviews, became a student in the department where I work. I noted this to my employer and supervisor and then talked with the participant/student about the papers that I teach and assess. We agreed on an approach that was acceptable to us both where another lecturer marked assessments and where this was not possible, the work was moderated by another lecturer.

One of the consequences of this research was that there was always going to be some distress for participants, since the nature of the bereavement is distressing. The issues were about responding to the distress, and whether the research causes, or allows the expression of, distress.

### **Responding to pain or distress**

Parkes (1995) wrote that in research interviews where a bereaved person becomes upset "this is no place for scientific detachment in the sense of the interviewer acting like a fly on the wall. If the respondent is in need of help, the interviewer should not hesitate to provide it (p. 175). This quotation reinforces the idea that the researcher role carries with it responsibilities that extend far beyond not causing harm to participants. One of my beliefs in the research was that pain is a normal part of bereavement and that I had to support and acknowledge that pain. The nurse voice said, "But how much pain and distress is 'too much'? At what point does it become 'harmful' or 'wrong'?" An experienced bereavement researcher, Rosenblatt (1995), also raised these questions. In this research pain was part of all the meetings with NZ grandparents and parents. Almost all of the people I talked with paused and cried, or had tears in their eyes. These were the times we stopped talking, or got out a hankie or had a hug and

acknowledged that this was very real and painful to remember. I, too, found their stories sad, upsetting and physically exhausting; and I was only the listener, not the person who was re-visiting this experience. However, it was Jenny's second letter that precipitated me into facing raw distress and trying to decide what was the right thing to do.

### ➤ **How to respond to Jenny's distress?**

My especial concern about participants' distress was for the three UK grandmothers, who were at a distance where I could not assess the impact of revisiting their experiences by meeting with them face-to-face. For Elisabeth and Colston, I was not so worried - for Jenny I was. However, it was not that the research process was causing distress, it seemed to be the opposite; the chance to write helped amidst the distress. Jenny wrote at the end of her first letter,

The "bottom line" is I feel so many things but mainly I feel confused or isolated in my grief and still carrying so much pain. I don't know if this is the sort of letter and information you need but I feel it's helped me a little by writing about it. (Jenny 1:3)

By the end of her second letter she lifted the curtain on the distress she felt about her daughter, Sue's, rejection of her.

The death of Jordan has had a profound effect on my relationship with Sue. Immediately following Jordan's death we seemed close as normal, but ever so gradually Sue stopped phoning and then stopped dropping in. She said phoning me was difficult for her - she hasn't been able to explain why. But by the end of December (6 months after Jordan's death) after I called her, she said she found my company painful and even though she knew I wasn't doing or saying anything wrong, I upset her and she was worse after talking to me or being with me. She did try to let me know I wasn't to blame and that she did love me but she couldn't visit anymore or phone me. Of course I was devastated! I was being rejected without knowing why. Never, through all the previous painful losses of my husband, parents and Jordan's death have I been in such mental pain. For 3 months I kept trying to keep in contact by popping in or phoning but gradually I became ill. Christmas was difficult but Sue and Chas did come for the day along with Chas' parents and my brother-in-law was staying with us, so we made an effort and got through the day but our mother/daughter relationship has taken a severe beating. When I developed influenza again and began to look and feel like death myself, only then did things begin to change between us. Sue came over to say goodbye to her uncle who was going home and when she saw how ill I looked she said to me later she was so shocked she knew she had to try and get back on the right road. Perhaps she felt cutting me out of her life was in fact more painful than being with me. We are nowhere near to how we were and I doubt if we ever will be,

but I do see her and Chas every week or so but we are both having to make enormous efforts to get any pleasure from our contact. (Jenny 2:4)

I struggled with how to respond to that letter. After I read Jenny's letter I wrote in my journal and talked with my supervisor about the pain I felt being 12,000 miles away, being unable to go and see her, and yet responsible for the opportunity for the outpouring of feelings. I even wondered if the fact we could not meet face-to-face could mean that it was easier for Jenny to share feelings – my supervisor suggested the idea of telephone intimacy, as in the film "Sleepless in Seattle". My researcher voice said I was too far away to fulfil the responsibility I perceived to facilitate a counselling referral. The most I could do was to encourage Jenny to take up that option. My nurse voice kept wanting to "fix it" – at the least to set in place some strategies for talking through these issues and exploring other losses which Jenny's family had had.

*The one thing which I feel very sad about when I read your letter is the last bit about your relationship with Sue. It is similar to another situation that has arisen in a family here and for whatever the reasons that Sue has felt for avoiding contact I am very sad for both of you. Clearly you have both, and particularly you, had a lot of losses in a short period of time. It does take a lot of time and energy to work through that doesn't it? That is why I quite liked the work of Worden when he wrote about bereavement because he pointed out that bereavement is not something pathological (like an illness) it is normal but is extremely hard work, living through feelings and putting life back into some semblance of order.*

*Have you thought at all about talking through, some of the things which have happened, with anyone- even like a counsellor? Sometimes it can be of tremendous value to have the quality (albeit paid for) time and attention of someone who does not have a vested interest and therefore views as family and friends do. Do just ignore this part if it seems that I have stepped out of line. But part of doing this research has been a sharing and caring within the families who I have met and talked with here and that caring extends to the 3 of you who have willingly chosen to write and share very personal things from the distance of the UK. I wish I could give you a hug and we could have a coffee together - as it would be possible if we were both here or there. The least I can do is tell that you that I appreciate you sharing with me and I hope that 1997 moves on to being an easier year physically and emotionally for you. I also enclose a few excerpts from an excellent book that some families have found useful here.*

*(Alison to Jenny 2:2-3)*

It is important to realise with hindsight that Jenny knew what she needed to do to live with her bereavement, and I was just a small part of the whole picture.

At the time I did not fully see that; I had to wait until Jenny wrote back in her next letter.

I was saying to my sister how helpful writing to you is and although we've never met when you write and send me a big hug I feel comfortable and can almost feel your arms around me - thank you for all your efforts on our behalf and also your kindness. (Jenny 3:3)

After the helplessness and concern I felt with the previous letter, I felt somewhat reassured that the research itself was not causing the distress - rather that it was a means of expressing the distress. Time moved on over the next 18 months to a more peaceful note in Jenny's letters.

I am so looking forward to reading the completed thesis and I want to thank you for including me in this study - it has helped me enormously. I've popped a photo in this letter so you can put faces to names. As you can see Sue and Chas are once again smiling, and Lee [their newly adopted son] is such a happy loving, little boy - he has done as much for our family as Sue and Chas have done for him. We are all looking forward to celebrating his 3<sup>rd</sup> birthday on July 1<sup>st</sup> our first one as a complete family. (Jenny 7:3)

My perception, now, is that the research has been given the privilege, through Jenny's letters, of hearing the reality of her distress, and how she worked through it herself. I am grateful that, from her perspective, writing letters for this research provided the "listening eye" in the same way that interviews can provide a listening ear, because I had not confidently held on to that belief when I felt the pain and despair in her second letter. It is a reminder that I was perhaps fearful that there might be truth in those concerned, well meaning comments of colleagues that the research might do some harm.

### ➤ **Distress caused by, or pre-existing, the research?**

It was through Jenny's letters that the distinction regarding distress became clear to me in two different forms. First, the research process **causing** pain or distress, for example, by exploring the experience to the point that a participant felt distressed or unsafe. Second, pain or distress that **pre-existed** the research and where the process of the research enabled a sharing of the pain but participation in the study did not worsen the distress.

#### Research causing distress

I had actively sought to avoid the research process causing distress during interviews by being alert to when it was time to stop talking and to suggest



ending the interview. In some instances I chose not to touch on certain areas of discussion or questions I wanted to ask and held them over to the next interview. This particularly occurred in the first interviews where people told the story of what had happened and, in doing so, relived some of those memories. For some people it was clearly physically and emotionally tiring to do so. I had budgeted for the costs of a counsellor for participants who wanted or needed to explore issues further which arose in a research interview. However, none of the participants chose to take up this option and I did not identify anyone who I felt might benefit from considering this option. In the case of Jenny, Colston and Elisabeth, I had always been aware of the physical distance and delay between writing and receipt of letters, which meant that I had no opportunities to respond to distress at the time of writing. In large part, I had to trust to the process of the research - that they had all made considerable effort to contact me and take part, that they had time to think about taking part and that they all had links to SANDS, which offers excellent one-to-one support on request. It was only with Jenny's letter, that I had a short-term crisis of confidence in the process. As with the interviews, I actively sought to minimise distress caused by the research through letters by establishing a safe and supportive relationship in my letters and carefully considering the questions that I asked in letters. However, I was aware of the limitations of letters. They sit as bald text that goes back and forth between the writers. They offered no opportunities for me to "read" participants' responses to the letters from their facial expressions and no chances to give context to what I wrote with the intonations of my voice.

One of the things I had not anticipated when I posted the confidential draft copy of everyone's stories to all the parents and grandparents, was the distress that this part of the research process might cause. Many people had asked me, in the course of interviews, how the research was going and what other people had said. I, therefore, felt that a chance to read each other's stories before the study was completed was an important aspect of the partnership and also of member checking for agreement to the final written form. What actually happened? Twelve of the 20 participants spontaneously commented that it had been really positive, helpful or confirming to read other people's stories, as we shall see in the next section, and Catherine made the comment which is in Chapter 4, that this was her story. However, one participant was upset about their story. After

contrasting it with other stories they felt it was inadequate and that it was not a "good" story. I had not anticipated that reaction. From my perspective all the stories are outstanding and are unique; they "really" share multiple constructions of grandparent bereavement. I talked with the participant about the uniqueness of their story, of the chance to expand and re-write and of the fact that reading that story had had a powerful effect on another family member who had gained insight into how the participant had felt when their grandchild died. We agreed to leave it a few weeks and then I would go to visit and we would edit the story. In the end whilst the distress could not be "undone", the participant decided to leave the story unedited because it represented their story in "their words".

### *Pre-existing distress*

Clearly, everyone who took part in this research shared some of his or her pain or distress that pre-existed the research. Yet, as the next section highlights, all participants found different reasons to value revisiting their pain as part of this research. I was conscious at the end of some interviews that the levels of pain were high for some people and I reiterated, before leaving, that they were welcome to ring me or that I would telephone them in a day or so. The comment several people made was that, in looking back over the 18 months to their first interview, they recognised that it had been very painful for several days after the interview as they relived memories. In that sense, the research did worsen the pain. But, after the first few days things improved, to the point of feeling better than they had done prior to the interview and that their feelings about their grandchild had "come to feel good" over the next few months. This suggests the importance of looking at the consequences of research, not just in the immediate time period but in the longer term as well, since this research is only a small moment in people's lives. If we only focus on the short-term outcomes, then, clearly this research was about sharing a considerable amount of pain. But in the longer term, that sharing is the opportunity for some people to re-construct, and re-interpret events, with new insights.

## OUTCOMES OF THE RESEARCH FOR PARTICIPANTS

The original challenging comment I encountered when planning the research had focused on the potential “harmful” outcomes of this research and “distress” has been explored in the previous section. I had anticipated that there might be some benefits for participants since a large part of this research study focused on participants’ stories told either in letters or indepth interviews. There is a range of evidence that telling one’s experience, as a narrative of events, helps to make sense of life (Polkinghorne, 1988), of health care (Brody, 1987) and of bereavement (Rosenblatt, 1996). From our own personal lives we are aware of the frustration of fragmented superficial conversations rather than the chance to talk or write in detail. The comments in this study from the participants’ perspectives, and my own view, focused, outstandingly, on the beneficial or positive aspects of the research. These included:

- gaining insights into where this experience fitted in their lives;
- gaining a sense of meaning from the experience of having a grandchild/ child die;
- a chance to challenge accepted discourses of bereavement;
- a chance to talk “when no-one else wants to listen”;
- a memorial for their grandchild or child; and
- flow-on effects in families.

However, I fully acknowledge that there may be participants who might have felt unable to tell me that the research had negative outcomes for them. Given the nature of the relationship that I had with each participant I do not have a sense that this is likely to have happened for many participants and this is supported by the fact that eight participants commented spontaneously that it had been “good” to take part. A further seven responded to my question, “*What has it been like to take part in this research?*” with comments of “good” or “helpful”.

The benefits perceived as arising in this study were also identified by Hutchinson, Wilson and Wilson (1994) in a review of research studies ranging from neonatal death to nursing experiences in Vietnam. The areas of similarity were: catharsis; self-acknowledgement; sense of purpose; self-awareness; healing; empowerment - “telling one’s story and really feeling heard can be empowering” (p. 163); and providing a voice to the disenfranchised, as “in

depth interviews can give a voice to the voiceless ... who have never been allowed to tell their story" (p. 164). The latter was particularly poignant for grandparents like Terese (see p. 131) and Jenny (see p. 360), who felt passionately that grandparent bereavement was not acknowledged by others.

### **Gaining insights into where this experience fits in the lives of participants**

One of the clearly identified strengths of conversation in this study was the opportunity it provided for people to re-interpret their bereavement with the perspective of where it "fitted", both in their lives and in the wider context of other people experiencing the same bereavement. Some of Jenny's comments, earlier, highlighted how writing her thoughts down in letters and answering the questions I asked, had helped her to live with Jordan's death. Elwyn, too, commented on the insights interviews had given her by being able to talk about her other experiences of bereavement which were linked with Daniel's, death.

*Alison:* *And has it been alright talking to me about this?*

*Elwyn:* I have really enjoyed it. It's probably, I am not quite sure where it has put it all, it probably helped me to understand me a little bit. And helped me to take it out and think about how I felt about things and I am quite sure that that has been good for me. I feel it has.  
(Elwyn, 2:38-39)

Elwyn returned to the idea of insights in the third interview.

*Alison:* *Would you have liked somebody to talk to with things like Daniel's death?*

*Elwyn:* Well it is probably something I haven't thought about before but I think that these sessions that I have had with you have probably done an awful lot for me.

*Alison:* *That's wonderful*

*Elwyn:* I really feel it has and not just with Daniel I sort of .. even with Lindsay... [Elwyn's husband, who died twenty years ago]

*Alison:* *We have covered the two and they are very interlinked, aren't they, for you? And Daniel triggering the feelings that you could not talk about when Lindsay died?*

*Elwyn:* Yes, that is quite right. (Elwyn 3:14-15)

Part of the insight which people seemed to gain was that the experience was

common to other people. Elisabeth having seen the draft of everyone's stories, wrote,

I knew I was benefiting from sharing my experiences with you and also my grief was moving along between letters and questions. It was very comforting to find that other parents make the same comments and have similar feelings. (Elisabeth 7:1)

Jenny, too, wrote that having to "think quite hard and deeply" was of "tremendous help" and had helped to feel that she was not alone. "Thank you for making me feel normal and not alone, while I have been travelling towards acceptance of a life without our grandson and a new life within our changed family" (*Jenny 5:4*). These comments are consistent with the potential for narratives to empower participants "to apply understanding" (Mishler, 1986, p. 119).

### **Gaining a sense of meaning from the experience**

The idea of everyone's stories being accessible through self-help groups or booksellers as a book, arose almost intangibly from comments that there was little information about grandparent bereavement for grandparents. It was an idea supported in principle by everyone. For some, this was the most important value they saw arising from the research; making a contribution for future grandparents. As such, it was, in part, a benefit to individuals, since that sense of contribution could enhance one's sense of worth of self and experience. For me, too, it became a very important part of the research for "living knowledge" (see p. 11) to disseminate these amazing stories into the public arena and not kept shut inside an academic thesis. Rose, whose daughter Ruby died and whose mother, Marie, took part in the research, was clear that the writing from the research might help people in the future.

I mean you are in a state of shock when your baby dies and you don't know what the hell you are supposed to be doing. And you do need something or someone to say "You want to do this now even if you think you don't feel comfortable do it because you can't do it later, you have got to do it now". So I mean that is it and that is the only thing that comes out of all the books we are trying to write to try and save other people some of the pain that some of us have gone through. I mean you have to go through it but if you can do anything to lighten the load it is worth something isn't it? That is our theory - so that is one of the reasons that Ruby was sent to teach us so that we can, perhaps, pass something along. (Rose 2:10-11)

Elisabeth, too, valued the fact that the research, to which she had contributed, would have benefits for other grandparents in the future. "I think the finished product will be of great use to bereaved grandparents who don't quite know what is expected or how to express the great sense of loss and sadness they feel"

(*Elisabeth 3:2*). Jenny supported the idea of a book because she had recently seen the value of a book of stories and experiences about adoption.

I, too, would be pleased to see a book of grandparents' letters relating their experiences in coping with the death of a grandchild. Sue and Chas [her daughter and son-in-law] are progressing with the adoption and she [Sue] let me read a book written by other adoptive parents. The variety of types of adoption and the experiences faced was very helpful and also hopeful. So if a book to aid grandparents has the same effect it will be very welcome and needed very badly, I'm all for it. (*Jenny 3:2-3*)

The perceived benefits of having their experiences written as an academic thesis did not weigh as strongly with participants, as the idea of a book which was publicly available, and rightly so from my perspective. This differed from Gordon Riches and Pamela Dawson's (1996c) reflexive account of a constructivist study of 32 bereaved parents which suggested that the academic perspective was an important part of having a voice.

We would argue that this collaborative approach empowered interviewees in the sense that our temporary "honorary membership" of the bereaved-parent community added an "academic voice" which was seen by its members to give weight to their perspective and, in small measure, to reduce the isolation which arose from their failure to be heard by the wider society. (p. 364)

The participants in this study, perceived that a book of stories would be heard in society, in a way that an academic thesis would not. A recent example of similar work, made widely accessible, was the recent publication by Lois Tonkin (1998) "Still Life - hidden stories of stillbirth and forbidden grief". This is a book of stories from NZ women who had stillborn babies which serves as a reminder of the practices in the 1950s onwards where parents were refused the chance to see their dead baby.

### **A chance to challenge accepted discourses of bereavement**

Several people commented that it was "nice to talk about what it was really like" as opposed to having to fit into established discourses of bereavement. In this,



there was a sense of having a voice to challenge the views held about bereavement. One of the widely held beliefs in the community is that the pain of bereavement diminishes, almost exponentially, as time extends from the death. Yet the experience can be very different. As Ailsa said, things do not improve and can even get worse.

I think that people are like that with any bereavement though. They feel after 3 or 4 or 5 months that it should be, because they have got on with their lives they feel that you should be getting on with yours. And I have always tried to make a point of saying to family "Don't forget about them in 12 months time". Not to my family but to other people's families if they've lost .... like the funeral we went to yesterday, people should remember those parents in 12 months time not just in the first few weeks. Because we all tend

bereavement discourses. One widow wrote, "I would like to see a future study that emphasises the extra stress on experiences when they [bereaved people] don't show "appropriate grief" based on social standards (p. 165).

### **A chance to talk "when no-one else wants to listen"**

Rachel was happy to take part in the research because it provided a dedicated time for thinking and talking about Samuel.

*Alison: Why were you willing to talk to me?*

*Rachel: Because I like you and I think it is important to find out about grandparents. There is not a lot for them. I think it is also a chance to talk as well to somebody that is quite nice. Because you run out of people, apart from Cot Death people. (Rachel 2:9-10)*

For Pip, too, the research was an opportunity to take time to think about Gracie.

*I would talk to anybody really. And I quite enjoy it, it is quite good having a focus like you are coming and we talk about Gracie. Which is quite good really. People ring up sometimes and they want to be supportive but they don't want to talk about Gracie. (Pip 2:23)*

Riches and Dawson (1996c) also found that talking was an important outcome for participants. Writing of an interview with a mother whose twins were stillborn they concluded,

*The interview lasted 3 and a half hours. In her case, as in many others, she had not previously had the opportunity to tell her story from beginning to end. Maybe this is amongst the most important findings of our project (p. 363)*

Reading the comments from Pip and Rachel above, it is important to remember that they have families and friends who still do talk about their dead children.

However, in a situation where families and friends might not talk about the child who had died, this could make some parents, or grandparents, vulnerable to taking part in research such as this – just for a chance to talk. This is a different perspective to the views that I originally encountered from colleagues, which implied bereaved people are vulnerable and they may not be fully competent to consent. In contrast, people may be able to consent but may be rendered more likely to consent because of the lack of opportunities to talk about their grief with family and friends.

## Flow on effects in families

The consequences of talking to one or more members in a family did mean that the research affected the whole family. As Boss (1987) wrote, "perhaps the family wants the system disturbed, which is why they elected to invite an outsider in" (p. 152). In this study there were flow-on effects of the discussions that I had with participants when they, then, shared ideas or information with other family members. However, to the extent of my knowledge, these were minor and positively perceived. This may reflect the fact that it was predominantly families who had dealt with issues arising from the grandchild's death which took part in the research. For Rachel, the flow-on effects were perceived as being positive, because it meant she talked more with her mother about Samuel.

*Alison :*        *One of the things I was going to ask you was do you think your mother's feelings have changed as time has gone on?*

*Rachel:*        Yes, I do. I think she is... I don't think I can talk to her as much now about it because ... I don't know why. Because I think that everyone thinks, not that I should be over it, I don't mean that, but that it is a long time and it is coming up to 5 years ago. So, I don't really, I suppose, talk as much - it is more of the [other] kids now.

*Alison:*        *Would you like to talk more?*

*Rachel:*        Yes, probably. But after you had been to visit her [Rachel's mother also took part in the study] she rung me up and she said that she, too, hadn't really thought about it for quite a while. And we went through all the nice things that he [Samuel] used to do. And, I think, I remember saying to her that at the start I had forgotten [some of those things]. But as she was talking it brought back things and she told me her nice memories and things like that. That was nice. But that probably hasn't been talked like that for a while now, for a couple of years. (Rachel 2:2-3)

Similarly, for Sarah, reading the book of stories of other participants was a chance to read how her parents had felt when Matthew had died and to gain insight into their feelings.

## A memorial for their grandchild or child

Creating a memorial is similar to gaining a sense of meaning from taking part in the research but also reflects wanting to have something permanent to mark the existence of their grandchild. For Elisabeth, writing about Martin has been a tangible acknowledgement of his existence. "Writing has helped me greatly to

come to terms with Martin's death. I enjoy writing his name" (Elisabeth 7:Appendix). For Marie who saw Ruby just once, after she was born and before she was transferred to Auckland, there were few memories. Her own story and that of Rose, her daughter, became a very physical, tangible link to Ruby that could be held in her hands and read, re-read and re-read again. The importance of the research becoming a memorial became the impetus to change from pseudonyms to real names in participants' stories. Wanting to have a memorial in a form other than a headstone on a grave or memorial plaque was the reason why many people chose to have their real names in their stories. Thus, the stories became a written acknowledgement of their child/grandchild and a memorial to their lives and deaths which could then be a legacy given to future families who might have the same experience.

## RESPECT FOR THE GIFT

For me, one of the most striking aspects of this study was how privileged I felt at the gift people gave me, a stranger, of spending time sharing their stories and ideas with me. The question was how to acknowledge and hold those stories in a respectful place. In the research literature there has been debate over who owns participants' stories and how they are used. As Riches and Dawson (1996c) described, there is the potential in research for participants to make stories and for researchers to take them. "There is a danger of informants merely becoming a part of our research career - at every stage from the moment of contact to the final writing up of our findings" (p. 362). To make such "use" of a gift is clearly contrary to the idea of partnership as used in this research. My perspective has been akin to that of Lincoln and Guba (1989). When they refined their original thinking about naturalistic inquiry, they emphasised the need for a "more cooperative paradigm of research" (p. 236) because without it,

when participants do not 'own' the data they have furnished about themselves they have been robbed of some essential element of dignity, in addition to having been abandoned in harm's way. If they are accorded the dignity of ownership, they have the right to shape that information's use and to assist in formulation of the purposes to which they will lend their names and information. (p. 236)

Adopting this position about participants' ownership had consequences for a number of decisions.

### **Ownership – is member checking a threat to credibility?**

As I discussed in Chapter 4, member checking serves a purpose that is both ethical and methodological. In terms of ethics member checking facilitates the ownership of data, interpretations and the whole study. In this research the first consent form I developed enabled participants to indicate if they wanted to edit their transcripts, allow quotes to be used in the thesis once the participants had seen the context in which these were used and see a final draft of the thesis for comments. I constructed these opportunities to provide participants with control over their material. As the study unfolded I needed to offer more opportunities for participants to review their material. This included the opportunity to: comment on the developing group constructions; negotiate a final joint construction; edit and re-edit their story; read other participants' stories and have time to decide on the use of pseudonyms or real names. As I discussed in Chapter 3, the methodological purpose of member checking as stated by Guba and Lincoln (1989) is "the single most crucial technique for establishing credibility" (p. 239). However, the methodological purpose can, I believe, conflict with the ethical purpose to facilitate ownership. Sandelowski (1993) wrote about the pitfalls of member checking,

*this technique that may serve paradoxically to undermine the trustworthiness of a project. Indeed, what is often lost in the discourse of member checking is the recognition that both researchers and members are stakeholders in the research process ... there are different stories to tell and different agendas to promote. (p. 4)*

The question, in the situation Sandelowski described, is whose story gets told? When I offered participants several opportunities to edit their stories for public view I sought to respect their gift to the research by according them the partnership "rights", which writers expect, to refine, rework and review their material before it is published. So, the text was a partnership. My original premise was that, without participants' willingness to share their pain with me (their gift), this research would not exist. I believed that having asked them to revisit that pain I had no grounds to cause them any further pain by presenting material or aspects of their experiences that they were not willing to have on public view. Therefore, I made a conscious decision that this thesis would tell the stories with which the participants were happy. By upholding this position, I placed the ethical use of member checking over the methodological use. For example, my decision to give participants' wishes precedence over the stories

that I might have wanted to tell, would imply, using Sandelowski's (1993) perspective quoted above, that I have undermined the trustworthiness of the study. However, I do not believe that I have done that. First, the claim of member checking to establish credibility, when it is a relationship and process which participants construct in different ways, needs considering (see discussion p. 138). Second, I have not been placed in a position where there was something that I felt was important and which a participant did not want to include. People have willingly shared personal and private thoughts. I believe this is because of their commitment to the research. In addition, when I asked for their agreement to include quotations I often wrote a comment explaining the reason this particular quotation would illuminate the text.

### **Joint ownership of a book - how to manage it?**

The consequence of planning to present participants' stories in a book meant that this was outside the original agreement to include quotations and material in this thesis. I had sought informal consent as part of discussions with all participants as part of the later interviews or letters. The premise that participants own their texts and have the right to determine in what form their story is included in a book meant that a further consent form was developed and approved by the accredited ethics committees. We completed this consent process before I formally contacted potential publishers, so that I knew exactly who had consented to what with regards to publication. In terms of the ownership of material, one of the important parts of the consent form was the agreement about use of potential royalties arising from a book. The agreement we developed was that any royalties from a published book would cover my production costs of compiling the book. Beyond these costs royalties would be given to self-help groups nominated by participants.

### **Seeing beyond the end of the study to "afterwards" not "aftermath"**

Vangie Bergum (1991) writing about a phenomenological study of women's transformation to motherhood wrote:

*The very fact that these women talked about their own experience made a difference in their lives ... while the completed study and the transcripts (which were given to each women [sic] may gather dust on the shelf, it is*



also possible that they may re-read them at some later time, causing renewed reflection. (pp. 67-68)

This served to remind me about the ethical responsibilities which I needed to plan for in advance of the end of the study. The gift which participants have given this study has to be handled wisely; it is not just for the duration of data gathering and writing up - it is a legacy for all time as written materials in the public domain. I will not be there when participants read and re-read material, but the process of editing and checking has endeavoured to ensure that participants are comfortable with the materials produced, such as this thesis. Lincoln and Guba (1985) called this the "Principle of No Surprise" (p. 358) where, with repeated opportunities for participants to review material, there should be no shocks in store for them in the final case report. In addition to "no surprises" for participants, I came to realise that texts such as stories and transcripts are likely to pass on to other family members if a participant dies. This has meant ensuring that material was acceptable to the participant for other family members to read - which in some instances meant editing, re-printing and destroying earlier transcripts.

Just as participants might re-read material, so the materials put out publicly can have an ongoing life after the study has ended. The full "report" is this thesis, but aspects are presented or planned as articles, conference presentations or workshops. I also refer to the research in my everyday conversations and in lectures about research methods. As the study has progressed other people have referred to it and discussed it. This means information about the study moves into the public arena, where the material takes on a life of its own in terms of how other people debate, refer to or misinterpret the material, which takes control away from the participants. Knowing that this happens meant I needed to consider where material is held or accessed, and to ensure that all information in the public arena is owned by all of us (participants and myself) as an "acceptable" construction of this research. Clandinin and Connelly (1994) made a firm reminder of this responsibility,

because personal experience methods involve "real people" and not just texts we need to pay the closest attention to the aftermath of the research (Lightfoot 1983) ... we owe our care, our responsibility to the research participants and how our research texts shape their lives. (p. 422)

Their use of the word "aftermath" carries, for me, connotations of the events after disasters such as war or flood, a situation I am seeking to avoid. Instead, I have focused on "afterwards" – after the formal study has ended. Part of the planning for afterwards has been to offer participants the opportunities to comment on their quotations to be included in articles or conference presentations and to then have a copy of such materials. Inevitably this consultation process means allowing sufficient time for participants to reply to confirm their agreement or their requested changes. However, not to consult would be to take away their ownership of the data and to renege on the concept of partnership. There are some participants who have indicated that they do not feel concerned about the need to be consulted on the use of their stories. They have decided that, given the experience they have had in the development of this thesis, they are happy to entrust me with "guardianship" to handle their stories with their best interests at heart.

## AND SO TO CONCLUDE

This chapter has explored a range of issues, choices and decisions that emerged in relation to ethics in this research. I believe several points in this chapter are worth noting. There is the perspective that participation in bereavement research can be constructed by people as a positive experience; a view which contributes to the ongoing debate about the risks and benefits of bereavement research. In particular, participants' comments in this chapter are reminders to stop and consider how participants construct their experiences, and not to assume, as I did with Jenny's letters, that distress expressed in the research is necessarily a harmful outcome. I also believe this chapter demonstrates the potential of constructivist inquiry as the theoretical framework underpinning this work. It offered a process of dialogue and debate around and across the three participant group circles which responded to a range of ethical issues, such as multiple family members' differing wishes. Finally, woven throughout the whole study were the implications of viewing participants' contribution to the research as a gift and a partnership.

The first part of this thesis has tracked the research story, in terms of beliefs, issues and decisions that formed the context of the "findings" of this research.

Entering the next part of the thesis moves into the worlds and experiences of the individual participants told in their words. The stories are cradled in the centre of the thesis because they offer a bridge from the first part of the thesis to the third part. They act as a transition from the theoretical underpinnings (Part 1), through the personal pain (Part 2) to the conceptual view and discussions of grandparent bereavement (Part 3).

## **PART 2**

# **THE STORIES OF GRANDPARENTS, PARENTS AND HEALTH/BEREAVEMENT PROFESSIONALS**

## INTRODUCTION

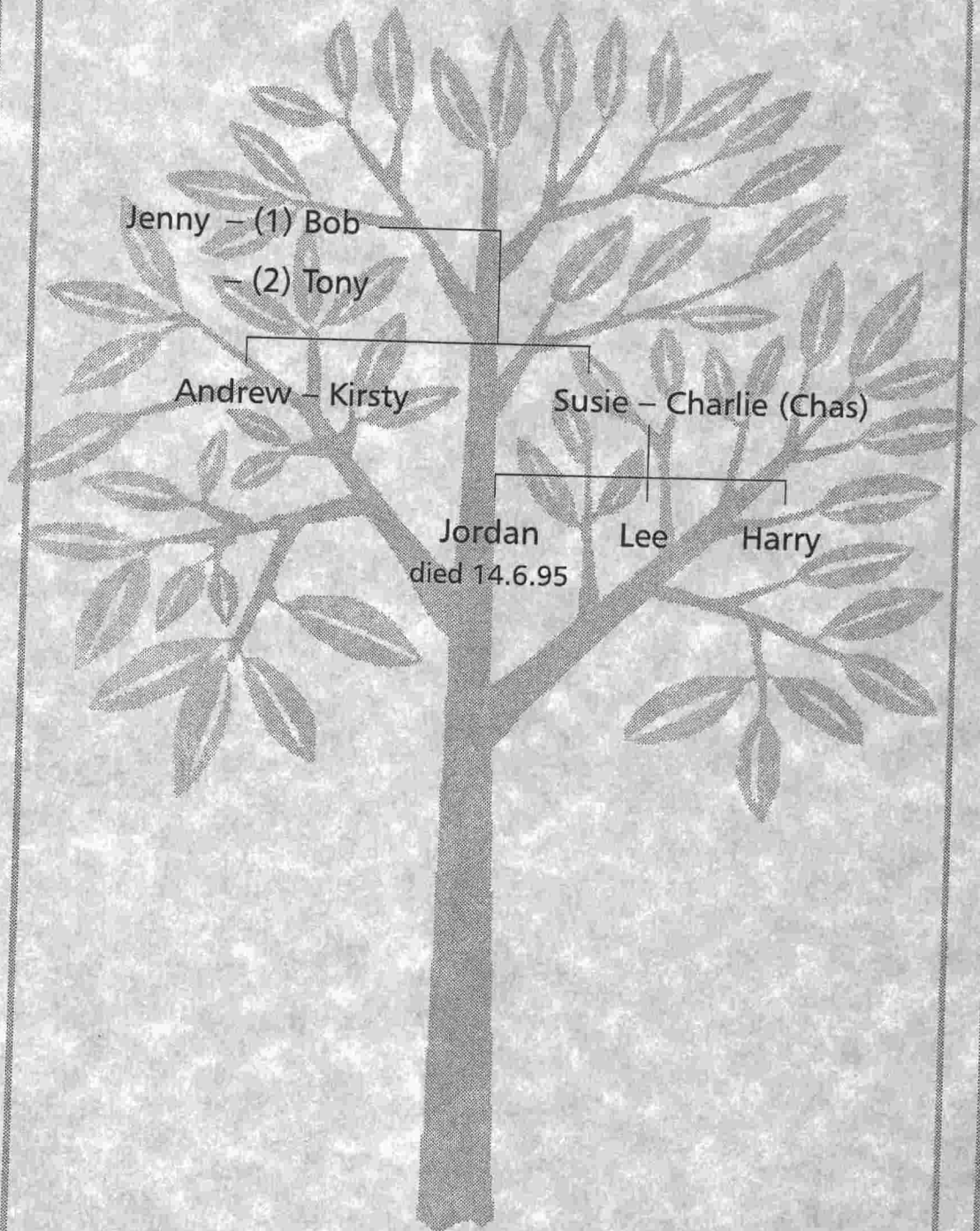
This second part of the thesis is a compilation of all the participants' stories. The stories are in their words, as they shared their pain, experiences, feelings and thoughts in a series of interviews or letters. They are shared in the spirit of a gift, for all of us to read, re-read, and to take time to hear the pain at the death of a loved child or grandchild.

The stories are presented in the sequence of the age at which the children/ grandchildren died. Where there are stories from more than one family member, the stories are grouped together and begin with the stories of the parents of the child. The positioning of the parents first reflects the emphasis which bereaved grandparents place on putting their child, the parent, before their own grief. Each grandchild is introduced and there is a family tree with the names of the people who appear in the story. Where possible, if pseudonyms have been used, the names are unique in each family's stories. As I explained earlier, many participants have chosen to use their own names as a tribute to their child/ grandchild. Where participants wish to share a special photograph, or an item that symbolises their grandchild/ child, then we have included these at the end of their stories.

As I explained in Chapter 4, the stories offer a wider perspective than a snapshot focused on the death of a grandchild. The stories reflect the way in which participants constructed their experiences of grandparent bereavement within the context of their lives and families, and not as an event that occurred in isolation. In particular, parents weave the story of bereaved grandparents through their own story of being bereaved parents. This emphasises the context of grandparent bereavement as situated within the family and focused on the parents.

## Jordan was stillborn

This is the story of his grandmother, Jenny





## JENNY'S STORY

### Who I am

I am a grandmother whose first long-awaited grandson was stillborn. Susie and her husband Charlie, with help from their family doctor and specialists at our local hospital, became pregnant four years after first trying. All was well, even to being told their pregnancy was near as perfect a "text book" confinement. So when, just 3 weeks before the expected "due" date, Susie couldn't feel the baby's usual early morning movements she rang the maternity hospital and drove straight in for a scan. Their baby was already dead. Of course our family and friends have been really supportive but when I'm asked, "How are you?" or, "How are you feeling?" I don't know how to answer.

### How did I feel?

When I arrived at the hospital and was taken into a darkened room to be with Susie and Charlie and told their baby was dead, I knew how I felt then. Pain, such pain and an over-powering love for my daughter and son-in-law and the need to try and "make everything alright again for them". When Susie was induced, so she could have a natural delivery, that was very bad. I felt very proud of Susie, she kept herself as composed as was possible. She endured two days of discomfort, pain, questions and examinations from the doctors and midwives - only breaking down when she could see how desperate Charlie was feeling and trying through her pain to be strong for him. Thankfully, her labour was relatively quick - the hospital called for me at 3am, to say she was asking for me. Initially, I felt physically sick and faint - knowing my darling grandson was about to be born, knowing the total silence that follows will be so painful. Instead of a crying, breathing bundle of joy they would be seeing a still and silent baby - so very still. I needed to be with them. We got to the ward by 3.25am to find Susie sitting up in bed and trying to smile, to make us all feel better. Yes, I was so proud of her - I knew this phase wouldn't last long, the shock would begin to wear off and then her torment would begin. When we were able to hold our grandson, it was wonderful to look on his beautiful face and touch his tiny fingers but I felt I wanted to breathe life into him. I knew it had no way of making any difference but he only looked asleep. The urge to sing a lullaby to my first born little grandson, as I'd done for his mother when she was newborn, was almost too much to bear.

### **Jordan's funeral**

Susie and Charlie, Andrew and Kirsty [our son and daughter-in-law], Tony and I were all married at our local church so we asked the Canon, who had married Susie and Charlie, to officiate at the service for Jordan. Since their wedding the Canon had retired but he was so kind and supportive to us all. The chapel at our local crematorium was filled by family and friends and many work colleagues. Charlie carried Jordan's tiny coffin, himself, and placed a musical soft toy (a present from Jordan's proposed godparents) on top of the casket. I placed a single cream rose on his coffin. We sang two hymns, the first I believe was "Love Divine", although I am a bit vague about that as I was upset and couldn't take it in. After the hymn the vicar addressed us for a few minutes. He played a tape of dolphin music which was very special to Susie whilst she was expecting Jordan - the piece was "Ave Maria" so beautiful with the sounds of the dolphins against the noise of the crashing waves. We left the chapel after singing "All Things Bright and Beautiful". This was Charlie's choice - he wanted people leaving with the feeling of hope, not despair. Two days after the funeral we had a short service to inter Jordan's ashes at the Garden of Rest in our church grounds.

### **How did I feel?**

We had all been focusing on Jordan's funeral wanting to do small, special things for him; choosing flowers, music, the service format, knowing this would be our only chance of giving of ourselves to our very special little person. Close family and friends came back to our bungalow, after the service, and, with the help of Charlie's Mum, I prepared a buffet lunch, which we ate in the garden. This was a continuation of our giving, by helping our children in any way possible. Once Jordan's ashes had been interred instead of the comfort of knowing everything had been completed I felt nothing was left "to see to". That there was a dark, gaping hole before me. My focus had disappeared. I know that after a death, making plans for the final goodbye keeps the bereaved family focused, but later the loneliness and depression seem worse than the shock experienced by your loved one's death.

### **As time went on – how did I feel?**

I felt I was able to be of help by keeping the day-to-day routine going. Susie and Charlie are very organised and business minded so I didn't need to do nearly as much for them as I'd have liked. I felt I needed to let them set their own pace, and help when asked, but I was always nearby, or at the end of the phone - they only lived 2 miles away. I slipped again into the role of taking care of my child who was hurt. But I knew

Susie would resent too much interference, so I always asked her before doing anything in, or around, their home. Over the next weeks and months a whole range of emotions filled my head and heart. I needed to be with Susie and Charlie every day, or to speak to them on the telephone, but I knew deep down they craved time alone to try to begin their new life without their cherished baby.

#### **How do I feel nearly 8 months on?**

I feel a double pain. The despair of seeing my own child suffering so badly and also the hollow emptiness of a grandmother whose dreams of holding and nursing her daughter's baby going unfulfilled. I call myself Jordan's nanny but then a voice in my head says, "You're not really a nanny yet". But part of me says "I am" - so what am I? Where do we go from here? The "bottom line" is I feel so many things, but mainly I feel confused and isolated in my grief, and still carrying so much pain.

#### **Postscript two years later - does time help to heal?**

It's well over 2 years since Jordan's death and of course we have travelled a long way emotionally. I still feel pain when I see my friends with their lovely grandchildren or Nannies pushing their grandchild about on the green or at our superstore. I have a lot of "If only's" still to conquer. So I try to be positive and thank God for MY children and their happy marriages, the love they share and their good health and prospering careers. We have had good news just a few weeks ago - Susie and Charlie have been approved by the Adoption Society, so we are hopeful that before too long they will be a family and realise their dream. [As Jenny explains in her postscript on p. 437, Lee was adopted and a while later Harry was born].

#### **What about grief as a grandparent?**

If asked about grief ten years ago I'd not experienced any so I would have felt it was like a great sadness and one that can be lived through relatively easily on a day to day basis. But I now know how different every loss is; how all encompassing, how dark and miserable each day can seem, how you can cease to function emotionally but also how physically ill you can become. When a child like Jordan dies you feel impotent to find any answers to the many questions we asked and that our children asked. We feel cheated by something that can't be expressed. We did talk and share our feelings at the beginning because speaking about Jordan seemed to make him a reality and not a dream. But I didn't talk about my own feelings as a grandma. My feelings and needs seemed less important than theirs so I put myself second for a long while. My grief

was acknowledged around the 6 month mark because both my parents had died within 10 months of each other and just 8 months prior to Jordan's death. So I began to express my pent up grief because I couldn't suppress it any longer.

### Unprepared and unexpected

I had never thought before about the possibility that my grandchild might die. Like most people, when you know your child is pregnant all you have to do is contain your impatience for the weeks and months of waiting before the inevitable beautiful baby arrives. There's never a worry, if no previous medical reason exists, of not holding your new-born grandchild. Jordan's death has made me more aware of how tenuous life is - to get pregnant and have a baby nine months later seemed normal and easy but I now know how often pregnancies do go wrong. So, our faith in the future isn't automatic - we still have hope but it is always tempered with caution and the realisation that life can, and does, go badly wrong.

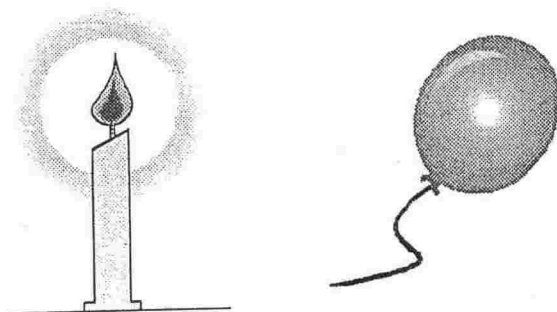
### Memories and anniversaries

With a stillbirth there are no memories as you'd have with an older grandchild so the photos and letters and cards are very important. Susie and Charlie have also been given a photo, hair and footprint from the maternity home and these are very special to them. I always think of Jordan when I see candles alight. A family friend wrote a small verse in her sympathy card which has stayed with me ever since:

*"A little candle, never lit, Yet still shines in the dark."*

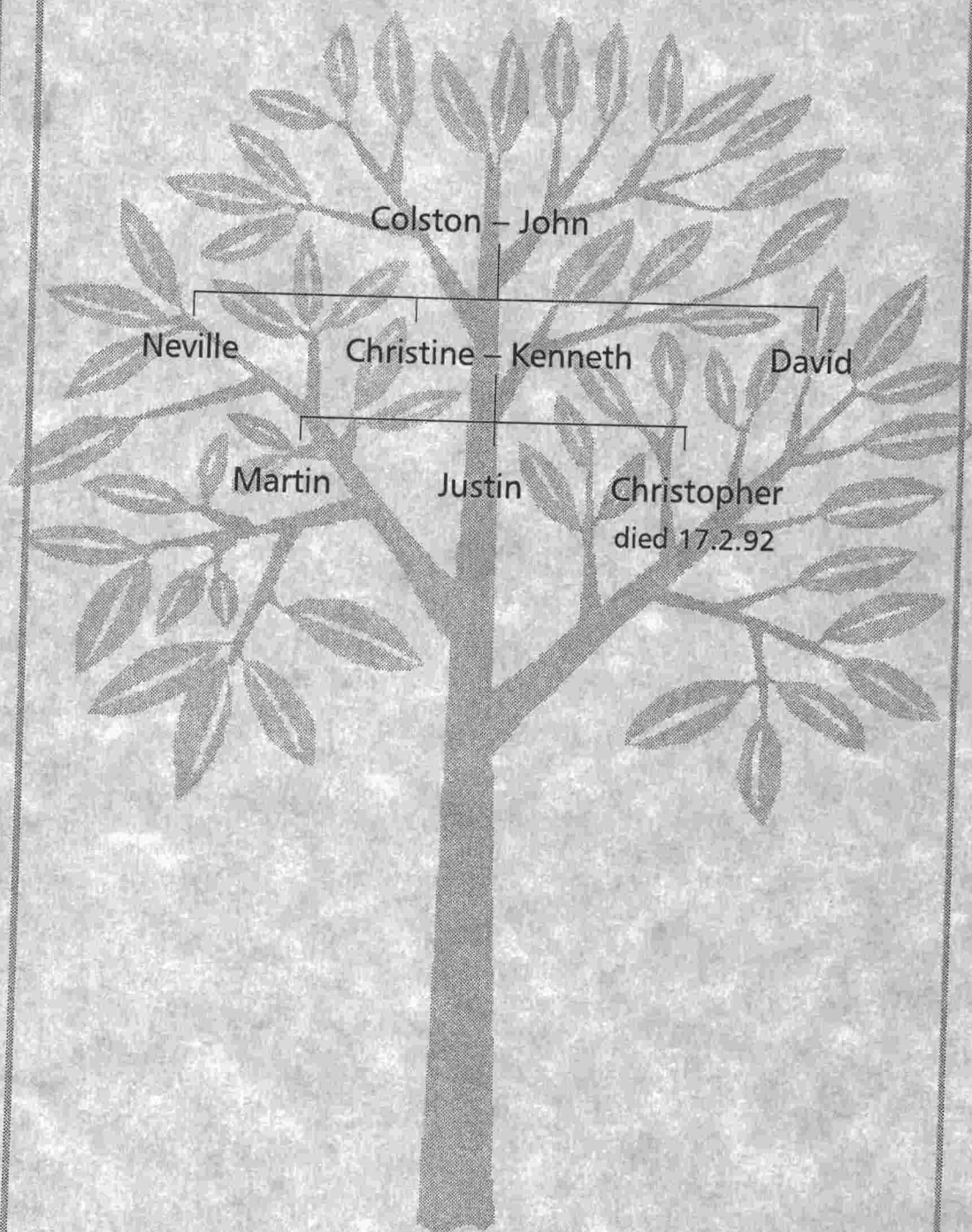
Also, Jordan was with us so briefly that his spirit seemed transient to me. On the first anniversary of losing him I took a blue balloon, with lots of streamers, down to the Garden of Rest. And told Jordan how much we loved and missed him and that Nanny and Granddad couldn't hug him so we were sending our love up to him - I kissed the balloon and let it float up and away.

**For Jenny, a balloon and a candle symbolise Jordan.**



## Christopher was stillborn

This is the story of his grandmother, Colston





## COLSTON'S STORY

### About us

I was born in 1930 and, because of the War, spent the latter part of childhood into my teenage years with my grandmother in Bath. This was not a happy situation. Then I trained as a nurse in a London hospital and met John, who was a student at the associated college, we were married in 1954. We have two children; Neville born in 1955 and Christine born in 1957, then David born in 1960, slightly before his time weighing 4lbs, which in those days was small. He only survived a few days, suffering intracranial haemorrhages, which I was told was the result of a very rapid second stage labour. I did not see him after he was born, being kept sedated for several weeks due to hypertension, but John was allowed to see him and, with my father, went to his funeral in the cemetery chapel in Bristol. In 1972 I developed rheumatoid arthritis which has progressed steadily, affecting several joints. This led me to give up the nursing job with the local doctors' practice. Eventually, I undertook theological training and am now a lay minister in the Church of England. Recently, I underwent major surgery on my rheumatic shoulder; three months on I am still recovering well, and have been told to be patient and allow 6 months for full recovery. Now the other shoulder is showing signs of being affected by the disease.

John is a graduate engineer. After industrial experience in Bristol he began teaching engineering in technical colleges, finally being fortunate in being granted early retirement in 1987. We now live in a bungalow, I can't cope with stairs, and enjoy life as far as my disability allows. We enjoy travelling and have visited many interesting places in Europe, the Caribbean, USA and Malaysia. We have a cabin cruiser on the local river which gives us and our family pleasure; also a trailer caravan which allows us to get around. Both being deeply committed to the local church, our time is a little limited.

In 1992 my daughter, Christine, gave birth to a stillborn son, her third child. There was no apparent reason for Christopher's death; he was a good size, at term, with no hint of trouble until his heart rate was lost on the monitor during the latter stage of labour. Postmortem found nothing abnormal at all.



### Christopher

Christine was in labour in the local well-run general hospital, Kenneth, her husband, was with her. We had Martin and Justin, their other children, with us. We had a phone call at about 11.30pm saying Christopher was stillborn and, "Would I go in and see Christine please?". I found Christine and Kenneth in a room; Christine nursing her dead son - a picture I will never forget. I just sat on the bed and held her hand; there was nothing else to say or do at that time. I was fully involved with their sorrow, but kept it to myself until, finally, Christopher was dressed and laid in a Moses basket, and Christine was asleep. Then I went home and shared it all with John. We didn't sleep that night. I still carry in my memory the picture of Christine in the hospital with her dead baby in her arms, wrapped in a blanket. Also, of the midwife taking great care in bathing him and giving Christine a choice of clothes for him, then placing him, so carefully, in a lined Moses basket; Kenneth taking his photo. These photos Christine still carries, with those of Martin and Justin.

The next day we got Martin and Justin up as usual. Kenneth collected them and told them what had happened. That day the local parish priest came into the hospital chapel with Christine, Kenneth, Martin, Justin, both of us, Kenneth's mother and Christopher in his basket. He conducted a simple service and we said "Goodbye" to Christopher, leaving Christine and Kenneth with him. Until Christine came home Kenneth needed to have the boys with him, they went into hospital every day. Many questions were asked and answered simply and honestly. I had great respect for the way Christine and Kenneth handled the boys. We felt quiet sorrow for them all and also that we have been bereaved. We all wept when we said "Goodbye" to Christopher; he was a perfect baby. There were many postmortem investigations, but not answers, which made everything very difficult, no reason for his death was ever found. The obstetrician was a friend of mine - she was shocked too. To return to the funeral, after all the postmortem examinations which went on for weeks, Christopher was quietly cremated and his ashes scattered, which Christine now regrets. She would have preferred to have had them interred in the local cemetery - but that is hindsight.

For us there certainly was double grief, even triplicate - for Kenneth and Christine, for the fact that Christopher had no chance, then for Martin and Justin and our own sadness at the loss of an eagerly awaited grandchild. Although, I don't know quite how

to say this, the fact that he was the third boy may have taken some of the edge off. We all longed for a daughter/granddaughter. So the pain was, and still is in a quieter way, for Christine, Kenneth, Martin and Justin, my own is secondary to theirs and their needs.

I did find difficulty in deciding how much to be seen to be involved with Christine's and Kenneth's grief and how much to leave them to their own devices. Kenneth still copes by not talking about Christopher. John, too, to some extent, although this research study has started him talking again. Christine and I chat about him, but I let Christine take the lead and am available to listen and respond. In the early days it was a struggle to let go and leave them; not to jump in with both feet when they needed to work their own way through. I hope that I am right in thinking that I am closer to Christine than my mother was to me when David died. My mother didn't really talk about David at all. Although, she did give Christine some money to buy flowers for her "great-grandson who didn't make it". That was quite a breakthrough. The fact that my parents were in London when David died and we were in Bristol didn't help - but we never had the openness that Christine and I have.

### **Memories and anniversaries**

It is now 5 years since he died but Christopher is still a member of the family. Christine always has a child-like decoration on the Christmas tree for him and I light a candle quietly in my study. We have just passed his anniversary. I always send Christine and Kenneth a card and Christine has a flower arrangement on the font in their church for him. We were away this year and I intend to put some flowers on "George" for him. George is a teddy bear sculpted for the local SANDS group and placed on a pedestal in the children's area of the local cemetery, with flower vases on the base. There are usually flowers there. As I said in my last letter Christine was deeply aware that he should have been in the new school intake, along with other friends' children, but I think she has worked through that now. She is working in the school happily and is very involved with the children. We all now think of Christopher as a boy, rather than a baby.

Christine has photos of Christopher. She has a small album, which is very precious containing the scans, photos, lock of hair and various mementos. As much as I would love a photo I felt it an intrusion to ask for one, they are so precious to her. This I

found a sadness since we have photos of Martin and Justin almost at birth. It was something as a mother I had to let Christine have for herself. I carry a mental picture of Christopher in Christine's arms and in his Moses basket, but no actual photo. He was unlike the other two. Martin was three pounds, but did not look premature, just a mini baby. Justin was seven pounds and Christopher was ten pounds, his hair was not as fair as Martin, lighter than Justin - he looked so healthy.

### **Postscript a year later**

I felt my family record was incomplete without a photo of Christopher, but I kept that feeling to myself. Then Christine had a slight mishap this week, rushing downstairs she exacerbated a slight back injury as she missed the last step. The GP recommended lying on the floor for a day or so. I spent a day keeping her company, when we were able to talk without interruption except for the occasional "ooh!" - an exclamation of pain as she changed position. Carefully, I mentioned the subject of photos of Christopher and my feelings, knowing that she had some photos but I couldn't ask for one as I felt they were so personal to her. I felt that was a border I could not cross. Her reaction was interesting, she had only been thinking recently that I hadn't got one and wanted me to have one. We have annual school photos of Martin and Justin but none of Christopher. She has also been thinking that it would be a good back up for her since neighbours had been burgled and, if she lost her copies, we would still have ours. Now she has given me the negatives we have some copies to go with the rest of the others and intend to add one to a multi-photo frame of other family photos. Christine accepted my thoughts about not asking for a photo and is pleased we can have copies now.

### **Support for the family**

Christine and Kenneth went through all the usual stages of grief as did we all, but I was helped by the amount of support they received, especially from the local SANDS group who were available to her even whilst she was in the local hospital. I have now joined the group, as their only "grandmother" and am very impressed with all they do both locally and nationally. Locally we are a very caring group, but low key, not imposing ourselves on mothers in distress but available through the local district hospital and community services, GPs, or the hospital chaplain who has been to some of our group meetings.

As a family we were probably better off than many bereaved parents and grandparents. We had support from various sources. Christine had help from the hospital staff who were very understanding and shocked themselves. When I arrived at the maternity unit in the middle of the night I was greeted by staff who were as stunned as we were and said so. I did have support from the local clergy, some of whom are friends and know the family. They gave me permission to be angry and shout at God, quoting the Psalms - reminding me of how the Psalmist shouted at God - and encouraging me to do so. This helped both of us. Our Christian faith did eventually get us through, plus many friends especially in the church. I had to support my mother, as well as Christine and Kenneth, and I felt in the middle. We talked to Martin and Justin about Christopher when they opened up, and still do. Having lived through the trauma of my own child's death I was stronger and more able to cope with Christopher, but that did not make Christopher's death any less of a shock or any less painful. I was just better equipped to cope with it, with my own feelings and with those of Christine and Kenneth, but perhaps not with Martin. Justin, being younger and of different temperament, seemed almost to have taken it as part of life; Martin, being older and more aware of the excitement of the prospect of caring for a new baby, needed more help in coping with the sadness. They both do still make occasional references to Christopher. Justin is sorry, because he would no longer have been the youngest in the family. When my mother died in January 1993, Martin's immediate reaction was "Now Christopher has Nana to look after him".

The issues for grandparents following the death of a grandchild are as many as there are grandparents, I can only speak out of my own experience. It is important to be as supportive as possible to the whole family. I had to face four ways of coping; with Christine and her family, with my mother and also with John who was not as able to express his feelings as I was, although they were there. I felt I had to be strong for them all and, to some extent, keep my grief to myself until Christine was able to cope with feelings other than her own. Having said that, we all, including John, did have a good cry when we said "goodbye" to Christopher in the hospital chapel.

### **Moving on**

Looking back now after 5 years I feel I can take an overall view, less controlled by emotion, although this involvement with your study is bringing back emotions, thoughts and feelings. But they are no longer raw; they have matured over the years

when some have lain dormant. Since Christopher died the rheumatoid arthritis has become worse, partly due to stress, partly to the natural course of the disease. There certainly has been growth following Christopher, Christine has matured in a way I wouldn't have thought possible, she has certainly helped many other people in her situation which is good to see. Now, there is little we don't discuss between us, but John and Kenneth say very little, Kenneth apparently copes by saying nothing. The older generation of the families won't talk about Christopher, even his paternal grandmother which, I think, is hard for Christine and Kenneth.

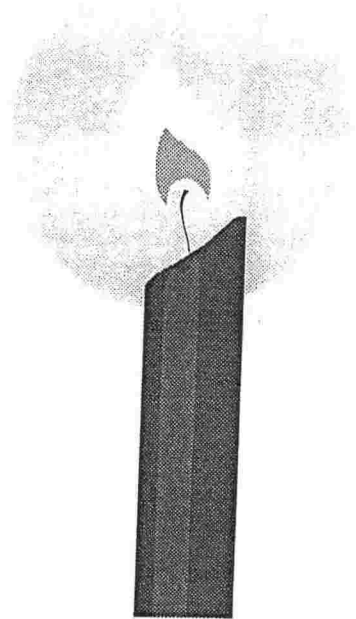
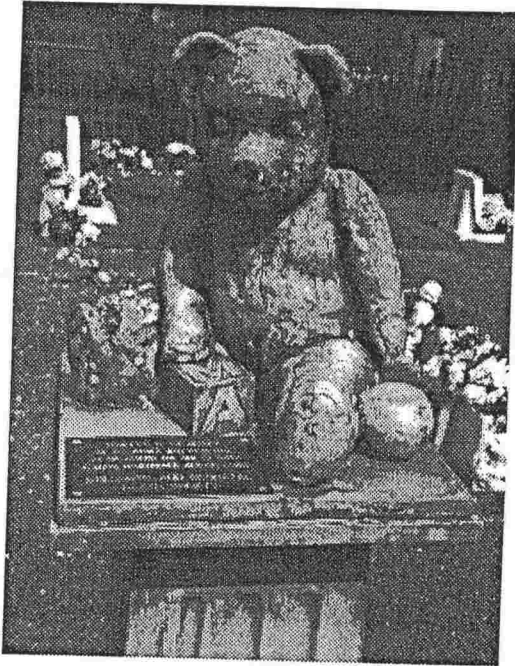
### Reflections

I think Christine and Kenneth made very wise decisions when Christopher died, particularly in the way they handled Martin and Justin. The only regret was, as with my father, that the ashes were scattered. Now, apart from an entry in the hospital book of remembrance, there is nothing specific to remember Christopher by. Having George (the SANDS teddy bear sculpture) helps. I had never considered the possibility that a child of mine could die right to the moment of David's death. Since then I have been aware of the possibility and of my own mortality, yet did not consider the possibility with Christopher. The pregnancy was the least complicated of Christine's three which went to term. The phone call from Kenneth saying that he was stillborn was shattering, despite the death of our third child. Initially it feels that one is the only person to have a grandchild die, as it does to have one's own child die. Going home a few days after David died and seeing all around life going on, as usual, for my neighbours was hard. I wanted to go out into the garden and shout, "Don't you realise what has happened?"

When Christopher died, I did have to think very deeply about death, especially in relation to my faith and the love of God. That has, I hope, taught me more understanding of other people's doubts. My Christian faith and belief convince me of life after death, but what form that life will take is veiled. We only have hints from the Bible. Unlike Martin, I don't think of Christopher "being with" other family members, but I do think I will be reunited with him eventually, as I do with David.

My answer to the question people ask, "How many grandchildren do you have?" is usually "Two". This depends on who is asking, but rarely do I tell the story of Christopher now, unless it is relevant to the listener, such as a bereaved parent or grandparent. This does not mean that he is no longer a reality.

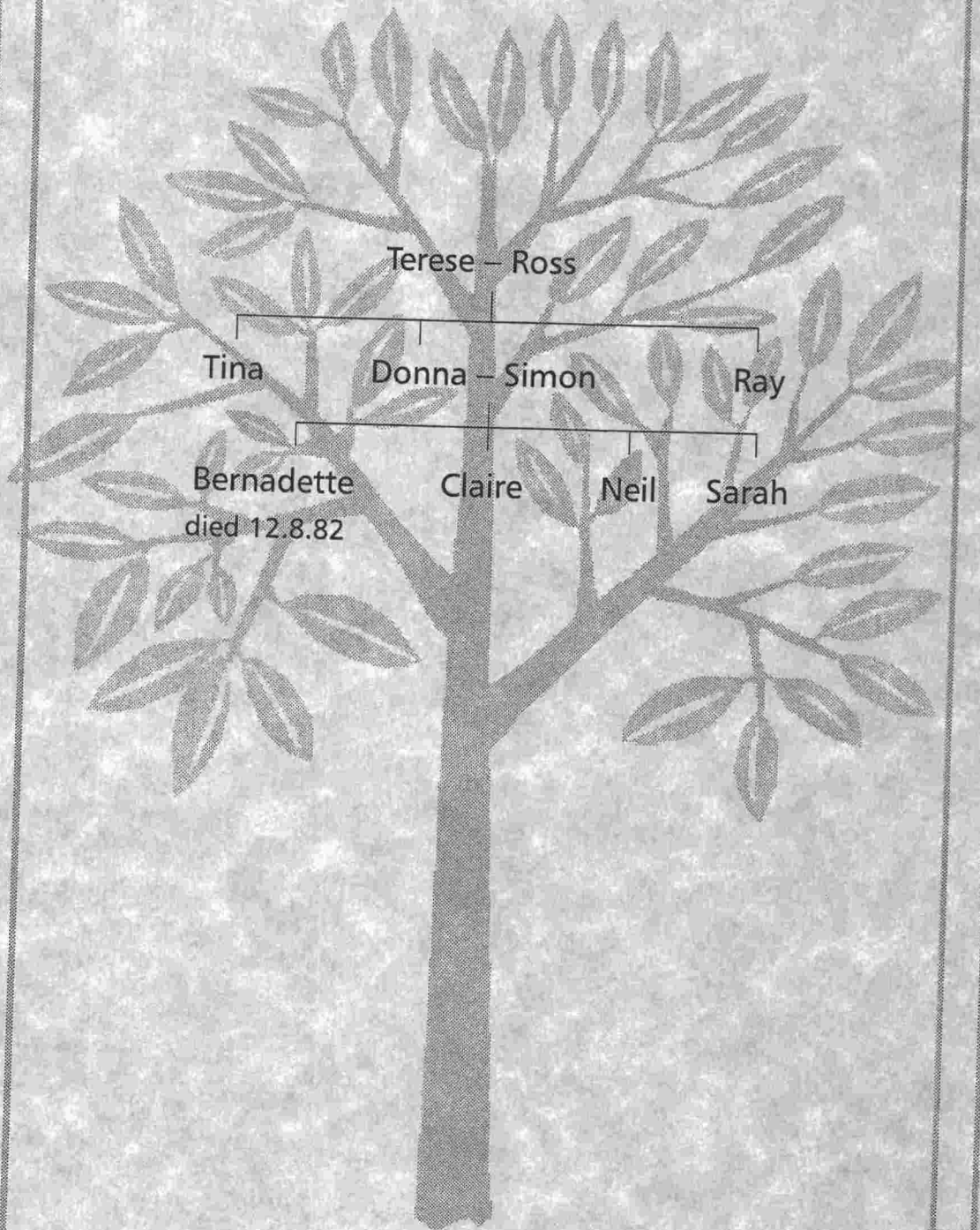
*For Colston, George, the teddy bear sculpted for the local SANDS group, is a reminder of Christopher. The candle that she lights in memory of him also symbolises Christopher.*





## **Bernadette was stillborn**

This is the story of her grandmother, Terese



## TERESE'S STORY

### About us

I was born in Milton in 1935, second youngest of ten children. I lived in the country and remember my growing up there as a happy time. I married Ross at 20 years of age and the following year we had our first child, Tina. Eighteen months later we had Donna and moved into our new home where I have lived for 39 years. Ray was born 4 years after this. At the time of my granddaughter, Bernadette's death, Tina, my eldest daughter, was living in the area with her husband and two daughters. My son, Ray was at Varsity and still living at home. Donna, Bernadette's mother, had moved away to the North Island for a couple of years. Later she came back to live at home. A short time later Simon, her partner, who is from the Hawkes Bay, moved down as well. They then lived together and Bernadette was their first child. She was unexpectedly stillborn 16 years ago.

### Bernadette's birth and death

Bernadette was stillborn. Well, I remember the day because it was my birthday. We, my husband, my son, and myself had gone out for dinner that night. As we were coming home, Donna had already been into the Maternity home and she had been sent home to wait until she was more ready. And I remember when we came home we saw Donna with her friend and then she was taken over to the Maternity home again. So we followed them in. We went up with Donna and Donna went into the room and we heard the nurse say that she could not hear a heartbeat. We went into the sitting room, Donna's friend, my husband and I, and we sat wishing it wasn't true, and hoping it wasn't right. After Bernadette was born they brought her in and asked if I wanted to hold her, which I did. I couldn't see why she was dead really, because it was a perfect little baby. Then we saw Donna again and then we went home and Donna stayed there, it was hard to leave her. I never held Bernadette for very long but she was dark and she had a dimple on her chin, which was a trait of my husband. What I'll always remember is holding the baby like this [pause] and I could not believe it, you know. I'll never forget that. When I think of her, I think of holding her in that green wrap [that the nurses put round her] because it is the only memory I have of her.

I remember that friends came the next morning and I did not want to see them and I told my husband to tell them I was still asleep. But I could hear them and I just didn't

feel up to it. I remember when I rang up and told my sister she said, "Oh, perhaps it was for the best". I couldn't believe she said that because of Donna and Simon not being married.

I think having people around was harder for Donna than for me - because she kept everyone at a distance. I think she found it really hard to talk about it. At the funeral she had her friends there. We had a graveside service out at the cemetery, which was where Bernadette was buried at the bottom of my grandparents' grave. I think we talked about this and I suggested it because we more or less didn't know what to do and I thought that might be a good idea, if we were allowed to do that. Donna did like the idea but I didn't know if they allowed that or not, fortunately they did. I arranged to have Bernadette buried there at the bottom of their grave and arranged for the priest. That was very pleasing to have the family buried together. My husband was with me in helping with the funeral. At the funeral Donna asked me not to go near her because she could not cope with it. I think it was because she thought she might completely break down if I went near her at the time and that she wouldn't be able to handle it probably. I could understand at the time why she would feel like that. I think she understands. She does realise that I have been upset about that as well. Donna's friends and our family came back to the house for a cup of tea. That was quite good.

### **After Bernadette died**

It was hard for me because at the time Donna and Simon were not married. Although, Simon felt very deeply about it, Donna did not get the support from him. His way of coping was just going away from it, which he did. I don't think I worried too much about Donna and Simon not being married. Donna and I, we saw each other often. Donna wanted me to take all the baby clothes, so I did that. I don't know if it was a good thing to do, probably not. I didn't know at that time, perhaps that would stop the grieving process, it might have been better if she had kept them, it might have helped her more. Although, when she was expecting Claire, she got most of those clothes back again. But at the time I thought, "Well, perhaps it wasn't good to do that". But Donna said it would probably help her.

Over the years we have begun to talk more about it, and more so since she started midwifery training. At the time Bernadette died, Donna did not want counselling. She let us talk but, looking back, I really think that she did need counselling. So that she

could talk about it, because she couldn't really talk about it - even to me. Other people would not talk to me. I remember that I was working part-time at a place and I remember trying to talk about it to someone at work and she did not want to listen to me. I remember that we went out for a walk in the lunch hour and I started to talk and she did not want to know. That hurt. I remember that for the first couple of days at work it was very hard to talk to people.

### **Why Bernadette died**

There's one thing that I wish Donna would do, and that is find out the results of the postmortem because we still do not know why Bernadette died and I wish I knew WHY she had died. Donna, I think, needs to do it on her own, but I'm not pressuring her to go and see. I think she needs to know what caused the stillbirth because to be there in the Maternity Home and then be sent home and yet two days before that all was fine and she was perfectly alright. What happened in between? I often wonder about that ... but still it's past and then what good would it do? Although, I feel it could give an ending and it's important to know. [Postscript: shortly after this interview Donna did get the postmortem results.] Donna got the postmortem, but I don't think it helped her much, it said that Bernadette was normal and perfectly formed, so it wasn't a great help to her, she said.

### **Children after Bernadette**

I saw a lot of Donna when she was having her other children, she would be round here. Donna had a miscarriage when she was about 9 weeks pregnant after Bernadette. I know when Claire was born, that was Donna's second pregnancy after Bernadette, she was special because she was after Bernadette. The doctors and nurses took special care of Donna before Claire was born, they did not want anything to happen. When she was pregnant with Claire I was still anxious because of what had happened and when she had Neil, the same thing happened again and Sarah, the same thing happened. I don't think the anxiety got any less and I remember the relief and the joy of when she had Claire and everything was alright. I know Donna talks with her other children about Bernadette. She talks about her, and the age she would have been. They know all about her and, because they know, every now and again they talk about her like "She would have been 16 now".

### Reflections

I thought before Bernadette died, "It only happens to other people it doesn't happen to me". Bernadette's death has made me more aware of what other people could be feeling, especially cot death, and what the families go through. It is hard and you feel compassion alright but before that death you used to feel for them but you could not have the same understanding. Bernadette's death changed my family. I think I felt closer to my husband at the time. I think we had more understanding; we seemed to be closer together. I think it's the old saying, "Until it happens to you, you don't know what it really is about. It always happens to other people". I think I came closer to Donna since that time. We do remember Bernadette and we do talk about her but you can still see it hurts Donna and it will never go away. I still see Bernadette as that wee baby I held. I do think of what she would be like if she had lived, living with the family; and what she would be like, what she would be doing at school and things. She is part of our family although if someone says, "How many grandchildren do you have?" I usually say, "Five". I don't include Bernadette because it saves a lot of explaining and talking about it.

I suppose my pain over Bernadette would have been until Donna had Claire - I don't know whether that grief carried on for that long. When I think about the pain and grief going away, deep down it will always be there but in a different way than it was 16 years ago. It seems that my generation, we didn't have the same worries as parents have today. You took everything for granted, well, I did. That everything would be alright and you never thought of having a stillbirth or anything else. You just took everything for granted that things would be OK and normal.

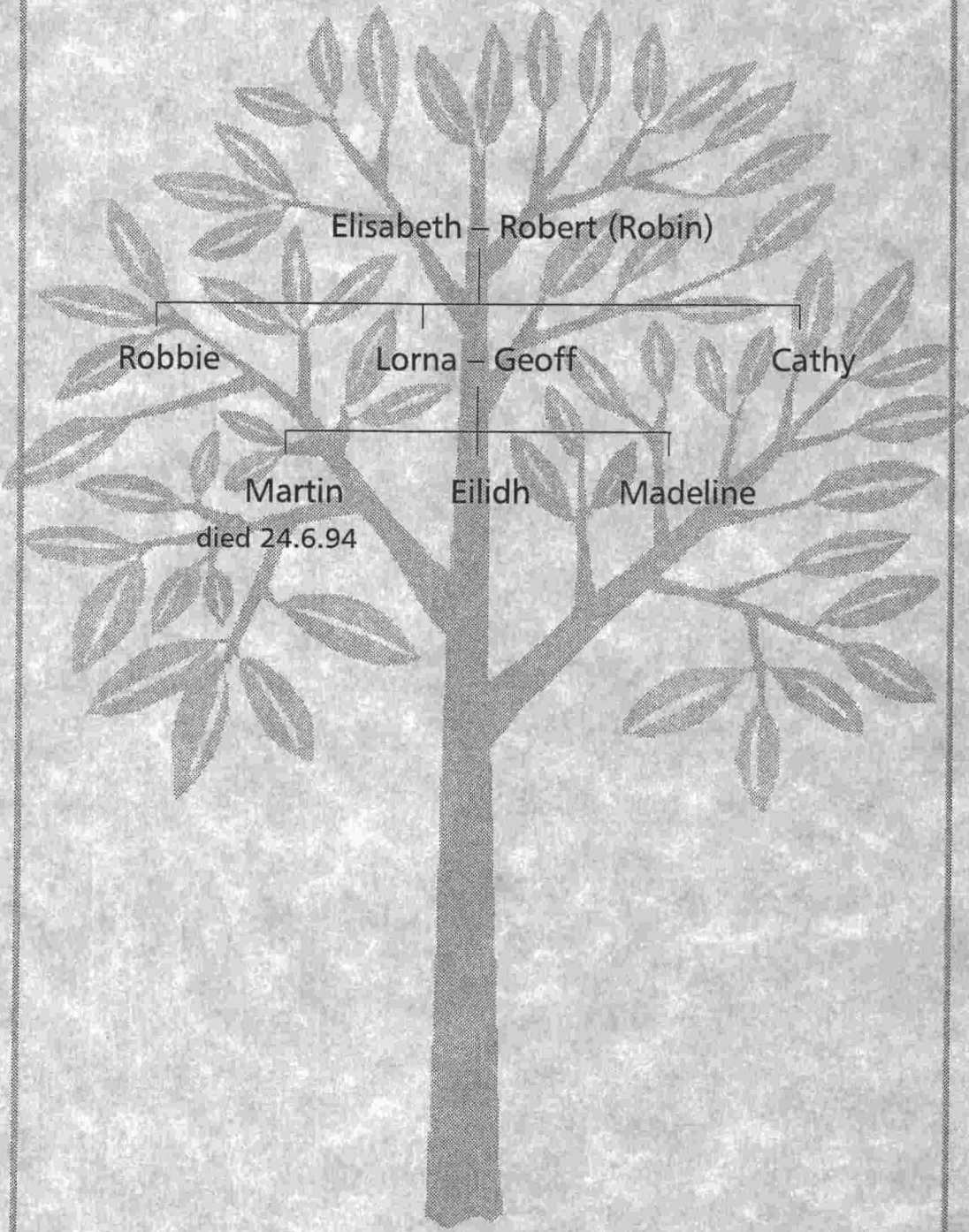
*For Terese, a rose and pansies symbolise Bernadette.*





**Martin was born prematurely  
and died soon after birth**

This is the story of his grandmother, Elisabeth





## ELISABETH'S STORY

### About us

I was born in Scotland in 1934 and had two brothers. I was brought up in Glasgow and Fife and educated at local primary and comprehensive schools. I trained as a registered general nurse at Edinburgh Royal Infirmary from 1953 to 1957 and went on to be Assistant Matron of the Church of Scotland Eventide Home, Ayr from 1957 to 1959. I married Robert, a General Practitioner (GP), in Ayr 1959, and had three children, Robbie (36), Lorna (34) and Cathy (28). We have two grandchildren - Martin born and died June 1994, and then Eilidh born October 1995. Another grandchild is due in July 1998. [Postscript: this baby was born alive and well, named Madeline]

Here is my little story. It may be of some use to you. It has helped me to write it all down. Nothing prepares one for the loss of a baby; it is a very special pain. As grandparents, we watched with deep sadness as our young folk suffered.

### Our first grandchild

Today is the 27<sup>th</sup> of September. This was the due date for our first grandchild. Sadly, Martin Ewen was born on the 24<sup>th</sup> of June after our daughter Lorna went into premature labour following the sudden loss of her waters. This dear little baby weighing only 900gm was whisked off to the Neonatal Unit where he died one hour later.

Lorna, 31, and Geoffrey, 32, were very excited about the arrival of their firstborn. The pregnancy followed a normal course and Lorna looked and felt very well, continuing with her work and being seen by her GP and midwife on a regular basis. There was no hint of any problem and she was confused when she woke early one morning to find she was "leaking". The doctor immediately admitted her to the Maternity Unit at Aberdeen where a scan gave the news that all the waters were gone. Geoffrey was working off-shore on the oil-rigs and it was his parents who went to hospital with Lorna, as we live 200 miles away. I left home and travelled to Aberdeen and at 7pm I arrived at the hospital to find Lorna sitting up in bed, quite clearly in shock. Two days previously I had visited Lorna and had left a healthy, happy woman looking forward with great joy to her first baby. Now she was confused, tired and needing the support of a loving husband.

Staff at the hospital were considerate and careful to give accurate information always indicating that this was a serious set-back for the baby. I left her in a small room, which was warm and comfortable, and hoped she would be able to rest. Phone calls were made by an anxious brother-in-law to reach Geoffrey and try to arrange for his transport home via Norway. The morning news from the hospital was satisfactory - no change. On my way to the hospital, I did some shopping and ate lunch, arriving at the ward for visiting time at 3pm. Lorna's room was empty and Sister told me she had gone into labour at 12 o'clock - after I had left home. At the labour ward I sat in the waiting area and staff kept me informed. It all seemed unreal. Events had moved so fast; how I wished Geoffrey was there. He had reached Stavanger in Norway and was due to fly out at 4pm. Doctors and midwives went in and out of the labour room and a special team was on standby to take the baby to the recovery room as soon as he was born - if he was alive. How would my dear Lorna cope with this situation?

Martin was born at 4.12pm and immediately rushed off to have resuscitation - a tiny bundle wrapped in a green cloth. Immediately after the birth I went in to see Lorna and she told me that Martin might not survive and, if he did, he would have a long hard struggle ahead. We drank tea and talked of Geoff and Martin and listened to the cautious midwife while she worked to tidy and repair Lorna. At 5.20pm the Doctor came to tell us that Martin had died. He had problems with his breathing as his lungs were not properly developed and there were other complications also. We hugged and wept quietly and the midwife brought Martin to meet his mother - a dear little baby wrapped in a shawl and wearing a blue bonnet. For me, this was the start of a new pain, watching my child grieve and wishing I could take her grief away. The thing which always symbolises Martin for me is his little sleeping form - it is etched clearly in my memory - a tiny bundle in a blue bonnet and shawl so small. Life and death in one hour.

Geoffrey arrived at 6pm, confused and stunned by the news, which Lorna had asked Sister to give him on his arrival. I left them together and met the Chaplain who talked comfortingly and told me about procedures for registering the death, funeral etc. This was a shock as I realised all this lay ahead of Lorna and Geoffrey. The Chaplain then went to see the couple and invited me to join them while he blessed Martin and prayed for us all. Geoffrey was going to stay at the hospital as Lorna was being transferred

immediately to Rubislaw Ward where mothers go after miscarriage or death of a baby. This very special place gives counselling and comfort to couples who are shocked and hurt by circumstances which should be happy.

### **Martin Ewen Reid - born and died 24<sup>th</sup> June 1994**

Martin was buried in a quiet, rural village cemetery opposite the parish church. Lorna and Geoffrey are regular visitors and we also find comfort in that tranquil place as we pause at Martin's grave. An inscription on his gravestone reads:

AN HOUR OF LIFE, A LIFETIME OF MEMORIES.

This is true for us all. The Hospital Chaplain, who took the service at Martin's funeral, afterwards told me that seven babies had died between Friday and Wednesday, this included a set of triplets. What a lot of heartbreak for so many people. Aberdeen Maternity Hospital serves a very large area, including the Scottish islands, so there is a sizeable population.

As a grandmother, it was a great privilege for me to see my grandson and I will never forget him. For the first time in my 59 years I thought seriously about loss of a baby. Nobody close to me had ever lost one and I had had 3 children with no problems. As a nurse, with a GP husband, we knew of patients who mourned silently for lost babies. I could share some of my feelings with Lorna and Geoff, but often I felt I must be strong for them and hide my feelings as they were struggling. I wanted to shelter Lorna and Geoff, take away their grief and suffering, stop their pain. All impossible, I had to learn to treat them as adults, as parents, and to listen.

### **Grieving for Martin**

I had no maternity experience in my nursing training so knew little of a mother's grief. This was to change. My husband, now retired, felt the loss of his little grandson deeply. We look at other children and think what might have been. We are close with our daughter and son-in-law and have watched them come through their grief and mourning and felt their pain, sadness and understood their anger. I lost weight after Martin died. Some weeks later I realised I had been in a state of shock and had been working on "auto-pilot" for some time. This passed with time.

Our friends were sympathetic, some more than others. People told us stories of their loss, some of whom had never spoken of it before. One friend said she was sorry, as

she wanted me to be a grandmother and hoped I would be one in the future. I felt angry and hurt and told her I **WAS** Martin's grandmother. This seems silly and trivial now but at the time it seemed so thoughtless. The support I had was mainly from family. Sadly, some friends were hopeless - some quite good. Most people did not mention it and thought it best forgotten. My minister from Church did not realise how devastated we felt and this was difficult. I could have done with more discussion about grief but my husband seldom talked about it as he knew I would weep, and still do. He felt the loss of Martin very deeply and grieves quietly.

Grief took on a whole new meaning after Martin died. The double grief was almost unbearable - watching your own child and her husband grieve - and feeling deeply the loss of our grandson. It seemed so enormous and as a person who was usually in control of my public emotions, I suddenly found I would weep in the most unexpected places and with the most unexpected people - this was difficult and quite hard to accept. Even yet, I have moments of deep sorrow, usually when I am alone, and at home, but it passes more quickly now. I still keep busy and, apart from Martin having a very special place I can't say life has changed, but it has made me more aware of other's loss and grief.

### **Support from SANDS (Stillbirth and Neonatal Death Society)**

Lorna told us about SANDS and we knew she derived much comfort from the meetings. The sister in Rubislaw Ward had given her some SANDS publications, one especially for grandparents; which Robert and I found helpful. Ten months after Martin died, Lorna had the local SANDS group meeting at her home and I was able to be present, since I was visiting Lorna at the time. The women were a happy group. Some were pregnant and anxious to compare notes of their experiences, but others spoke of their hurt or anger at events that had taken place since the last meeting. At this local meeting business was arranged, fund raising continued, but my overall impression was one of women sharing grief with those who cared and understood. There was a lot of hurt amongst these women and they needed each other. Someone said it must have been hard for me, as a grandmother, to be with Lorna when Martin died and I was invited to talk about it. It seemed the natural thing to do and gave me a chance to mention a few things that I had thought, but not spoken, before.

### **Moving on**

Writing this story has helped me greatly to come to terms with Martin's death - I enjoy writing his name. Sometimes, I look at a little boy and think he would be the age of Martin if he had survived. It is hard to imagine what he would have looked like and my memory of this perfect, peaceful little baby returns often and I am so glad I was there to see him and hold him. Martin's death, for me, has meant the hardest problem I have ever coped with. Lorna and Geoff have both moved on and grown in many ways - this brings me great joy.

### **Another grandchild**

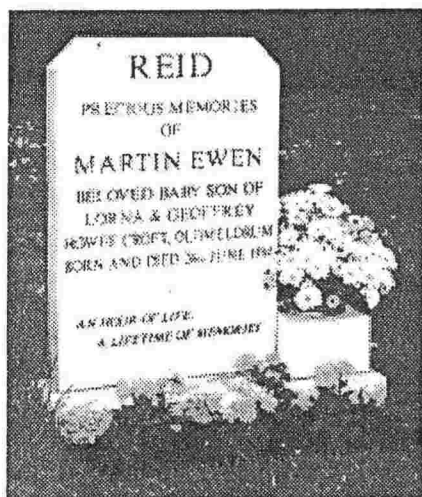
For the birth of their next baby, Geoff was able to be with Lorna all the time and Eilidh Charis Elizabeth Reid, weighing 5lbs 13ozs has taken over their lives, 24 hours a day! (Eilidh is pronounced "Ailie" and is Gaelic for Helen). As grandparents, it is a great joy for us to see Lorna and Geoff so happy and we share this with them. Martin is very much in our thoughts as we speak of him often. Eilidh will grow up with the knowledge of his short life but the very important place he has in the family. My feelings about Martin have not changed after Eilidh's birth but he seems to have moved into a more comfortable position. Two years have past and having Eilidh is a great comfort.

### **What can grandparents do when a grandchild dies?**

These would be my thoughts from my experience.

- Take your cue from the parents. Try to be helpful and understanding to their wishes - do not take away their responsibilities in any way. Allow time to mourn and express grief in the family and with friends when possible.
- Try to pave the way for friends and not-so-close family to share in the grief and understand how the parents feel. Grandparents' grief must be worked through when time allows and should be shared with other grandparents who have lost, if possible.
- If the parents want to keep the lost baby's memory fresh and present, then bring the baby's name into the conversation. Remember birthdays, Christmas and other important family times.
- If there is a grave, visit it when you can. This lets the parents see that you remember every day, not just the special occasions.

*For Elisabeth, the important symbols of Martin are his hand and footprint as well as a photograph of his gravestone.*

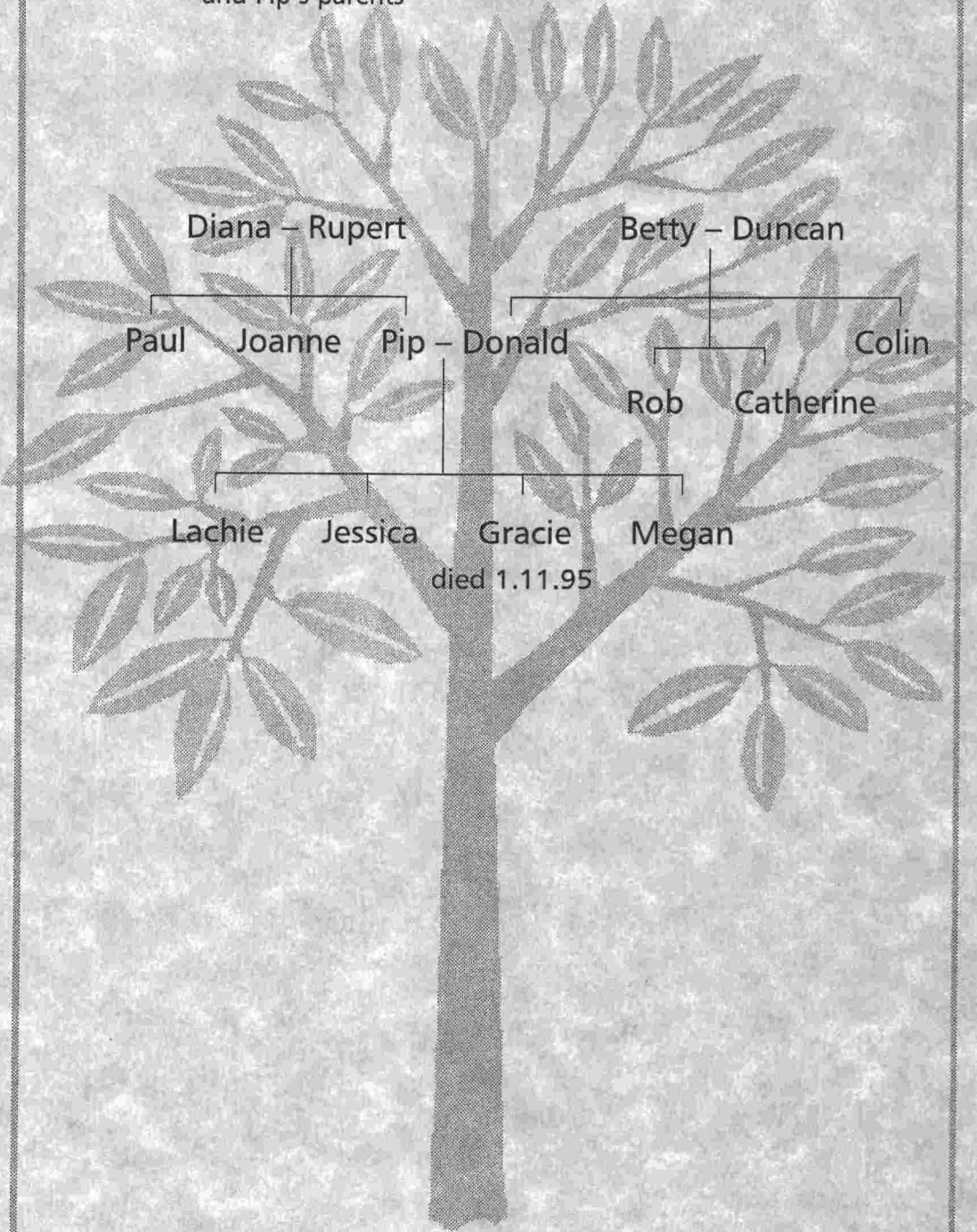




# Gracie died soon after birth

These are the stories of her family

- of Pip and Donald, who are Gracie’s parents
- of Betty, who is Gracie’s grandmother and Donald’s mother
- of Diana & Rupert, who are Gracie’s grandparents and Pip’s parents



## PIP AND DONALD'S STORY

### About us

We both grew up on farms and started to have children when Pip was 23 and Donald was 28 years. We live and work on our own farm and Pip also works as a Plunket nurse. We have two older children; Lachie who was seven and Jessica (Jessie) who was five, when Gracie was born. Gracie died soon after she was born.

### The Story of Gracie

**Pip:** Historically, I'm not very good at having babies. Lachie, he was a difficult delivery. He was a posterior position in labour and I went to Dunedin to have him. I went to Oamaru initially to have Gracie and decided, because she was posterior position and nothing was really happening, that this wasn't going to work. I said to my GP, "I think I'll go home now". So, I went home and I rang up the obstetrician who delivered Jessica and said, "Please can I have my baby in Timaru with an epidural please?" and he said, "Alright". It was lovely because we went up there and he had organised the same midwife who was with Jessica's birth, to be there. They don't have to do that, I should have been under the midwife who was on duty, but he had rung up and organised for me to have the midwife who had been with me when Jessica was born. I went quite nicely with an epidural. Gracie was born and she was delivered quite normally. The midwife passed her to me and then she cried and then she started to look a bit strange and I thought, "Perhaps she needs a bit of suction?" so the midwife suctioned her a bit. I said to Donald "You had better take her because she looks like she needs to be held upright" and at that stage everyone was feeling, "Isn't this great!". Then Donald said, "She's still quite flat<sup>1</sup> isn't she?" She was looking a bit flat at that stage so they took her over and started to work on her. We were in the operating theatre, obviously, because I had the epidural. They worked on her for quite a while but she never really rallied again. For a little while she did do a couple of breaths on her own but that was about it really. After that had been going on for an hour, they were still working on her and we were still in the room, I said to Donald, "I think I'll go somewhere else now". So we went through to the other room and I could hear them in the operating theatre saying, "Who is going to go and tell them?" It was pretty obvious what was going on, really. You get to the stage where you think, "Do you

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<sup>1</sup> Not breathing and responding actively.

want a brain damaged child?" And you go through all that stuff. The paediatrician just happened to be the obstetrician's wife, which was really nice. It was a kind of tense situation, you can imagine, and they worked really well together.

Gracie did die - it was bad luck, wasn't it? They brought her into us and we dressed and bathed her and tucked her into her bassinette. Donald was pretty wrecked and we both went to sleep. In the morning, about 3 hours later, the obstetrician came back and he was going to operate in theatre. I thought, "God, I'm pleased I'm not in theatre this morning" because he had been up until 5 o'clock in the morning. Obviously he and, his wife, the paediatrician had gone home and discussed Gracie because they didn't know why she had gone really pale - like she had bled. They thought it was a bleeding thing and so they came back and took some more photos. They wanted to do a few tests and stuff but we didn't particularly want to do too much. They took a bit of tissue for chromosomal stuff and they x-rayed and did non-invasive type stuff. I never at any stage thought about sending her to the morgue - it wasn't really an issue. I don't know why it wasn't, it just wasn't. So we bundled her up and the woman from the SANDS (Stillbirth and Neonatal Death Society) group came. She was absolutely wonderful. She was great for the practical things like who is a good funeral director and things like that. I was slightly neurotic, I didn't want Gracie to go into a casket that was going to give off horrible fumes when it was burnt; so we had to get a little rimu box made and all that sort of stuff. It was all a bit involved really.

Then we went back to Granny Di's house (that's my mother) and all the family were there. My brother and his wife, and my sister and their kids came out and we had a party for Jessica because it was her birthday. Then we came back home and we were all pretty wrecked by that stage. People said to me, "Are you sleeping?" and I was saying, "Yes, sleeping fine, having difficulty getting out of bed". Lachie and Jessica went to school the next day because it was Jessica's first day of school. Then visitors started arriving. The minister came up that day so we sorted out those sort of things. That day, Betty [Donald's mother] came down and I think she was a little bit blown away by having the baby here. I think Dad was, too, and I think he'll probably say the same thing. Betty was just great - like she has dealt with quite a lot of grief, having had her husband and son die, I think she knows what to do. Two friends had been up and cleaned the house and filled the fridge so all we had to do was get food out of the

cupboard and deal with it. Betty was just kind of there but she was really unobtrusive. She likes to do things like the dishes and read the children stories whereas Mum is much more inclined to get into organisation mode. Mum organises, which was great on the day of the funeral; she just organised all the food. And Rupert, my father, he was good. He brought a bottle of whisky and sat and drank it with the minister. It was useful and the boys sat round too and had a yarn - he is a lot more open whereas I guess Mum would be more inclined to coping mechanism stuff - busy, busy, busy.

When we brought Gracie home we popped her into the office because it was the coolest room. People came and saw her. That was really nice. Lots of people did that. I guess that the thing is that, if you have a baby who dies and no-one sees her, they are going to forget so I thought, "If we make an impression they might remember".

### **Gracie's funeral**

We had her funeral here in the garden by the blossom tree and we just invited people that we wanted to be here. It was a really lovely day. We had Gracie down in her wee box on the table. This idea of bringing dead babies home was quite strange to a lot of people - you can imagine. We had invited our neighbours and friends, pretty much Kiwi blokes and they thought this quite strange behaviour. So we had her down under the crab-apple tree. She was sitting in the sun and she got really warm - it was really uncanny. Liz, who is now a good friend, said, "Can I pick her up?" I said, "We'll take her inside because she is getting a bit hot" and we didn't want her to smell. So we brought her into the living room and Liz picked her up and said, "This is really weird" picking up this little baby that you know is dead but felt warm. All the women held her that were here and some of the men. It was really nice and they all went home about half past two because we took Gracie down to Oamaru to have her cremated there.

There was one small interlude in Oamaru. We [Pip, Donald and all 3 grandparents] got down to the place where you get people cremated, and they have that little curtain, where the coffins go behind the curtain. I said to the undertaker, "What happens to her now?" He said, "Oh, we are going to cremate her in the morning" and I said, "Oh no, you're not, if you do that I'm taking her home, I'm not leaving her with strangers overnight". And everyone thought, "Oh God, that is a bit stupid". In the end the guy said, "We can do it this afternoon as long as we get the papers signed". So, I said, "Let's do it". So we went to the pub for an hour until we found out that it had been

done. Otherwise, I would have got her and brought her home and just taken her back the next day. She had been with us the whole time and I wasn't about to leave her - particularly in an undertaker's.

### **Making choices for Gracie**

**Donald:** The choices we made - it was almost like amnesia at the time, really. You are aware of what you are doing but, I mean, you haven't had any sleep for days. And it was Jessica's birthday when Gracie was born. There was so much going on - it was pressure time farming as well. In a way, I think you just sharpen up, I'm not too sure - you become acutely aware of what is going on at that moment and you forget about it shortly afterwards. Our parents supported our choices. My mother doesn't tend to get in the road and I think she was pretty happy. I mean a lot of what we did was learnt and it has happened before. Not that we have had a baby die before, but I mean the process of what we went through is learnt. So we probably learnt it from our parents so therefore it was pretty straightforward. It was only the business at the crematorium that Pip talked about where things got a bit tense.

**Pip:** Having a private funeral was great. I wouldn't have it any other way. I know I really feel grateful that we did things like death and funerals when we were in nursing training and we talked about it quite a lot and it was always like second nature. Like I knew what to do and that made it so much easier. For someone who actually had to sit down and go through all those choices it would be much harder - I felt like I had a head start.

### **Reflections on grief and Gracie's death**

**Donald:** Well, I suppose it is coming to terms with grief really - that is the thing. My mother is totally different to Diana in her approach to grief. I am not sure how Mum copes with it - but she does. They have both got quite a religious base which I think helps, I am sure it helps, or having some belief. And I think, for everybody, coming to terms with it is the big one. I mean, grief for everybody is different but it is being able to talk about it, I think, afterwards. We are getting better at grief. All of us, I think. I mean, there are aspects of every family death that are different. Like, whether you know they are going to die and how long you have got to come to terms with it, the age differences between the kids and the parents or brothers or whatever. It is all different, but I think perhaps we are getting better. We can talk about these things a lot more



openly now than we have in the past. Sometimes, perhaps, when people die when they are old it is easier to accept and grief is a bit simpler. And perhaps you can talk about what is happening and what you are feeling but if you don't want to, you don't - as simple as that. As I say I do talk to Pip about how I feel. I do wonder how Betty feels and how she copes. Because you don't expect, I think, to lose a husband, then a son and then grandchildren. It is not normal, I would have thought.

**Pip:** Some things are important to me - like my grandfather's funeral was in March and my mother and Rupert numbered the grandchildren without including Gracie. And I thought, instead of eight, there should have been nine. So it can feel like Gracie doesn't count. It reinforces the feeling that she isn't seen as "part of our extended family" when she very firmly is "part of our nuclear family". But my grandmother (Gracie's great-grandmother) was different again to my parents, you see the generation back. All her siblings died and so she had dealt with dead people before and dead children and she was really good, although her memory is not that good now. She came in here and she moved the baby and picked her up. Like most people picked her up and held her but Nana picked her up and she kissed her. That made it easier for others who were finding it a wee bit difficult. It was interesting when Granddad died, Nana and I were going through the photos of all the things and when we got to Gracie's photo she remembered that and she said, "Here is my precious little baby" and all that stuff. Those sort of things are really nice because my other grandmother doesn't remember at all. She was really funny and she said, "You can have another one". It didn't matter because you know that is not what she would have said had her memory been better ... I was waiting for someone to say it.

Looking back, I think grandparents are there to support the parents and they do support the parents to the best of their ability don't they? Practical things were helpful. These thoughts are for me and it might be different for other people but I knew what I was going to do so I didn't want anyone else to have input despite any kind offer. It may be different if somebody was in an absolute tizz about it. You get a real adrenaline buzz but for the first 6 weeks or so, you are all level-headed really, or I was. About a couple of months ago it was a bit worse. I don't think a year is going to be such an issue but a couple of months ago it felt like that was the end of the chapter sort of stuff. I guess nobody had mentioned Gracie for quite a while and I guess grandparents have a role in



remembering to remember. It is the acknowledgement that is important to me. My parents often acknowledge the other grandchildren because they are there. But, because Gracie is not there, she is not acknowledged so much.

## BETTY'S STORY

### About us

I grew up during the Depression. At a time when families were large I was an only child. I spent my childhood with my parents in North Otago and my grandparents, who lived in Oamaru. I worked in the School Dental nurse division before my marriage in 1956 when I moved to the farm in the Haka Valley and lived there for 32 years. We had four children; three boys and a girl. My husband died young and I managed the farm with help until Donald took over. He lives there now with his wife, Pip, and their two children, Lachie and Jessica. Their third child was Gracie who lived only a few minutes after birth. She was my seventh grandchild.

### When Gracie was born

Gracie's death was so unexpected. I mean, I have got eight grandchildren who are really very fit and healthy and I don't think you contemplate anything going wrong. You just don't think of it happening in your family. I have got photos of them [the grandchildren] all there and they are really very fit, all of them. I mean, some of them are prone to getting colds and things but on the whole they are reasonably bright and happy. Gracie was born the day that she was expected and she was a much bigger baby than the two other children that Pip and Donald have and she was just perfect in every aspect. It was so hard to reconcile the fact [she died] when she looked so perfect.

I had never seen anybody fitter during pregnancy than Pip was. Even a fortnight before the birth she was up here at a nursing reunion going to dinners and parties. But, at the same time, the baby was in the posterior position and when I said to my son, "What about the position?" He said, "Oh we're not talking about that" and it turned out it was a difficult birth. She had had the first child posterior and that meant an ambulance to Dunedin from Oamaru and that worked out alright and then the second child I think might have turned at the last, I'm not sure, and then they were faced with this dilemma once more. So they went to Timaru, to the doctor who had presided at the second birth. I think Gracie might have been born about half past one in the morning and the hospital staff worked for an hour and a half, after birth, on her. Gracie breathed normally and cried at birth, she was nine pounds and then, after 4 minutes, she went into arrest. Afterwards, I think the theory was that it was a burst blood vessel in the lung wall, which had ruptured after she breathed and she was more or less drowned in

her own blood and they couldn't deal with it at all. About half past four in the morning my son rang and said, "The baby has just died". Well, it was the biggest shock, having known that Pip was so well and knowing that they had coped with the last posterior baby and I just couldn't believe it, really. But, in a way, I would have hated to have a sickly baby and an impaired baby perhaps. I think, sometimes, that it is easier if they die at birth, rather than having developed a personality.

Well, it was shock on the day - in the morning - I was still in bed at about half past four and I lay there thinking, "What on earth will I do?" A helpless feeling. And then I thought I would get up and have a jolly good bath. Of course I had a busy day because I was in charge of catering at a quite large open day put on by our weaving class, which was attended by over a hundred people. And I had food and things to gather up and it was on top of me in a way but it was too early to start preparations at half past four. I was anxious to get to tell the others of the family but I didn't want to ring until at least half past six. I was in a tensed-up state when I arrived at the Weaving Open Day because I knew I should have been down there with Pip and Donald and yet, I was torn by commitments here as well. The tutor of weaving was about the first person I saw and I told her. Everyone was very sympathetic. I got home at about three o'clock and then I think I rang Donald and said, "What can I bring?" They eventually decided that I would take some cheeses and biscuits and things and I made wild stabs at what they would like. And the one that I took the least of, they liked the most, and it was Whitestone Blue Vein - it was lovely. People just stood there and ate it - I think under those circumstances you eat to cover up what you are thinking and feeling. So I was concerned, as I say, to get something to take down and I didn't quite know how long I was staying so I came home and tried to pack. I think I took off fairly early [the next day]. Then of course I called on my friends in Timaru. I had said I would call on them. I always like to stop for a cup of tea on the way down there because it is a long time on your own - you need a cup of tea to keep your wits about you driving down to the farm. I think I got to the farm just as the school bus arrived at about four o'clock. The children had gone to school that day because Jessica was so keen to start - it was her first day at school.

### **Time with Gracie and the family**

When I got down to the farm I was a day late getting there because I was involved in the Weaving Open Day on the day of her death. Pip and Donald had had Gracie out in

the Toyota with them, way up on the hill and with the movement there had been some bleeding from her navel and they had to undress her and redress her in another gown. All this performance was going on not long after I got there. Pip's mother, who is a nurse, said to me, "What do you think of all this? Can you cope?" and I said, "I didn't think that I could, but I can". I don't know that I would have carried the baby about all day at the funeral which Pip did, but it helped Pip therefore it was the right thing to do, I guess.

I only stayed for the weekend after Gracie died. It was a Friday for the funeral if I remember rightly. I stayed Saturday and Sunday and I tried to take the children out to visit some of my friends who are still in the district. Lachie and Jessica were fighting and they were really upset. There had been too much going on and they couldn't quite understand it and so the little girl had a very big cry on that Sunday. By Monday, I could see that they were going to go off to school sports and Pip was going with them. I thought they are best to deal with this their own way really. But, you know, I felt very much for Pip and Donald. During the weekend Pip talked a lot about it. I don't know that I talked about how I felt. They still talk about it quite a lot.

### **Gracie's funeral**

We had our service for Gracie in the garden at the farm. The trees, the Spring trees, that was the laburnum and the crab-apple tree, absolutely in full blossom. We stood under these trees and sometimes you could hardly hear what the minister was saying for the buzz of bees around. There were about 30 people, their friends, neighbours. Lachie and Jessica were there for the funeral but, when we went into town for the cremation service, they were minded by a neighbour so, in that way they didn't realise what the next step was going to be. And it was, perhaps, a bit difficult to explain exactly. You see, going to the cremation meant another 55 miles trip - Pip and Donald probably talked it over, I don't know. Jessica and Lachie wouldn't have understood. It was a particularly quiet, sad journey, both there and particularly coming back, because I was in the car with Donald and Pip. It was much worse returning than it was going because Pip held the baby all the way there.

So Pip and Donald had planned that they were having Gracie cremated and they were going to scatter the ashes on a particular part of the farm where my husband's and son's ashes are scattered. But they couldn't explain this to Jessica and Lachie. The

children, I think, thought that the baby was buried because they had seen the farm animals buried so I don't know what Pip and Donald have done about that. The fact that they can't explain to the children about cremation, that is the problem. Although, the children were there when we scattered the ashes of my son but they were too young to know. They were playing about in the tussocks and they were quite oblivious to what was going on. They knew that we had gone out in the Toyota for a drive and were up on the top of the hill. I think they know now, because Lachie said calmly one day, "Oh, we threw out some flowers here for Uncle". So he knows about it, that that's the place, but they probably can't visualise the difference between the baby they saw and the fact that she will be ashes.

### **Other grandchildren**

My younger son, in Wellington, and his wife were having a baby a fortnight after Gracie was born and I was afraid to tell them on the day that I got the word from Donald. I wanted to get my son, not my daughter-in-law, because I knew that she gets very emotional and I thought it was no good getting her on the phone especially as she was having to face a caesarean. So I tried and tried and they have got kids that lift off the receivers and it was engaged forever. In the end I rang his work and he still wasn't at work. Then I had to go to the Weaving Open Day so I left a message with his secretary at work and she was so terribly upset because she hadn't had a baby very long before. Colin, my son, when he heard, rang my daughter because he knew she would know. He sent down some flowers. He couldn't get down from Wellington. Sarah, his wife, discussed Gracie's death with her doctor and he said he had only once seen one case similar and it had been a caesarean baby but it is a fairly rare condition apparently. So that is why I think it is pretty much one off.

### **Looking back**

I think that experience brought us all closer together. I hurt more for Pip and Donald than for myself really. I wanted to be with them but all the decisions were made by them and were what they wished. My only wish was to be there with them.

### **Talking about Gracie**

I have said to several of my friends "Would you like to see photos of Gracie?" Some of them say, "Oh, no" whereas others that I haven't given that chance have said they'd like to see her - so I mean to show them. People's reactions are different. I had quite a lot of support [after Gracie died]. My friends at the Church Fellowship gave me a little

pink rose. Several people wrote letters and a lot of people talked about it. One of my friends at Red Cross was a lady who had lost a baby about 40 years ago and she talked at length to me about that. She said that it almost cost her her marriage because the doctor had said to her husband, "Now, I don't want you ever to mention this to your wife again" - this was in Australia. And they never mentioned it until there was another death of a baby in the family and they both suffered in silence and yet she was ever so keen to talk to me that day about it. And another church friend talked to me about not seeing their baby and not being told the sex of the baby and how distressing this could be. You see, I haven't personally had the experience but so many talk about it.

#### **Other babies in the family who died**

I had been an only child and I had desperately wanted other brothers and sisters. Well, it had happened with my mother; she had had a baby brother and he apparently lived for three and half months. He was a sickly baby who didn't survive. Then my mother had a son, three years before me, which I didn't realise. She only spoke of it once. I think he would have been stillborn or premature but it was never spoken of. I think it was much healthier, the fact that we talked about Gracie's death. Although, personally, I think Pip went a wee bit over the top but it helped her and I think I am much closer to her since then.



## DIANA & RUPERT'S STORY

### About us

Rupert grew up in the Waimate area, where his family farmed, and Diana lived in Christchurch. After we married we lived on the family farm outside Waimate. We have three children and eight living grandchildren. Our ninth grandchild, Gracie, was the third child of our daughter Pip and her husband, Donald. Their two other children, Jessica and Lachie, were five years and seven years when Gracie was born. Gracie shared the same birthday as Jessica, she was delivered at full term and only lived a few minutes.

### Gracie's birth and death

**Rupert:** When Gracie was due to be born, Pip and Donald called in to leave Jessica and Lachie with us on their way to hospital. Later that night, Donald rang from Timaru to tell us they had a daughter. He said, "Things are not looking too good, I'll get back to you. They are working on her now". A couple of hours later he rang back and he said, "It's all over - she took one breath and that was about it." Having a grandchild die is one of those things that you don't think about do you? It's not going to happen to us.

**Diana:** You do think of those things because we had Annie, a grandchild, previously, who was born with a disability. When Donald first rang, he was obviously upset and I sensed that because, when I said to him, "What's wrong?" He said, "It's really serious", so I knew then that something was wrong. Whereas, when Annie was born they could tell us, "It's her heart" so there was a difference. It is definitely a shock, I go straight into overdrive. What do we do now? How are we going to cope with this situation?" Like you would, if anyone came with any emergency to your door.

The day that Gracie was born was also Jessica's fifth birthday and we were planning to have a party for her. I worried from the time I spoke on the phone to Donald as to which event I would treat first - the birthday or the birth and I couldn't think how I was going to go about it. I should not have worried because Pip rang me just before seven in the morning. While I was talking to her on the phone asking her exactly that question, "What she would she like me to do?", Jessica walked in. So, I just passed the buck and said, "Mum is on the phone, would you like to talk to Mum?" Of course the

children knew that Pip had gone to have the baby so Pip dealt with it. Later when I talked with Pip she asked me lots of questions like what she should do and who she should contact. Then Jessica and I went to town to buy a gift for Gracie. In the morning we had said to Jessica and Lachie, "Do you want to give Gracie something special of yours, or will we buy something of her own?" They decided they wanted to buy her something, so away we went and bought her a couple of soft toys to put in the cot. Pip said they would be home sometime later in the morning. She was going to come to our house but we weren't home when she arrived because my daughter-in-law very kindly said that she had lunch ready for us. So we had lunch there [at our daughter-in-law's] but I was a bit uneasy because I thought Pip would be home. I rang home and Pip answered the phone. I felt really guilty afterwards because she and Donald had only just gone to sleep. We woke them up. Anyway, we came up here and had this quiet time that was very different for my family. I don't know that any of us actually cried, nobody shed a tear. We all just felt so sad.

#### **Gracie at Jessica's birthday party**

**Diana:** Once Pip, Donald and Gracie arrived we spent the rest of the day here. Gracie was handed round. She was actually handled a lot. Everyone had her. It was quite a busy day, that day, because we had the other grandchildren. They came to Jessica's birthday party, too. Everyone was very apprehensive and everyone felt very sorry for Pip and Donald. Wee Astrid, our son's daughter, had only been born just a month before Gracie so that was a bit difficult. I think the other grandchildren accepted it quite well. They realised Gracie was dead and played with her and talked with her. Well, the girls did - the boys didn't. The boys were a bit apprehensive. They were in the room and, all of a sudden, someone said, "Let's go outside" and they ran off.

We did some crazy things really when you think about it. Like, when wee Annie was born, another girl in the district who had lost a baby just previously rang me up and said, "I'm ringing you to say take photos because I felt I couldn't take photos of a sick baby". So, when Gracie was with us we took all these photos. There were just packets and packets of photos. We were all looking forward to seeing the developed photos - it was then that we realised we had exactly the same photo of Gracie many times. I said to Pip, "Really". But that is just one of the things you do, that you have to laugh at. There was another thing that made us laugh. My elderly mother, who at the time was under quite a bit of stress with my father who was not well, came down to stay. She

was holding Gracie while we were busy doing this rimu box for Gracie. Mum was sitting nursing Gracie when she said, "You know, this child hasn't moved!" You had to laugh at her because she was so sincere about it.

You can tell by some of the photos of Pip and Donald that they were very stressed but we had the birthday party just for the kids. Everyone was getting a bit tired by the time it got to five o'clock and you could sense that. Suddenly the rest of the family went their own ways to their own homes and we then had to think about how we were going to cope with the funeral. I wondered whether Pip and her family would go home that night or whether they wouldn't and Pip suddenly said, "Yes, I think I want to go home. We are going to have Gracie at home for a day or two before we lose her." By the time we got everybody in the car, with the car-seats and then there were flowers and a lot of extra things like groceries, we couldn't fit Gracie and her cradle in the car -there was no room for the cradle. I had a white polystyrene box that the salmon for Pip and Donald's wedding had come in, so Gracie, all snug in her shawl plus her toys, went in the box. It fitted between the front and back seats in the car long ways. There were also Jessica's birthday presents and the cake and all those silly little bits and pieces that had to go in. It was like a family going on holiday.

#### **The next few days**

**Diana:** Pip had very definite ideas and she knew exactly where she was going and what she was doing, so it was very easy. There was one thing she said that I didn't agree with. It was when she rang me and told me what she was going to do. Like, "We are going to have a day at home and a day going around the farm and then a day doing something else". I started to get very protective of Pip for I wondered if she would find it hard to give Gracie up.

**Rupert:** It was a wee bit worrying because Pip gave the impression that she knew Gracie wasn't going to come back again but she wanted to do as much for Gracie as she could while she had her. And Gracie was with them all the time, and everywhere they went farming; she went to the top of the valley and all that sort of carry on.

#### **Counting Gracie**

**Rupert:** When someone asks how many grandchildren we have, we include normally the ones that are still about, that we still have - not that we had.

**Diana:** When my father died somebody said to me, "You didn't include Gracie in the death notice" and we didn't either, did we? We said, "and great-grandfather of his eight grandchildren" and at the time I hadn't thought about it. I will always regret that. Possibly, it is easier for other people you are talking to, to continue with the conversation if you say, "there are eight" than if you say, "there should be nine" or "one died". It makes it really hard for the conversation to continue. So, in any sort of death, you become very protective of the people you are in the environment with. We have a video of Gracie's days with us, just as we have videos of all our grandchildren. It is nice to know that if you wish to sit quietly and look at it, you can. Pip and Donald keep the video.

### **Providing support**

**Rupert:** I think our role was mainly support for Pip and Donald because it must have been a far bigger shock for them than for us because it was removed a wee bit from us.

**Diana:** And also it was Pip and Donald's thing and they had to grieve in their sort of way and we didn't want to intrude on that. That was important for them to do what they felt they wanted to do. So, all that we could do was to be supportive at that time for Jessica and Lachie. Pip, Donald and Gracie were there [in Timaru] and we were here and it was important that they had their time together. I mean, I didn't believe at the time Gracie died in hospital that there was any way I should suddenly pack everyone up and go off to Timaru. I felt it was really important for them to do what they wanted to do before they came back here to face that other environment. Really, you are trying to make the whole thing run as smoothly as it can, so that everyone can do what they feel they want to do. You get gut feelings at times like this and, if you go with your gut feeling, it is usually quite right. It doesn't matter what anyone else thinks or says - like taking Gracie shopping. Who would have thought that Gracie was in the car park whilst Pip went shopping? Even if it was only for material to line Gracie's rimu box.

**Rupert:** We are a generation older than Pip and Donald and death was a thing that you didn't think about. You didn't talk about anything like that when we were brought up as children. You never went and saw the body after death; it was unheard of for anyone. So what Pip and Donald did with Gracie was very different. The important thing in this situation is to try and support the parents as much as you could and the

background type of support - not up front too much. Not trying to take over and organise things.

### **Thoughts about Gracie's death**

**Rupert:** It is different thoughts isn't it? Than for somebody who has lived some life. Whereas for Gracie, all you can think about is, "What were her prospects if she had lived?" Whereas, for somebody that has lived for a while, you can think, "Well they have done this, that and the other thing". Like when there is a wake. Dad was like that, he said, "When I die - celebrate life. The grog cupboard's full and all my mates can come up" and that was what he wished, virtually.

**Diana:** And that is what it should be, because everyone has gained a tremendous amount from those experiences of that person and what they have given them. But with Gracie, it was really different because we never knew her at all. Gracie's death was a very different experience and I think that you don't have the same kind of feelings of loss and emptiness that you have with other deaths - especially if you have known somebody for some time. I didn't, anyhow. It was more of a numbness and absolute disbelief, than an emptiness. It was a different feeling for me as a grandparent.

**Rupert:** I suppose all my life dealing with animals and livestock, you accept that things die for no reason at all; there appears to be no reason at all. I don't know whether you accept it or you learn to sort of switch off a wee bit and think, "Well, it happens. It's part of the way Nature has got things organised".

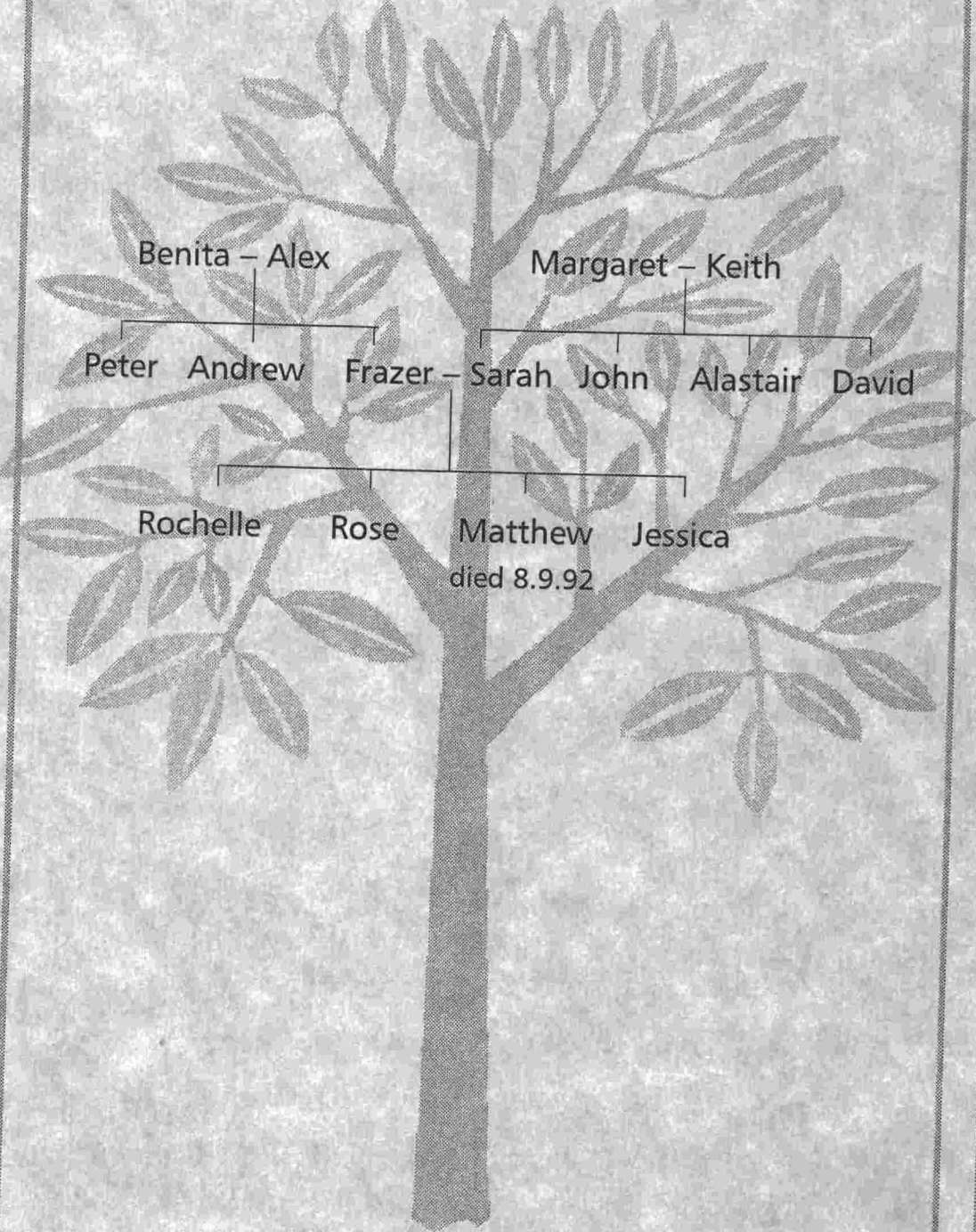
**Diana:** As you grow older you realise that as long as there is life, there is going to be death and it is as definite as the day is long. And from the experience of birth you have the same experience of death. So, I do believe as you get older, especially as a grandparent, you have learned to realise that this is what life is and you just can't brush it under the carpet. I definitely think that Gracie's death was a growing experience for me. It made me more of a rounded character because you can understand a bit more about somebody else if it happens to them. If you don't have these experiences you are really are a loser because you have no idea what other people are experiencing. You think you do but you don't really, unless it happens to you.



# Matthew died at the age of three days

These are the stories of his family

- of Sarah & Frazer, who are Matthew's parents
- of Margaret & Keith, who are Matthew's grandparents and Sarah's parents
- of Alex & Benita, who are Matthew's grandparents and Frazer's parents





## SARAH & FRAZER'S STORY

### About us

Frazer was born in Dunedin and grew up at Seacliff and Tapanui then Dunedin. Sarah was also born in Dunedin and grew up in Omarama and Clydevale. Frazer is a lawyer in Dunedin. After an enjoyable career as a nurse, Sarah is now at home focusing on her children and husband. Our four children were born in Dunedin. Rochelle is our eldest daughter, then Rose, then Matthew, and then Jessica. Matthew died, aged 3 days, from hypoplastic left heart, a condition where there is not enough heart muscle and it is incompatible with life.

### Matthew's birth

**Sarah:** When Matthew was born it was a normal delivery and his apgar scores were very good. A good friend of mine delivered him and that was very special. He was born on the Saturday morning. He was happy all day, feeding very vigorously as if, "I haven't got much time I've got to get on with this". He wanted to feed all the time. On Saturday night, I remember him being awake and looking around, I sensed his calm nature, and that he was looking around and taking everything in. It was about midday on Sunday that something seemed to be wrong. He was very clammy and cold and perspiring. One of the nurses called a paediatric registrar who turned up instantly. Matthew went up to the Neonatal Intensive Care Unit. He looked really silly in an incubator because he was so huge and all the others were so tiny. Matthew was eight pounds three ounces, which was my biggest baby. Within two hours they came and called us into a side room and told us that he wasn't going to live because his heart wasn't formed properly. I can remember the cardiologist because he was very matter of fact - there was no emotion at all. He didn't show any emotion whereas the paediatrician was kind and very compassionate. I felt sorry for the cardiologist because I thought, "He just doesn't know how to cope with this, he's pretending that it's like a sore thumb or sore toe".

**Frazer:** It was probably due to a fortunate combination of circumstances that the grandparents were able to be around. As Sarah said, he was born on a Saturday morning and, naturally, the grandparents had been around to see him that day. I had been home with the other kids and then, on the Sunday morning, he'd been crying and a bit unsettled and they said, "We'll just take him upstairs to do some tests and he'll be

alright. We'll be back in a wee while." The girls and I must have been up at my parents, and so I went over there at lunchtime and said that he had been taken upstairs for some tests. It was all a little bit unsettling. I also put a phone call through to Balclutha, to Sarah's parents on the farm, to say that he was having these tests done but there wasn't any reason that this should be ominous. I went back to the hospital after lunch. It was a couple of hours later when they made a fuss of wanting to talk to us in a separate room, because Sarah had been in a room with three or four others. And so we went in and, as Sarah said, it was all explained to us - which takes a wee while to sink in. I went out to the phone to ring my parents, and I still remember what I said, I could hardly speak, my mother answered, and I said, "It's me" and she said, "What's the matter?" I said, "He's going to die". She said, "We'll be there right away". She hung up and I hung up. So they came on down and then, at about the same time, Sarah's parents turned up, because obviously they had had some concerns, although they hadn't said they were going to arrive. So we had everyone arriving. And I think, coincidentally, Sarah's sister-in-law arrived with her children, not knowing about this, so we had everyone at the scene immediately. While it was obviously an extremely traumatic time, I think it was very important to have grandparents able to assist. Of course it would have been very hard without them. Sarah's parents took Rose back down to the farm and then, I think, Rochelle went to some friends. It was very difficult at the age they were at, a 2-year-old and a 4-year-old, because they would be initially very upset but they would be over it in 10 or 15 minutes and back to their normal sort of boisterous behaviour, which could be a bit hard to cope with.

**Sarah:** We were told he was not likely to live for more than 24 hours so we decided to keep him in the hospital. We were in a big room and he was in either Alex' or Benita's or Frazer's or my arms for the whole night. I got a few hours sleep and in the morning the doctors came and were surprised that he was still alive and they said there was nothing more they can do, "Go home. Take him home". It was about half past seven in the morning and I decided that we had to go then and there. And I was running round saying, "Come on, come on I've got to go" and I felt this urgency to get home.

#### **Matthew at home**

**Sarah:** And so we got home and it was a really special feeling taking him home. When they first suggested it I thought, "Oh no, you can't have a dead body in the house." It's really silly but I remember thinking that. But it was very special to have him at home

and my brothers and their families came and met him. Frazer's parents stayed with us the whole time, which was wonderful. People came and brought their children, our next-door neighbours came and it was very special.

**Frazer:** We were horrified at the idea, initially, of going home. As Sarah said, the idea of having a baby in the house might be considered, with all these tubes and cords coming out, was not really our field. It wasn't very homely looking. There had obviously been the paediatrician encouraging us in that direction and it wasn't really until the next morning, the Monday morning, that we realised that what we wanted was to be out of the hospital and at home. It was touch and go whether we made it. He had these attacks about once an hour and you could hear the irregular breathing.

end is near". He was right and so I got Mum and Sarah up and this time he didn't catch his breath. We came into the other room and my mother had got all these clothes that she had prepared for him in anticipation of his birth and so she dressed him.

**Sarah:** When Matthew died during the night there were funny little events which happened that make you laugh. Frazer's mother has an obsession with toilet seats, I think, with living in a house with all males, she likes the lid down. After Matthew had died I thought, "I've got to go to the toilet". I rushed to the toilet and I didn't look to see the lid was down and pee'd all over the floor. I said, "Oh no" and Benita came out and said, "What's the matter?" and I said, "I've pee'd all over the toilet seat, you and your bloody toilet seat down" and so she started laughing and Frazer came out to see what was happening and started laughing too. Every time I see a toilet seat down I remember that incident. I found it very special that Benita bathed Matthew after he died because she had given the girls their first bath and that had become her special job that she would do this. For me it was just nice that somebody else wanted to do it but she was so grateful for the chance. And it was special having Alex there because he knew what to do, because your mind is so numb and unable to think straight.

**Frazer:** Then Matthew was put in his room and we all had a sort of semi-sleep after that. The next day we had all the arrangements being made and lots of visitors. Mum and Dad virtually stayed with us full time, during this period. Making funeral arrangements for a child is a bit hard to do because of all the decisions that have to be made. It's very hard when somebody comes with a question and says, "What do you want in his death notice in the paper?" We didn't even have his birth notice in. It was just beyond us to even really think about it, and so we gave that job to Dad. He's done that so many times [because he is a minister] and he was able to do that and so in that little way that helped. Just sitting there and going through all the arrangements, it was certainly very helpful to have parents there and also the type of parents who are experienced in that sort of area. They know what sort of decisions need to be made and what sort of problems there are going to be.

It was the first death we have ever experienced and for me, at the age of 32, that was the first time in my life that I had had death that close. I hadn't seen a dead body before Matthew died and so, for us, that was a new experience that we had never had

to deal with. Everyone knows that at some stage you are going to have family who die - grandparents, parents that sort of thing - but that's something you're used to, it's inevitable. The minister was coming to see us and I had made a point of going and spending an hour or two writing my thoughts down so that we could have a good discussion. We felt sorry for him. How do you conduct a service for a child at 3 days old? What do you say? But we wanted it to be unique in the sense that this was a child at the beginning of life. So, we put together all these thoughts and stories about the life of Matthew and conveyed them to the minister so that he had all these bits and pieces and anecdotes, from these couple of days, to put into his eulogy. Then Dad of course did a eulogy<sup>2</sup> and that was **really** good and was so personal to Matthew. That was what was so hard for my poor father, having to mix these roles of both being a minister and a public speaker and also being a grandfather. And what he said was superb; we've got a tape somewhere and one of the things he said was, "I hold you in my arms and look at your chin that will never grow stubble". It must have been so hard for him to actually say that. Mum gave a prayer and then Sarah's mother did a reading. It was good to have that degree of involvement and I think, at the end of it, by the time the funeral was all over, you couldn't have asked for better support from any quarter than we had.

### **All the support**

**Frazer:** There was nothing that you could have been critical of and so I think that helps with the process - we had all that support. We've noticed other people that we've struck who have had the death of a child that, sometimes, it has left bitterness. Whereas, for us, the support that we had meant that there wasn't anyone that you could be critical of and you could feel nothing but warmth towards everyone, whether that's family, people at hospital, people at the workplace, people in the community or people in the street. So, I think that helped us to cope with the whole process and made it that bit easier; it removed the extra stresses from us. As I said before, we sent the children away for that time, which, in theory, sounds a bit cold or callous perhaps, but it was hard for them to keep understanding, "Why is the mood in the house always sombre?" If you look back and say "If you must go through this situation, which is living a nightmare, then given the supportive network, we really couldn't have asked for anything better". Without doubt this is the worst experience of my life. I'd wake up at

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<sup>2</sup> Which is at the end of Alex & Benita's story.

night sometimes and say to myself, "Just as well I'd woken up because it was a terrible nightmare that I've had" and then you'd realise of course that it wasn't, and you were actually living it. After our first child was born, generally, I'm so tired after work I sleep right through the night. I never hear the baby cry and Sarah will be up feeding a couple of times, perhaps. But the only difference, the only exception to me, was Matthew, that I would wake up and hear him crying - but he was dead - whereas I never woke up to hear the others cry.

### **The funerals of Matthew and Granny Rose**

**Sarah:** My father's mother had just died as well [Granny Rose], so we had two funerals in one week. It was so much more shattering for everyone to have two generations die at the same time. I had never seen my father cry before, and I remember he walked into Matthew's room with Mum and just burst into tears and we all hugged each other and cried together. That was the first time that I have ever seen my father cry, for his grandson, and for his mother. I felt privileged to be able to share in his grief with him.

**Frazer:** I think perhaps that combination of circumstances, the great-grandmother dying just the day or so before Matthew's death, made it harder obviously, because it's another grief to go through. You go along to Granny Rose's funeral and you've got this eulogising about the wonderful life that someone had and all you could think of was, what was coming up in two days time [Matthew's funeral]. At the next funeral, what life is there to talk about? So, you feel a little bit cheated. It was good that we had such a public funeral for Matthew, and people around in the house and an open church service. The church was packed for a three day old baby and they shared in the whole process themselves so they were then able to be supportive. The support of the grandparents and the family made the whole process that much easier to get back into a form of existence, a form of life.

### **Reflections about grandparents**

**Frazer:** People are surprised that we brought home a baby to die here and that he stayed in the house and had all these people in and out. People talk about how it's got Maori overtones, with the family group and the grief and my parents. But it actually did help, it was good to have people in and out of the house. You need to have the support of parents and friends. It all adds up, I think, to the ideal way of coping with



it. I suppose we just assumed that we were supportive of my parents. It was a very stressful time for them. It would have been more of a nightmare for us, I think, without Mum and Dad there. I don't think we would have gone home on our own with just Sarah and me coping with and holding Matthew and not knowing, "Is he going to die?" or, "Is he not going to die?".

**Sarah:** Grandparents have the double grief of having a grandchild die - and their child going through grief as well.

**Frazer:** It was a bit harder for Sarah's parents, in a sense, because it was lambing season and they had that commitment down on the farm. They could only be up and back, up and back for brief visits. Sarah's father is a man of few words and so it was probably hard finding the right words to use. It's a time when people find it so difficult to speak, they don't know what to say and even now, looking back, you can say, "Well what do you say to someone in that situation?" There is nothing that you can say that helps anyway and people's efforts in that department aren't always all that helpful. But one of the things you can do that seems to express everything is to hug people. There seemed to be a lot of that. I can remember one or two instances here in the house where we would just be hugging each other or perhaps my mother would be there and Sarah's mother would come and join the huddle and I can remember Sarah's father doing that on occasions, too. On the whole he would be undemonstrative and would have said very little through the whole process. I think it would be very hard for Keith to see his daughter in these circumstances and it would have been doubly traumatic for him. You felt that it wasn't easy for Keith, being a man of few words, to actually cope with the situation in a way. Whereas my family, or my father in particular, is trained in speaking and expressing views and thoughts. But, at the same time, even though Keith said little, you got that very strong impression of, sympathy is not the right word to use, but of support and also of grief on his part.

**Sarah:** My mother was very positive about which photo she wanted of Matthew, which was one that was taken after he had died. It took Benita and myself a lot longer to accept that that photo was the best one of him.

**Our faith**

**Sarah:** I don't know how people handle the death of a child without faith. Because my faith is very important to me and I feel that has carried me through. I couldn't have done it without my faith. The girls [Rochelle and Rose] know and accept that Matthew is with Jesus and they are contented. In comparison, there was a woman I met, whose baby had died of a cot death and she told me that her children had needed counselling. But she was looking at it from a non-Christian view and her daughters thought her baby was buried in a dark hole and thought that they would be in a dark hole and they had dreadful nightmares. Whereas we have had nothing like that at all because the girls knew that there is eternal hope that one day we will go and be with Matthew. I suppose, for me, my grandmother, Granny Rose, was also from a Christian background and she died at the same time as Matthew. She was the matriarch of our family and to have known someone like her, I found a great help. Having Benita and Alex thinking along the same Christian beliefs was great.

**Frazer:** I think it would be very difficult for people to cope with the death of a child if they knew that that child was going to come into existence and go out of existence and its remains were going to be cremated or put in a hole in the ground. I think that would be very difficult to cope with. So, it is much easier to have the concept of where Matthew has gone, that there is life after death, and actually welcome that aspect to your own death. It still brings questions with it of course. People will say, "Well, there was a purpose" and you say, "I don't really agree, I can't quite see how you could ever say something good could come out of that experience". They say, "That is a way of teaching family members about values" - it is a very harsh way of doing that. I think as my father sums it up, "Certain things are just inexplicable" and I find that answer more satisfactory than those that say, "Well, there is a meaning for everything". I can't conceive of a meaning for bringing a child into existence for three days and taking his life.

**Jessica born after Matthew**

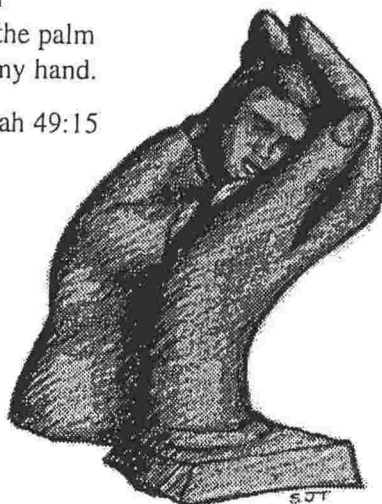
**Sarah:** Jessica was born a year after Matthew. He is very much a part of her family and she tells everyone that she has two older sisters and an older brother, but he died. It isn't important to her why he died, but it is important for her to acknowledge his existence and to express that to others. She was given a picture of a baby sleeping for

her first birthday and she call it Matthew's picture. It has pride of place on her bookcase.

*For Sarah & Frazer, Alex & Benita, Margaret & Keith the image<sup>3</sup> and words below are important reminders of Matthew. They come from a bookmark which Benita has and were put on the Order of Service for Matthew's funeral and on his headstone.*

See!  
I will not  
forget you . . .  
I have carved  
you  
on the palm  
of my hand.

Isaiah 49:15



<sup>3</sup> The original illustration on the bookmark was by Fred Kinghorn, printed by North American Liturgical Resources, I have had no success in contacting this organisation for copyright permission, hence the image above is an artist's impression of the image.

## MARGARET & KEITH'S STORY

### About us

When we married we worked on the Omarama station and eventually moved to our own farm outside Balclutha. We've got four children in the family. John's 38, Alistair's 37, Sarah is 36 this year and David is 34. We've got 11 grandchildren. Matthew was the third child of our daughter, Sarah, and her husband, Frazer. He died five years ago. Sarah and Frazer had two other children - Rochelle and Rose before Matthew was born. Matthew was fine when he was first born. The next day he developed breathing problems and the doctors found that he had a hypoplastic left heart. Matthew died at home, aged three days.

### Our grandchild - Matthew

**Margaret:** The year of 1992 was an awful year. Keith's mother, who was an absolute darling, Granny Rose, was ill and she lived with us for a couple of months or so before she died. The kids and everybody just loved Granny Rose. She died the day that Matthew was born and then he died the day of her funeral. Matthew's the only child in the family who died. None of my brothers and sisters did - we haven't really had anything like wee Matthew.

**Keith:** That's right, it was always something that happened to somebody else that you might hear about.

**Margaret:** We went to see Matthew the day that he was born and of course he was fine then. He was a dear wee soul. Frazer rang us the next day and said Matthew wasn't so well and had gone to Intensive Care and so we went to the hospital again.

**Keith:** He was in Intensive Care so we knew there must be something wrong but we didn't know it was that bad until we got to the hospital.

**Margaret:** Sarah was wonderful during this time. I couldn't believe her, she was quite amazing. After Sarah and Frazer had been told that Matthew would die they thought that they would take Matthew home and so we brought Rose home with us. And Rochelle stayed with friends of Sarah's. I felt terribly upset for the girls - they were so different about what happened. Even quite a long time later Rochelle was just so blasé

about it all. You know that was her wee way, whereas with Rose it was different. After Matthew had died he was in the bedroom and someone would come to the door and Rose would take them by the hand and say, "Come and see my wee brother" and she would take them in to see him.

We didn't really see much of Matthew. We were looking after Rose so we saw him when he was born and we saw him the next day and we didn't see him again until he had died. Whilst Matthew was alive, our son and his wife, who live in Dunedin, went and saw Matthew quite often. We went, but Matthew was only there for a couple of days. Our other children and grandchildren went to see Matthew when he was alive and the whole family, including the grandchildren, went to his funeral. I think Sarah was always terribly disappointed and terribly upset that she wasn't there when Matthew died. It really, really upset her, because she had gone off to bed to have a rest.

**Keith:** When you don't know when someone is going to die, then you have to do that.

#### **Matthew's funeral**

**Margaret:** Sarah rang and asked me if I would do a reading at the service. I didn't know how I was going to manage that - it's amazing what you can do if you have to. Well, I didn't have to - but I wanted to do it for her. Quite honestly, I can't remember now what I did for the reading. You are trying to help the parents and you really have to be very careful. They have to be left to do what they want to do, but you can see things that you think you could probably help with - but you need to check it with them. Like Sarah said she was going to drive the family and Matthew to the church for the funeral and I thought, "Goodness me she can't do that" and of course she can do that. She is only a wee dot but she seems able to do the most amazing things.

**Keith:** The funeral was not easy. I mean, it's one of those things that it's the parents that you are quite sorry for - Sarah and Frazer. They are always much closer to the children than the grandparents are.

**Margaret:** The minister, he was really nice. They can make such a difference and the funeral director was just wonderful, wasn't he? Nothing was a bother, Sarah was just not to worry. He was the same funeral director for Granny Rose's funeral. I thought Sarah and Frazer were wonderful being able to bear up enough strength to go to

Granny Rose's funeral when their little boy had died that night. At the time Sarah had said that they were coming to Granny Rose's funeral, I said to Keith, "Well, we'll wait outside for them" because they were going to be a wee bit late. The funeral director said, "There's no hurry, no hurry whatsoever". He said, "Just when Sarah comes, you know". So we waited and the funeral director said, "Here she comes". And we all went in together.

### **In the time after Matthew died**

**Margaret:** We thought about Sarah and Frazer a lot. It was such a short time from when he was born to when he died, not time to have a life. I think the fact, really, that he didn't live for too long was a help. It was awful to see anybody who had pain. Like, when we saw him and had just arrived in the hospital and this was before the morphine got started and he really was in pain, poor wee soul. It was a distressing thing. I suppose it is because Sarah and Frazer are both here, they are not suffering the physical pain Matthew was, and now wee Matthew has gone and he is not suffering but they are - I suppose that is partly why you think of them. It's so sad for parents - Frazer was just so delighted with Matthew and plans for taking him to Naseby and walks in the forest. He was just so looking forward to doing all these things with wee Matthew.

We used to ring Sarah and Frazer after Matthew died. I went through and stayed with Sarah for a few days because Matthew's ashes were still at the funeral director's, he hadn't been buried after the cremation. So I went through and stayed with her for few days. Sarah kept saying she thought she would like to go down to the funeral director and see Matthew. So I said, "Come on and away we go" - so away we went. Rochelle, she wanted to sit and hold the cask with Matthew's ashes. She was sitting holding it and she said, "Oh look Mum, they've polished the top and I can see my face". Then I said to Sarah "Would you like to go for a drive, dear?" and she said, "Oh yes", she'd like to". So I said, "Righto" and away we tootled. We went up towards Larnach's Castle and kept going up and up and up and I thought, "Oh gosh, this is ghastly". I came from the back country and that sort of thing didn't used to worry me. Mind you, that road is terribly steep and we're looking down at the sea. Well, my mouth felt dry and I thought, "Just keep driving right up the top and start going down the other side" on that horrible windy road. Rochelle and Rose started playing up and Sarah said, "If you don't behave yourself Grandma will stop and put you out here" and I thought, "If I



stop I'll never get started again". I was glad to get to the bottom of that drive. I stayed with Sarah. Because we were on the farm, it was busy, which meant that Keith couldn't, so instead I stayed with her for a few days every now and again. But she amazed me, she really did, because she could talk about Matthew all the time whereas Frazer couldn't and he just seemed to just go inwards. I suppose, too, it was terribly difficult for him at work, I suppose people were always mentioning it and he just wanted to be left alone. But Sarah was quite amazing the way she bounced back.

### **Talking about Matthew**

**Margaret:** We talk about Matthew and we're always missing him. Living in the country when something like this happens, everyone was just wonderful, they really were. They'd ring up and they'd bring food and all sorts. I think, being from the country - it doesn't matter what happens, people are always arriving and things and flowers. It's great. And we seem to have had lots of friends that you don't really know you have. I think it is awfully good to talk about Matthew a lot. Just include him as ... Just talking makes it easier. At Christmas time someone would say, "wee Matthew would be dancing round" or something like that.

### **Memories**

**Margaret:** Sarah has got a lovely photograph, we've all got one. It was a really lovely one of Matthew in his wee bassinette after he died - really something to keep. And it was nice that they had the photograph of him at home because when we saw him when he was very ill, with the tubes and everything, it just looked ghastly - poor wee mite. I loved that verse Sarah and Frazer had in the little death notice in the paper and the little slip we got, whatever it's called, at the funeral. The verse was "Hold me in the palm of your hand"; that was lovely. And the photograph of Matthew after he died and the tape of the funeral were special. I would not want to be without the photo on the wall, in the lounge and the bedroom. It is an image of him that I can say, "Hello" to.

### **Jessica was born a year after Matthew died**

**Keith:** You do think that perhaps Jessica might not have been here if Matthew had lived.

**Margaret:** She's a dear little lady, I used to say to Sarah, "I don't believe in people having these scans [ultrasound scans in pregnancy] and knowing what sex baby they are having before the baby is born". When you're having a baby you should have it

and that's just part of the excitement of someone saying, "It's a boy" or, "It's a girl". Well, when Sarah was having Jessica she said, "Oh, I'm going to have a scan, I'm going to know what it is Mum". I said, "Well, I think that's fair enough", especially because if she had wanted to with the others she would have. After the scan Sarah and Frazer were so delighted, absolutely delighted. Sarah said they were not telling anybody, which was good, so we thought it must be a little boy. Then, when Jessica was born, they had this little girl and I couldn't believe it and I think a lot of people felt that - because they were so delighted, you know - everybody thought it was a boy. But it was Jessica and she is a dear little lady and she adores Granddad.

### **Our feelings**

**Margaret:** At the time Matthew died I had such a sick feeling in the stomach - just felt so sick for Sarah and Frazer. We talked about them every day.

**Keith:** It is now four years on but the feelings about Matthew are not that different really.

**Margaret:** It is sadness - but I have got used to it now and I perhaps think of him as being a little boy. I often think of him as a little baby. It was just when I was at Sarah's a while ago it came up and she said, "Oh, now he would have been going to school". So you do think of it, but then you can't really imagine what he would look like.

### **Reflections – the deaths of Matthew and Granny Rose**

**Keith:** The two deaths were quite different. My mother's was not unexpected. It was almost getting to the stage where it was a release. Matthew was quite different.

**Margaret:** A death like Matthew's is difficult because you do definitely question WHY? Don't you? You think all these horrible people around, nothing ever happens to them, which is not a very nice thing to say. I think, too, Sarah and Frazer have a very deep faith and I think we would probably question more than they would. Because I think that they think there is a reason for it and I would rather like to know the reason WHY? than just accept it - which you have to. But you do wonder WHY? I felt angry sometimes.

*For Margaret and Keith, this photograph is a link to Matthew. The image and verse at the end of Sarah & Frazer's story also symbolise Matthew.*



## BENITA & ALEX' STORY

### About us

Benita was born and educated in Christchurch where she trained as a general nurse. After marriage she moved to Dunedin and had further nursing experience in theatres and geriatrics. After her three sons were all at school she did some obstetrical nursing and then worked in the areas of neurosurgery and haemodialysis from which she retired recently. She is involved extensively in Christian education in church and school and is a member/Convenor of several Christian committees and Councils. Despite all of these things she gives quality time to her sons, daughter-in-law and three granddaughters. Alex spent his first seven years in Auckland. He moved with his family, including seven siblings, to Gore where he stayed until going to University in Dunedin. He became ill whilst a student and spent most of his twenties as a patient, before surgery and newly discovered drugs restored him to health. After this, he trained at Knox College and married Benita - taking up his first appointment as Chaplain for five years at the Seacliff group of hospitals. Then followed eight and a half years in the parish of Tapanui. During this time, he and his family spent a year in the USA while he took a course in Clinical Pastoral Education. His next position was as Chaplain to the Dunedin hospitals and subsequently as a part-time minister in Dunedin. A younger brother of Alex' died of double pneumonia when only six months old.

### Matthew's birth

**Benita:** The story of Matthew begins for me, with a call at about 4:30 in the morning, with Frazer saying, "Could you come over and stay with the girls?" because Sarah had begun labour and was going down to Queen Mary. So they went down to Queen Mary and then, at about eight o'clock, Frazer returned. He didn't say anything to me, he swept into the house, Rochelle was away staying with her other grandparents, and he swept Rose up. He had the most glorious look on his face that I have ever seen and he swung Rose into his arms and he said, "Do you know you've got a little baby brother?" And I felt he wanted, instead of going over the child's head and telling me first and telling the child second, to tell his daughter first. Which delighted me no end. We were just so excited and he said, "Let's go down back down to the hospital now". So he put Rose into his car and I got into mine and all the way down I was just so excited because this was a boy after two girls. We had three sons ourselves and hadn't ever managed to change the sex. It was just so exciting and when we got down there

we went into see Sarah, who was sitting up with a big grin on her face with Matthew in her arms. She reached out and put him into my arms and said "OK, Grandma now get on with it" and took Rose onto her knee.

Then Matthew's wrappings were all a bit loose and he was kind of gurning<sup>4</sup> away and I put him into the bassinet just to be able to rewrap him and a little bit of anxiety stirred inside me. I thought, "I wonder how long it takes to pink up, he just looks a bit blue". And I thought, "I am just a little bit more anxious than I should be". At the same time Sarah looked across at me and said, "He's different from the girls; they fed, they bellowed, they fed and they shut up but while he's fed he has just gone on with a quiet cry all the time". Rose was sitting in the chair and Frazer wanted her to hold the baby and she didn't want to and she put her hands over her ears and that stirred a little bit more concern in me as to why she felt like that. However, we buried it all and went out. During the morning I took Rose into town shopping and said, "Well, we have got to go and buy flowers for Sarah and we have got to go and buy something blue. We have got to buy a boy's suit and then we have to ... " Those were my concerns and we went into a shop and bought a little boy's suit. Then we went into a shop and I ordered the flowers and, while I was waiting for them to be made up, I was looking around the shop and my eye cast on some of those little, tiny, small angels. I don't remember having seen them before then and the thought went through my mind, "Now what do you use those for?" And hot on the heels of that was, "They look like something that would go on a child's grave" and, in that moment, a feeling of absolute terror filled me. Then I remonstrated with myself and said, "You must know some of the best ways of scaring yourself", but I was still left with a sense of unease. Alex feels, when we discuss it, that I've seen that in retrospect, but I do remember the feeling of extreme anxiety was very real at the time. But, anyway, once again I buried it and we just rejoiced in the new baby and I went back to the hospital later in the day delivering the goodies and everything was well.

Next morning, next day, Frazer came in with the girls at lunch time. The girls rushed in and said, "The baby is not well" and Frazer followed up by saying, "He's been taken to Intensive Care, Neonatal Intensive Care" [NICU]. He was very careful about what he said, "They think he might have an infection". I was dishing up dinner and I

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<sup>4</sup> Making quiet gurgling noises

was really, quietly, in an absolute panic because, a child that was just over 24 hours old, "What kind of infection is this that it is so overwhelming?" They don't take babies to NICU unless there are very good grounds for it, they prefer to leave a baby with its mother. So, I tried not to show it. After lunch, Frazer went back down to the hospital and we kept the girls and at 2:30, the telephone rang and I answered it and it was Frazer. And as long as I live I won't forget the sound of his voice on the phone and Frazer saying, "It's me, he's not going to live". I just responded with, "We'll bring the girls and come down straight away" and with that we went down. And when we went in we found that Sarah and Frazer were both in distress because they had just been told that the baby had a cardiac condition - left heart chamber dysplasia and that he may die in 20 minutes or it may be in a few hours. We went up to NICU and the first thing that struck me was all these tiny little babies were up there and here was our boy at over eight pounds, twice the size of some of them, and he was the one who wasn't going to live. It was just so hard to believe after being told the day before that he was perfect, after the GP had looked at him. And it was then they said that there was no point in keeping him in NICU and he could go back down to the postnatal ward. Frazer and Sarah's nurse had come up with us and was taking the gear back down. From that time on Matthew didn't go back in the bassinette, he stayed in the arms of one or other of us. But, as they walked back down to the postnatal ward Sarah carried him and somebody pushed the IV pole<sup>5</sup> and the nurse had the bassinette and we formed a sad little train. I carried Rose down. She had sat on the stool up in NICU and it had squeaked and I was very conscious, you know, that a lot of it - she was very sweet - was way over her head. Rochelle was grasping some of it and was very distraught. Rose sang in my ear all the way down "The train whistle blowing makes a sleepy noise" and I thought, "She doesn't realise that this is a train and that it is a very sad little train". We went down to the postnatal ward and then Frazer and Sarah requested baptism for Matthew. So we did have him baptised and we made some phone calls to ask other people to make phone calls to other members of the family. I'm not sure at what stage Frazer went to try and get hold of his brothers [who were working in Europe] who had already been told of the baby's arrival and hadn't been warned that there was this disastrous diagnosis. Then Sarah and Frazer were shifted into a room with two beds and through the night we all took turns at holding Matthew in our arms. Sometimes in the night Sarah and I went for a walk around, while Alex and Frazer had

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<sup>5</sup> Matthew had an intravenous infusion (drip) running.



turns holding Matthew. And then the paediatrician came in at about 7:00 in the morning and he was surprised that Matthew had survived the night and his pedal pulses<sup>6</sup> were not too bad at that stage. Then he suggested that Sarah and Frazer take him home and I said if they decided to then I would come too and Alex backed me up by saying that he would come too.

**Alex:** Frazer was very reluctant at first, because of all the gear that he thought would have to be taken to the house. Matthew was on a morphine pump<sup>7</sup> and so on, but then the doctors decided to take him off the pump and it made it more manageable.

**Benita:** And the decision whether to feed or not to feed was another agonising one. Sarah had to make the decision about her milk supply and I know my heart just bled for her, because her milk was starting to come in a bit. She was quite distraught, having been through having a baby and all the joy and then everything about it to be dashed down. She looked, from time to time, utterly bewildered and had no idea what was going on. She did know what was going on, she was trying to be sensible and brave and it was all getting the better of her. And Frazer, he just sobbed and at one stage sobbed in my arms and said he would give everything, all his successful career, just to have his child back. And all the feelings ... I had always known that the worst thing that could possibly happen to me was to lose a child and so here was my child losing a child. And you have such strong protective feelings except that you know that you can't try to bear their pain for them. You can only - you have to get through it. But there was a strong instinct to stay with them and, if we left, it would be, to me, it would be like abandoning Frazer, Sarah and Matthew. For all the pain that it would cause we just had to see the whole thing through together.

So we got packed up and the hospital put into place all the auxiliary services that would be needed and we went back to Sarah and Frazer's home and we continued to take turns at holding Matthew. In the meantime, Sarah's brothers and their wives and family were able to get up to see Matthew during that Monday. Her parents had been up on the Sunday too and had taken Rose back home. Other friends had taken Rochelle and kept her until Monday. Then on Monday, Frazer could not bear to be without his other

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<sup>6</sup> Pulses in the feet that become fainter when the heart fails to pump adequately.

<sup>7</sup> Slow infusion of diluted morphine for pain relief.

children and he went to collect Rochelle and Sarah's parents brought Rose back. And the midwives were in and out, of course. They put in the morphine infusion as subcutaneous<sup>8</sup>, so there was renewal of that and other midwives came to check on Sarah. Friends and neighbourhood children came in to see her; there was a wonderful trail of people through the house. I think it reflects a lot of the quality of Sarah's relationships and involvement with other families and children. Neighbourhood children who came in behaved beautifully and it was really quite touching to see.

**Alex:** It's hard to imagine that any of that would have happened had we remained in the hospital. Going home really facilitated that caring aspect of the community and extended family. The hospital institution does not do this. At the time it felt like a big upset. The pregnancy had been a reasonable one, no great problems there. And the initial reports on Matthew, when he was born, were very favourable and to suddenly have it all turn around in the matter of an hour or two, that was the hard part, the very hard part to cope with. You know, you are all elated and then, suddenly, you have got the fear of death and it takes its place. And that leaves you in a tailspin, I suppose, really coping with that.

#### **Matthew's death**

**Benita:** The last hour or two of Matthew's life were extremely painful because he had prolonged apnoeic<sup>9</sup> attacks, kind of Cheyne Stokes<sup>10</sup> in a way. He would stop breathing and then, all of a sudden, there would be a long and very painful intake of breath that was loud and just dragged the heart out. Frazer and Sarah were exhausted and they lay down and tried to get some sleep and rest. I had handed Matthew to Alex at about two o'clock, I think with the noise of his respirations<sup>11</sup>, it was just really absolutely exhausting me. Each time he stopped breathing, you think, "This is going to be it". I handed him to Alex and then went to lay down and then, at three o'clock, Frazer came through and told me that he had died. And I can remember that we had a time of prayer together and then we went back out into the living room and Sarah invited me, which I thought was extremely generous of her, to bath and dress Matthew. It was extraordinarily generous because it was her right to do it, but I had always enjoyed one

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<sup>8</sup> Into the fatty tissue, as opposed to into a vein (which is intravenous).

<sup>9</sup> Not breathing.

<sup>10</sup> Long pauses between breaths.

<sup>11</sup> Breathing.

of the early baths. I had been given a privilege of bathing all the children very early because I always loved bath time with the baby. So I did and, with Sarah's agreement, I dressed him in the clothes that I had made and the woollies and so forth that I had knitted, and put him back in the bassinette in the bedroom. With that we had, the four of us, a short time of prayer together. Then, one of those funny things that happens, happened. I have a thing about putting the lid down on the toilet and nobody else in my family does, you see. And we were all standing around in the living room and Sarah had gone out to the toilet and Frazer came back and, with a half grin on his face, said, "Sarah is swearing about you" and I said, "Oh, whatever for?" He said, "You put the lid back down on the toilet so she's got to go and ..." Sarah's never allowed me to forget and so we all, in the middle of this tragic situation and of our grief, stood round giggling and with that, we went back to bed and we got some rest.

**Alex:** Of course it was too early to start planning things at that hour so you had to wait a few hours before you began that - like phoning people. And one of the things had been that our other sons, overseas, had got the initial report about Matthew being born and nothing about the problem and there was a bit of a timelag, of course, before they did finally hear that he had died. They never quite got on board with all that had happened out here and I think that they felt cut off from the family and that, even now, it's just something that they have read about but have not experienced. I think they felt that, when we were over in Europe 18 months or so ago. It is a chapter of our lives that they have not really known too much about and really could not enter into that whole experience in the same sort of way. It is a pity in a way that two of the uncles were not there and were unable to take part in it.

**Benita:** We felt the sadness of that because Sarah has great deep affection for both her brothers-in-law. Sarah boarded with us when she left school so she has been a part of our family for a long time and we quickly became very attached to this small girl. She was so different from our family and she has always been very, very dear to us and we felt that we couldn't have a better daughter-in-law. It was as if she was just made for us and not having had any daughters ourselves, it has meant that she has always been very special to us. We tried to talk to our other two sons, 18 months ago, about Matthew and I felt a sadness that they didn't feel that they could reach out. And I felt that what I wanted most was, them to talk to Frazer about it, and talk to Sarah too, but particularly

to Frazer about it. They were horrified at the thought and just couldn't, though they responded very nicely and appropriately when it did happen. But I realised that they had never seen Sarah pregnant and it was only just an episode, like you would perhaps read in a book, to them. Whereas, it has been such a very deep part of our lives.

#### **After Matthew died**

**Benita:** There was also a feeling of walking on eggshells, to try and do the right thing. Not wanting to say or do anything over the funeral arrangements yet knowing that Alex, and even myself, are more experienced in this. Sarah and Frazer had never ever, either of them, had to make any of these kind of decisions. And yet, because we are older and we have been through this in a parish ministry as well as hospital chaplaincy, you have got some ideas of what should be and could be done. And yet, having to be very careful of not taking over. I remember the funeral director saying to Frazer about having sheets that people can sign as being there at the funeral and Frazer saying, "Oh, no I don't think that is necessary" and I'm standing across the room and saying, "Yes". He said, "Do you think so?" and Alex said, "Yes, I think that's a good idea". And later on, after the funeral, Frazer going through those and saying, "I'm so glad that you made the suggestion that we should have them".

**Alex:** And the other decision being made was retaining Matthew at home right up until the time of the funeral. I guess that's increasingly happening with babies. That actually was helpful for the family and to the visitors who came. A few people were sort of taken aback when they arrived at the house after Matthew's death to be invited to go and see Matthew - he was in the bedroom. Some obviously were not keen but everybody did go and see him. That was particularly the role that Rochelle and Rose took upon themselves to invite people to come through and see Matthew.

And Matthew's headstone is out at Anderson's Bay cemetery; that is the site for the interment of the ashes for each of us. So, provision was made that we will also end there - mortal remains anyway. So, in a sense Matthew is blazing a trail for us to follow.

#### **Talking with other people**

**Benita:** There was another aspect that opened up for me as a result of all this. From time to time, afterwards, somebody, a woman who was perhaps older and sometimes

perhaps into her eighties, would stop and would initially ask how Frazer and Sarah were and then say to me, how she herself had lost a child. Almost a typical story was how they came home from the hospital and the child having been stillborn or died soon after birth and their husband, in the kindness of his heart, had asked somebody to come in and pack all the baby's stuff away. There had been no sign of any of the baby things that they had left out in happy anticipation and how they had been discouraged from talking about it at all - "You must get on with your life". Nobody wanted to talk to them about it and I felt that there were a number of these old people who were just almost waiting round the corner for me to be able to go back over all that ground.

**Alex:** I met other people who talked about their experiences where it had all been suppressed for them. Somebody told me that 20 years ago that she had had a baby that had died soon after birth. She wasn't even allowed to see it. Everyone else made the arrangements for the burial and she had never really come to terms with it all those years later. Every now and again it re-surfaced. She was at a meeting where I was speaking and she spoke to me after about how it was all still fresh in her memory - just triggered off by something that had been said. You can see that the old way of dealing with a baby's death certainly wasn't the best way of doing it by a long, long way. I guess my own experience was better. When I was a child I had a brother who died. He was only about six months old and he was cared for at home with a nurse and, after he died, he also stayed at home. I was small myself, I was only about five, I suppose, and I can remember being involved in that and the funeral service and going out to the cemetery and so it was very much a family event and that occasion is still in my memory. And so it seemed right and fitting that it was a good model for today for our own situation with Matthew.

### **Memories and mementos**

**Alex:** We have a couple of photos of Matthew that we keep right in the middle of the family photographs which are on the wall as you go down the stairs, because we always want to feel that he is anchored very firmly. In a way, that does anchor him physically while baptism did that theologically. You could say that wasn't necessary but emotionally, and for comfort, it is another thing that anchors him very, very firmly right in the middle of the family. He always will be there, always a part of us, not this poor little physically imperfect baby, who came into the world to leave it almost immediately.

**Benita:** And the other photograph we have of Matthew, is a lovely one of him taken in his bassinet after he died. It is lined up with a photograph that we have of the girls taken the week after he died and their faces are absolutely full of life and laughter. It has always been important to us. I see them on my waking and getting into bed at night - the two photographs are side by side and it seems important to me to always keep them there. It's life and it's death. Certainly, Matthew is still with us in a very real way. Every time I smell baby wool, I smell him. Because he was dressed, as he died, in the clothes that I had made him that were pure wool. I can still, if I pick up a ball of knitting wool, I can still smell him. A day or two after he died I was walking along the road with Rochelle and the wind blew her hair back, and I saw the outline of the bones of her face, and for a moment I saw him again so it was as if I have this memory within me that I only need to look at the other children and I will see him.

The image which is always Matthew for me, is on Matthew's headstone and was on his order of service, of a baby carved in the palm of a hand - God's hand. It is from the Psalms, entitled "Carved in the Palm of my hand". It is a paraphrase of course and it is a shortened version, I have a longer version of Isaiah 49 which says, "See, I will not forget you" and it goes back into the whole of the prebirth process. "I was with you when you were formed and I called you into being and I am part of everything that has happened to you, your deepest fears, your greatest hopes, I am part of them too". I will always associate that with Matthew.

Nowadays, I look at little boys that I assess as being about 3 and a half, even little girls. I say to myself, "That is the age that Matthew would be". It is a kind of remembering and I can do it without feeling a sense of grief. While I do that he is with me and if we remember that our memories are of him as a baby and if he was with us he would be three and a half.

#### **Jessica who was born just over a year after Matthew died**

**Benita:** Jessica is so delightful and she is just so lovely to look after. We get such a lot of enjoyment and I ask myself whether the intensity of our feelings about her have been heightened because of the loss. I suppose some of it comes from that but also she is such a little individual; that she is just so very special and precious just on her own without the loss of the child that went before her.



**Reflections**

**Alex:** I am sure that Matthew's death has been a formative experience coming at a late stage of my life. As we indicated earlier, I was coming to the end of my chaplaincy; it was just weeks away from the end that this happened with Matthew. I suppose that was the major part of my whole experience as a chaplain to go through it myself. So, from the pain something emerges of value.

**Benita:** I think that Matthew's death has heightened my feelings about children and families. About the need to provide an environment in which families can grow together and, if something like this tragedy happens, that hopefully you might be able to make a contribution. It is not an experience that I would have sought. So, I would hope that I would always have so much of "the Matthew experience" with me that hopefully, if I was ever called upon to share it, I could do so easily and particularly to be able to encourage the involvement of grandparents in the lives of their children, no matter what age or stage. Never to be frightened to give of themselves - no matter how much pain it is going to cost you.

**How does it feel now?**

**Alex:** I don't think that you ever completely get over it but a major resolution has taken place. However, there will always be occasions when it seems you go back into a space of coping with it, like anniversaries and that sort of thing and the other pain remains, like my mother and her baby son who died.

This is the eulogy which Alex wrote, on behalf of Matthew's family, and spoke at his funeral.

"Is it nothing to you, all you who pass by? Look and see if there is any sorrow like my sorrow which was brought upon me." (*Lamentations 1:12*)

*We echo those words originally spoken by Jeremiah in a very different context from ours. He was grieving for the doom descending upon Jerusalem. We grieve for the loss of a dearly loved baby and our feelings fit those of the ancient prophet so they can become our words today. And I deliberately say "our" because I see myself as spokesman for Sarah and Frazer, Rochelle and Rose, both sets of grandparents, Margaret and Keith, Benita and all the members of our respective families. And I know that our sons, Peter and Andrew, far away in Europe would want to be included. During the three days of Matthew Frazer's life we often spoke to him, knowing full well he could not understand what we were saying. But our words, spoken or unspoken, ensured that he could sense our love and our closeness as we cradled him in our arms. And as we did in those days so I want, now, to address myself to Matthew and speak to him as though he can hear me still.*

*"Matthew, your coming into the world was eagerly awaited. You delayed your arrival by about a week but we were over the top of the moon last Saturday when you were born at 8 minutes after seven in the morning. What joy you brought! Though no-one had said, "Hope it is a boy" – for we would have welcomed you boy or girl – yet a son after two lovely daughters was a special delight.*

*"And so, Matthew, you gave us the joy of your birth and in that first day of your life there seemed to be no clouds on the horizon. You were to us the perfect baby, as pronounced by those who delivered you. We delighted in your strong limbs, your finely shaped head and your eager feeding at your mother's breast.*

*"Just 30 hours after your birth the icy hand of fear gripped us by the throat when you began to take ill. We could not believe it was true, Matthew, when we were called at 3pm on Sunday with the news that scans and x-rays showed that your heart was incomplete and you were going to die.*

*"From that time on, Matthew, we were by your side and you were held by members of family in turn, until your death. What a tragically brief life you had among us, but oh! how much you taught us.*

*"As we held you in our arms we imprinted everything about you in our memories. Your life was telescoped into those three days. But oh! what sadness I felt as I stroked your cheeks and knew that they would never be bristly with stubble; gazed at that tiny mouth that would never utter words; those crumpled little ears that would not hear the play of your sisters' those hands that would not hold a pen or the hands of your mum or dad; those strong legs that would never take you to school or out into the world; that brain that would not grow to challenge and enrich others. We feel cheated Matthew, but we have to be honest also. We desperately wanted you to live, but we did not want you to suffer the agonies of the struggle for breath as your incomplete heart tried to keep up. If we could have traded, our most valued possessions or ambitions, for your life we would eagerly have done so.*

*"You arrived Matthew, just a day after your maternal great grandmother, Granny Rose, died full of years and with much achievement behind her. There had been something fitting about her departure in her 89<sup>th</sup> year and then the birth of her 21<sup>st</sup> great grandchild. You were to be the new generation carrying on where the old left off. But little did we dream that so soon you were to join her- indeed even before her funeral.*

*"Matthew, you taught us a lot. In your three days a lot of learning, a lot of pain and a lot of sorrow have been crammed. But you have enriched us in spirit in all kinds of ways of which we will only become fully aware later. Our gain though is not justification or recompense for what you went through. It is simply that we have to salvage something from the wreckage of our hopes. It is only by passing through the darkness of this despair that we will later be able to appreciate and value the light beyond.*

*"Matthew, your flawed heart in an otherwise perfect physical body has raised all kinds of questions for us. And not least for your paternal grandfather whose calling has made him no stranger to death and dying.*

*"Why should this have happened to you, Matthew? What did you do to deserve it? To attempt an answer to the second question, first. It was certainly not because of anything you could possibly have done, nor do I believe it was the result of anything which your parents may have done. This was not punishment. In an imperfect world where accident and disease lurk there is always the chance that misfortune will strike. For reasons we do not understand, Matthew, you have been the victim of this mischance. We cry out, that it is unfair – and it is grossly unfair. We have felt tremendous anger that this*

*should happen. Why, we ask, could not medical science have saved you and cured you? We have felt the agonising days of your dying. God is acquainted with grief. That comes through in the life of Jesus, his son. At the heart of the gospel is a cross, the symbol of suffering and loss. God weeps with us and one day he will wipe away all tears from our eyes. We have a hard job trying to describe what we mean. Our human words are so inadequate to describe the indescribably. We resort to poetic language to spell out God's truth.*

*Matthew, we commend you to the love of our God – and your God. We believe that the words of Isaiah are true for you, too. You are carved on the palm of God's hand – and upon our hearts!"*

*For Alex & Benita, the image and words below are important reminders of Matthew. They come from a bookmark which Benita has, and were put on the Order of Service for Matthew's funeral, and on his headstone*

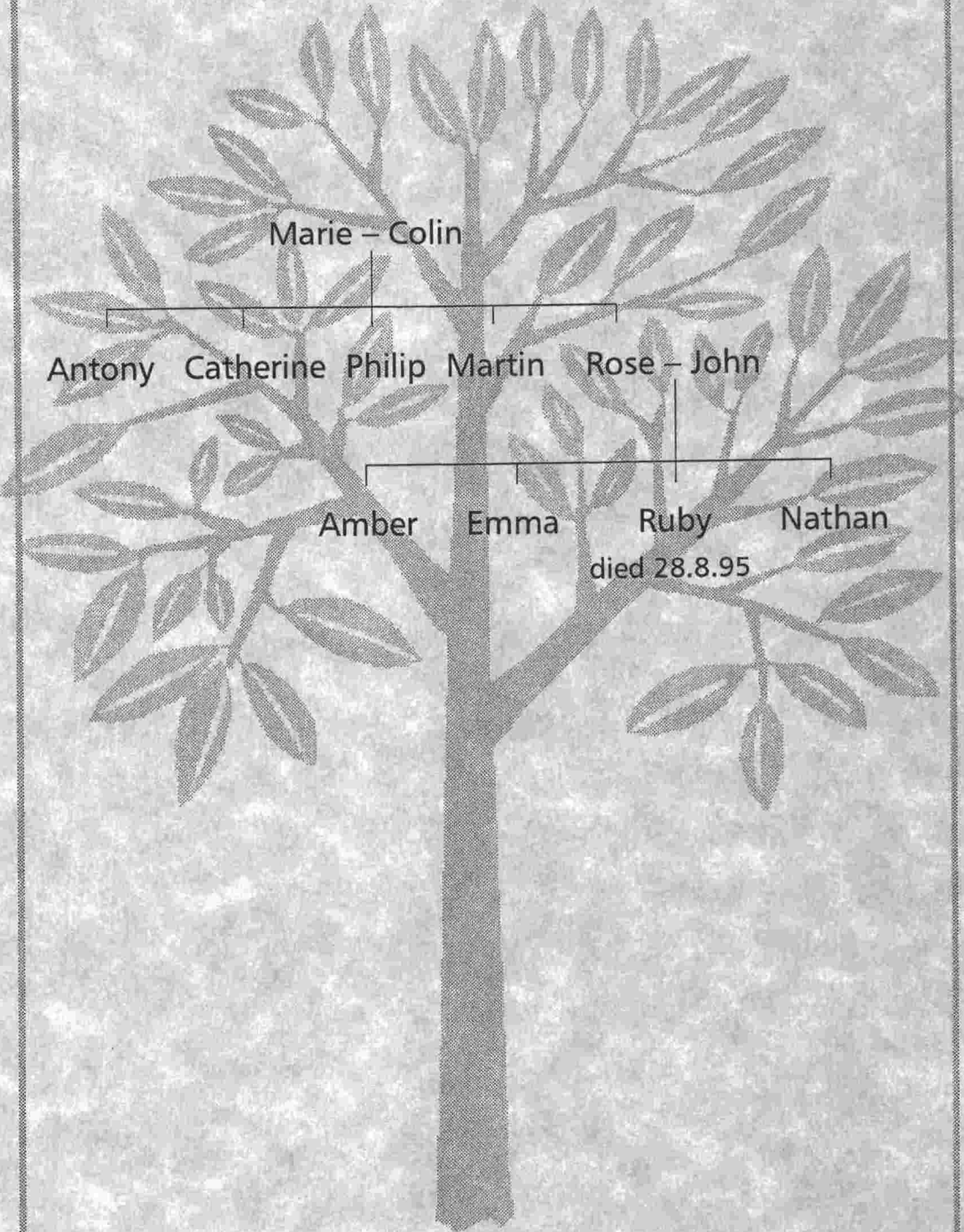
See!  
I will not  
forget you . . .  
I have carved  
you  
on the palm  
of my hand.  
Isaiah 49:15



# Ruby died at the age of nine days

These are the stories of her family

- of Rose, who is Ruby's mother
- of Marie, who is Ruby's grandmother and Rose's mother



## ROSE'S STORY

### About us

I was born in Dunedin in 1955, the fifth child in the family. I lived at home with my parents until I was 19 and had been working at Smith & Smith's for two years. After I had been working there for seven years, I decided to transfer to Christchurch for the next nine years. I met my husband John 14 years ago and, after a 3 year relationship, we got married. Two years later we had our first child, Amber. When she was 18 months old and I was pregnant with our second child, Emma, we moved back to Dunedin. The move was partly to be near my elderly parents but also for John to begin a job at Fortex. Our third daughter, Ruby, was born four and a half years after Emma. Ruby died, aged nine days, from congenital alveolar capillary dysplasia<sup>12</sup>. Our son, Nathan, was born 13 months after Ruby's death.

### Ruby's birth

Well, when she was first born I remember thinking she did not make any noise. And I said, "Is there something wrong?" but she was actually born with the caul (membranes) over her face which they took off. That's quite unusual I think. Then she cried and our GP checked her over and said she was fine and she was handed up to me. She was really beautiful. We had probably two or three hours sitting in the delivery room while we were waiting for a room in the postnatal ward and I fed her and she smiled at us. We just had a really nice time just the three of us, Ruby, John and me –a really, nice time. Then they said they had a room for us and I think they must have taken Ruby through first. It's a bit vague but, by the time we got to the room, the midwife on duty there had said she wasn't happy with Ruby's colour and she had taken her away to give her oxygen and called the paediatrician down. But by the time the paediatrician got there her colour was actually a lot better. And when the paediatrician came down the midwife actually said, "I feel a bit silly now because she looks fine". I think it was at that stage they did her blood saturation levels<sup>13</sup> and found that the oxygen wasn't as high as it was supposed to be. So they said, "No, we'll take her up to NICU". That was probably about seven o'clock the night that she was born, the Saturday night. By that stage John had already gone to do all the running around and everything. He was coming back. I didn't ring him at that stage. They just thought that she needed some

<sup>12</sup> A condition with which Ruby was born which prevented the lungs absorbing oxygen effectively.

<sup>13</sup> Level of oxygen within the blood.



oxygen and her temperature was quite low, lower than it should be and they thought she was cold so she went into an incubator. My midwife stayed with me all that time and it wasn't until nine o'clock that night, that we realised things were a lot worse than they appeared to be. I think my midwife rang John and I hadn't talked to Mum and Dad at that stage or anybody else because I was not with it at all. They had the heart specialist come up and do a scan on Ruby's heart and at that stage he was 99% sure that there was nothing drastically wrong with her heart but they couldn't see the pulmonary arteries going into her lungs. That was the only thing they couldn't get a fix on and it actually turned out to be what was wrong with her. She looked quite funny because she was so big in the little incubator and the Unit had all these tiny, little babies. So, by that stage, they were talking Green Lane in Auckland and then they said, "Oh no, we don't think it's the heart" and they were not sure what it was and they were giving her a drug to keep the ductus<sup>14</sup> open to keep oxygenating the blood. So, John went home and I went down to the postnatal ward to try and get some sleep and about four o'clock that morning I woke up and I just got this wee feeling - I went up to the Unit and they were working on her then and she nearly died. One of the midwives said, "You could lose her". So I asked for the priest. I wanted her baptised before it happened and they rang John at half past four. From then on it just escalated and then they actually got her stable. They decided she would have to go to Green Lane because they didn't want to risk doing an exploratory in Dunedin and then having to stabilise her again and move her. So everything was arranged and Mum and Dad came. I forget who suggested that I should get Mum and Dad to bring my girls [Emma and Amber], who were staying with Mum and Dad, in to see Ruby, because we didn't know how long she was going to last. And it's funny, when you're in that situation you can't really think for yourself and it was a really good thing to do to get Mum and Dad in, I think they would have been distraught if they had never seen her. So Mum and Dad brought the girls in and gave us money to get up to Auckland and all the rest of that. They couldn't hold Ruby but they had a touch of her and the girls had a touch of her, of course, and then they all went.

### **Ruby goes to Auckland**

Ruby was put into a smaller incubator for flying in and she had to go in a plane ahead of me because they couldn't get me on a flight with her. Later on, when I talked to the

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<sup>14</sup> Ductus arteriosus is part of the fetal circulation which normally starts closing after birth unless drugs are given to keep it open to improve the circulation in the heart.

paediatrician, she said they didn't expect her to make it alive to Auckland. She was a wee fighter, that girl. My next door neighbour said she would come with me, because John had to stay here with the girls to get things organised. So my next door neighbour came up with me originally. That was it, so we went up to Auckland that day and arrived there and she was in Green Lane Hospital and then they decided that it wasn't her heart, it was something wrong with her lungs. So she went across to National Women's Hospital and then they tried various things on her at National Women's.

But I think every night, or every morning, at four o'clock I would wake up because I had this bad feeling and apparently between three and six is the worst time for anybody that's ill, and that was her worst time. She nearly died three times around that time of the morning. On Tuesday morning, at National Women's, the nurse came for me at about four in the morning and said, "You'd better get down quick, she's on the way out" and I got down there and I told Ruby it was OK to die. But she fought so hard and I didn't want her to suffer again. She came back again, she wasn't going to go. I don't think she wanted to die until her father got there. They said, "You had better ring him" so I rang John and he arrived that night. I don't know how she kept coming back and she was so close to death, she looked dreadful. But she had different ideas about what she was going to do, that wee girl, and that's when they took her back over to Green Lane Hospital and put her on the ECMO<sup>15</sup> machine and things started looking good again. They said that we'd have to be very careful because she was having blood thinning stuff - aspirin or heparin - so that her blood wouldn't clot when it was going through all these machines. If she had a bleed in the brain she could haemorrhage and die and so we had to be prepared for that and she had a head scan every morning. Every morning it was "God, is she going to make it?" and she made it through so many. In the end apparently she was brain damaged from before she was on the machine. But the one thing that we were focusing on was, "If she gets through all these head scans then she's fine". They said, "If she makes it through the first 72 to 84 hours she's going to be alright". It wasn't true because they didn't realise that this condition that she had was so rare and they thought it was pulmonary hypertension which can be treated by ECMO. We just thought that she needed the time for these veins to get

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<sup>15</sup> Extracorporeal membrane oxygenation (ECMO) is a complex machine which removes blood from the body, gives it oxygen and then returns it to the body.

opened up and start working; they would periodically do that and then shutdown so that was why she was always coming and going really.

So everything seemed fine. It was funny, I rang Mum on Saturday night because at that stage Ruby was doing really well and they were reducing some of the medication and we thought that we were on the way to getting right. And it sounds silly, but Mum had had this dream where her mother had come to her in the dream and she thought at the time that I was ringing to tell her that Ruby had died and she thought that was why her mother had come. And I said, "No, she's fine" and then the next day we went to a friend's place and we felt weird all day. I kept thinking, "I don't feel right being away from her, something's wrong". We got back and they said, "No, no it's OK. She's not as well as she was yesterday, but she's alright". And then at about eight o'clock that night the doctors called us in and said, "Look if she doesn't pick up in the next day or so she's never going to and it's not fair to keep her going". We went up and we prayed and we did all sorts of things and we thought, "It's going to be alright". And then, the next morning, I went down there and I could see that she was just getting worse and worse and the doctor came in and said to everybody else in the room, because there were a lot of people in that room, "Do you mind going out?" and I thought, "Oh God, here we go". And he just looked at me and said, "You know, don't you?"

### **Ruby's Death**

They gave us plenty of time and we went in and we had her blessed before they did it and talked to her and said good-bye. We went and sat in our room. They didn't actually give us the choice to stay there because they said it would be very unpleasant. They didn't only have to turn the machines off, they had to disconnect these huge things going around the body carrying the blood around. I suppose it would have been a bit unpleasant to be there and watch that, so we just had to wait while they did all that and cleaned her up and brought her to us. That was it. We had to hang around for another day waiting for them to release her body so we could bring her home. Ruby fought so hard, she really tried so hard to stay alive and I think that's so sad that you know it wasn't meant to be, it was just never meant to be.

### **Telling Mum and Dad**

Mum even had to hear that Ruby had died secondhand. I was trying to get hold of her and I knew that Mum and Dad were going to pick up the girls because they had been

staying over at our neighbour for a few days. I rung Mum and Dad first and there was nobody home so I rung our neighbour and Mum and Dad were on their way over to her. So I had to tell our neighbour, so she had to tell Mum, when I really wanted to tell Mum myself but it just didn't work that way. Mum had to tell the girls because she couldn't keep it a secret from them for a couple of days. So that must have been hard for Mum to do that because she was very upset and that would have been really hard for Mum and Dad. They faced all the questions. We didn't have to say, "Well, she's sick because ..." or, "She's died because ..." and answer the questions that you don't know the answers to. I'm glad that someone had to do it for me because I don't know ... I would have got a bit lost. So, Mum and Dad had prepared the ground so that we could then go on with it for the girls. But they already had it quite set in their minds what was going on and Mum and Dad did a very good job with them because it wouldn't be something that it would be easy to do. I mean, our Emma was only four at the time and Amber was six. It is pretty hard to explain it to kids like that who were desperately looking forward to Ruby and very involved in the pregnancy. So, losing her was a bitter blow to them.

### **Coming back with Ruby**

When we got back to Dunedin, Ruby went to the funeral parlour and we saw her there. The girls actually stayed another day with Mum and Dad and we got ourselves together. The minister came round and blessed Ruby's room and all that sort of thing and everybody was wonderful. It was so good to get home and it was so good to see the girls but I think I got sick of hearing people say, "You're so lucky to have them" and I thought, "I know I'm lucky to have them but I want my other one, you know".

### **Ruby's Funeral**

The funeral; it was all unreal for me. I couldn't focus on all the people that were there - there were heaps of people. The church put on a morning tea for us, and John and I read out a couple of poems and did everything as well as we could do. It just passed like a dream, like it wasn't us there, it was just acting. But we decided to keep the coffin open against the undertaker's advice and various other people who said, "Oh no, don't keep it open, people won't like that". I talked about it to Mum and she said, "Do what's right for you" and we sat here and talked about it and she said, "If people don't like that, then that's tough and if they don't want to look at her they don't have to". But Ruby was beautiful, she looked absolutely perfect. So we decided that's what we

would do and, after doing it, most people have come and said how much they appreciated the chance to see her. Because all these people, who had sent cards and flowers while we were up there, had never seen her. So it was very special for them to get the chance.

It rained and rained that day and we went out to the cemetery and they were lying the coffin in the grave and it wouldn't go down and they had to pull it out again. I remember saying, "She's a stubborn little cow, she didn't want to go when she was alive and now she still doesn't want to". You sort of felt that you had to make some sort of joke because I know everyone was standing round feeling really uncomfortable about it. It sounds a funny thing to say but it was a lovely funeral, she got a really nice funeral. We played "Tears in Heaven" and apparently everybody burst out crying. It's a beautiful song and it said how we felt and it was written for the same sort of reason, so it was good.

### **Mum's Support for Me**

I ring Mum every day - that's the way we are. I mean I can just ring up Mum when I feel sad and when I feel happy and when we talk I know she remembers all the days that are hard for me and she always rings me because she remembers every anniversary and everything. I can say I wouldn't have got through it if it hadn't been for Mum. Well, I probably would have got through, I think you do, but it helps if you have someone you can talk to without having to feel like you have got to protect them. Because that's one of the things that you do with people, is to protect them from your grief because they can't deal with it. And I know it must be hard for Mum because I know that she has got her own grief but she doesn't put it onto me, which is good because we've all got to deal with our own grief - however we can.

Mum has made a very big effort not to put any of her feelings or put any extra stress on me by showing it. Like when I told her about the fact that, at Green Lane, the machines were just turned down and Ruby was left to die and we didn't get the opportunity to be with her. When I found that out, that it would not have been that unpleasant and that we could have been there, then I got very angry and I rang Mum and she was angry for me as well. I told her about the times that I have written to the doctor in charge since then, not necessarily to criticise, just to question the reasoning and Mum says, "Well, at least what you are doing might make sure that it doesn't

happen again". I don't know about how she went through her grief because she did it herself, which I suppose seems a bit hard but we have all got to do our grieving in our own way. It is like that day when I rung her and she had been crying and I said, "I'm sorry Mum", and she said, "What are you sorry for? I'm allowed to cry for my granddaughter if I want to". And that is right, there is no point apologising because somebody is sad.

She has always been very caring and she has tried to explain it to me, because I'm her child, and I always will be, and she wants to stop me from feeling pain but, of course, she knows she can't. I think she feels a double set of helplessness. Like I felt helpless because Ruby died and she's my child, Mum feels helpless because she can't help me plus she's lost a granddaughter. I think people of my parents' age don't expect to bury their grandchildren, they expect it to be the other way round, and it's a real shock. Plus nobody in our family has had a child die and it's a real shock to them. She's always thought very well of John but she's thinks even more of the way he dealt with Ruby. At the funeral he bent down and kissed Ruby. Mum started crying because she said she was so impressed with him showing his emotions. I mean a lot of men can't do that and I don't think John could ever do any wrong in Mum's eyes.

And she keeps my feet on the ground. When I moan about the girls she says to me, "You've got to be a bit more understanding" because sometimes I forget how deeply they've been affected by it. I mean, you have a tendency to. I do know how badly they were affected but you tend to forget about it sometimes, because children appear so resilient and not say anything. And she says, "Well, just remember this or that thing" So she keeps me in touch with things like that when I have a tendency to forget. And she reminds me of all the things that I should be thankful for that we can forget as well. I mean, you have a tendency to wallow in self-pity because it feels good and she can say to me, "Well, you had this or you had that". It's good to have somebody that will point that out to you every now and then so that you don't get too much into "Poor me".

### **My Dad**

John finds it hard that Dad doesn't say anything because he expects people to talk about Ruby. But a lot of people just don't feel comfortable about talking about babies dying, or anybody dying or death or bereavement or anything like that and so they avoid the



subject like the plague. John expects everybody to be as open as we are and it doesn't always work that way. It's just the way things are. John probably wanted Dad to give him a hug and say something but I mean, that was just never going to happen. He didn't even hug me, so he wasn't going to hug John.

### Visiting Ruby

I go quite a bit to Ruby's grave. The girls like to go as well and they go up and say "Hello" to Ruby which is quite cute. I don't think Mum has even been up to see the headstone - she is not comfortable with cemeteries. Funerals and things like that aren't things that Mum likes. As far as Mum is concerned Ruby is not there anyway. I mean we know she is not there, so Mum identifies with Ruby in a different space to what we do, which is fine. Mum told me the other day about an umbrella and that is what she has for her memories. Because it was raining cats and dogs on the day of Ruby's funeral she had this umbrella up to keep the rain off. Now she has it down in the basement and as Mum and Dad come in from parking the car she touches it and looks at it and that to her is the thing which reminds her of Ruby. I thought that was lovely. It surprised me. It was another one of those things that happen that surprise you about the depth of people's feelings and what things mean to them.

### Nathan's arrival, after Ruby

Being pregnant again was hard on all of us, including Mum. Mum was very supportive and helped me stay strong. When the big day arrived we knew that Nathan would be tested [to see if he had the same condition as Ruby], as soon as he was born, Mum and Dad were waiting for us to ring them. They were looking after our two daughters and as soon as Nathan was born they all came into see us. Dad took lots of photos. It was just as important to them [as to us] to see that he was fine.

*For Rose an angel symbolises Ruby, because when Rose was very sick and unwell during her pregnancy with Ruby, she used to say "She is being a little devil and she will be a little angel when she is born".*



## MARIE'S STORY

### About us

I was born in 1920, had two sisters and a brother. We grew up in the North Island and lived with a great-aunt in Auckland. My father's family were Maori, and so I am part Maori. I went to boarding school in 1933 and then on to teacher college for kindergarten. I stayed working in that area until I retired at the age of 60. I married Colin, who was also a teacher and lived outside Dunedin. We had five children, two girls and three boys - all with partners and their own children. At the time Ruby was born we had eleven other grandchildren. Now we have fifteen grandchildren and one great-grandson. Ruby was the third child of our daughter Rosemary [Rose] and her husband John, who live near us. They had two other children, Emma (six years) and Amber (four years) when Ruby was born. I am sure that it is usual to look forward to a new birth with happy confidence, if there had been no indications of problems during the pregnancy. So Ruby was born at full term. I expected that, as usual, it was the beginning of a happy new life. Therefore, I was not prepared for the fact that this time it was going to be different. Ruby was fine at birth but soon after she developed breathing problems and was transferred to Auckland for treatment. She died there eight days later.

### Ruby's birth

Well, it was really exciting when Ruby was born, because we'd been looking forward to it for so long. Rosemary rang in the morning and said, "Will you come and get the girls please because I'm in labour?" and I thought, "That's great", so we went up to collect them and she was looking so happy. We took the girls away down here and it would be about four hours later that she rang and said, "We've got a little girl" and we were so excited about that, too. But it was a little while before Rosemary rang and said Ruby had been taken to intensive care because she had turned blue. They had one hour, round about an hour, the two of them together, Rosemary and John, enjoying her, before they could see things were going wrong.

And gradually it turned worse. Rosemary rang and said, "We're going to have to go up to Auckland", so I was thinking about all the possibilities of that and I had a bad night of course. And then we got up early the next morning when we knew that Ruby was going as soon as they could get on a plane and we decided to take the girls up to

intensive care to see Ruby. We all wanted to see the baby. We weren't sure whether that was wise or not. But now, of course, I'm glad that we did, even though it was upsetting seeing her there and seeing Rosemary and John so upset. They had people there who were supporting them. Their GP was there. She had a long journey to get there to the hospital by nine o'clock or so and I thought it was really lovely of her to be supporting Rosemary in that way. Not many doctors would, would they? And to see this dear wee thing in the incubator all wired up, it was heartbreaking to see it and the girls were puzzled of course, but they were intrigued. I don't know how they felt. So then of course, it turned to financial worries too, because Rosemary's neighbour, who was also supportive, she wanted to go up to Auckland to keep Rosemary company whilst John organised things here. But you know the flight airfare to Auckland is so expensive so I managed to get hold of enough money to pay her fare. Rosemary, of course, went free. And then these 8 days of uncertainty started, "Was she going to live or wasn't she?" and, "What were we going to do with the girls?"

### **Ruby in hospital away from home**

It was hard having phone calls from Rosemary from the hospital and knowing the grief that she was going through and knowing that there was nothing that I could do about it. Nothing at all I could do except try to send positive thoughts and because she would know that I was feeling sad. She'd know how I was feeling but nothing I could do about it. If Rosemary was here and I could give her a cuddle and give John a cuddle, 'cos he likes a cuddle too. Just so helpless to do anything except say, "Oh, be brave". Oh no, I wouldn't talk like that. What can you do for someone who's going through that? You can't do anything, can't give them a lolly, like "Here's an ice-cream to make it better". Just try to be supportive and knowing that they've got something to learn from it too. That they can't understand WHY now but they will one day, I'm sure, that something good will come out of it. It was so hard during the next few days to feel my daughter's sorrow, and not to be able to be near her and comfort her except over the telephone. However, we managed to arrange for John to be with Rosemary and Ruby for those few days of stress.

### **Ruby's death**

I suffered for Rosemary and John knowing what an awful decision it was to stop treatment, but they had to make that decision and, in the end, I think it was the doctor who advised them well. It was inevitable that Ruby would die, obviously from the

postmortem results, she wouldn't have lived for very long anyway. But it was a comfort to Rosemary and John, I think, to get those results, because then they knew that nothing they could have done would have affected the final outcome. I still feel slightly numb about it all, my memory has got gaps and, because life went on - had to go on. I had to be doing mundane things when I would really just want to go to bed and cry and I couldn't cry in front of the girls [Amber and Emma].

When we went up to the undertaker's and saw Ruby there ... I'd never held her, of all my grandchildren. I've always held them when they were babies and my arms just ached to pick her up but of course I couldn't and I held her little hand and it was like marble, so cold ... There, that's a grieving too isn't it? I've never seen a dead body before and I've never touched one and she looked so peaceful there and then we had to go away and leave her there. And, of course, grieving for me. How awful for ... you see, I was grieving for Rosemary and John too and the girls. You have all of these extra ones when you are a grandmother. But then, you see, Rosemary would be grieving for us. Anything in the family affects everybody doesn't it?

### **Ruby's funeral**

Rosemary and John had the coffin open in the church and the church was full. There was quite an emotional feeling and they put a teddy bear in the coffin and Rosemary had sort of said good-bye and then John. It really broke my heart to see him touching Ruby's hand and then kissing her good-bye - he didn't want to leave her. And I hadn't realised how bad he felt. I'll never forget seeing him like that and then, of course, Rosemary and John carried the coffin out of the church. They were so heartbroken carrying this little coffin out to the hearse, I don't know how they managed to do to bear up so well. They both handled it so well, both of them, and then having to go back after the burial to the social thing with crowds of people and they were just so wonderful and they both seemed to have got extra strength to go through it. Rosemary didn't think that she would be able to handle any of it but she did and she read a couple of poems in the church and her voice didn't break at all she did it splendidly. I couldn't have done it.

### **Ruby's grave**

I don't intend to go to visit the grave at all, I don't feel that the body is really important. I sometimes think about her and it's five months now, and I wonder, and I

don't like to think how she is. I intend to be cremated and that will be "Whoosh" like that, but Rosemary and John wanted her to be buried. Rosemary and the girls go up to the grave once a week, at least. Rosemary goes more often, I think, and puts flowers there. I just don't quite see it that way, Ruby's gone and I didn't ever get to know her. So, in a way, it's not quite the loss it would have been for somebody who had had a baby for six weeks and had nursed it and held it and got to know some of its personality. The only time I saw Ruby alive, she was all wired up and eyes shut, she wasn't a person. And she wasn't a person when I last saw her at the undertaker's either. Whereas, when an adult dies you can sort of wonder whether maybe their spirit is around. My sister in Christchurch had a lovely father-in-law and he died. We knew he was dying and I was very fond of him, not that I knew him all that much, and I can remember being out at the clothes-line hanging up my washing and I thought, "He's died". And I sort of felt, I don't know I suppose I'm imagining it, I sort of felt a force going past me and I said, "Thanks for coming to say good-bye to me". You can sort of think that about an adult, but a baby that has had no life I don't know what connection you can form with it. I don't go to Ruby's grave because I don't think that she's there. But I also miss out not having known her. I can't get in touch with her personality because she didn't have one for me. I just don't know her, I only know her from the photo I've got of her and my few, very few memories of seeing her in an incubator. She's not been a person to me at all. If I'd once held her and seen her smile then it would have been different. She was a "no person" to me except through Rosemary and through my loss of not knowing her grow up. I still feel sad when I see other people with babies. If they are nice babies, I usually go up and say, "How old is she?" if they are around the age that Ruby would be. I guess that's what Rosemary is doing all the time. Knowing at what stage Ruby would be now and missing that. But that will fade in time won't it?

### **How I feel**

I don't think I would have wanted to talk to other grandparents. We have all got to handle these things in our own way. Everyone's different. It might have upset me more, I don't know. It's surprising though, talking to people, the number of people who have been affected in some way by death. I hadn't realised how many people I knew that had lost family until they get talking. That's good to talk too. One of my friends had a son killed in a motor accident just before Christmas some years ago. She said she could never come to Christmas happily because you never forget - she

connects it with that sorrow. I don't think I'll be like that, I think I'll grieve all the time. I've got a little photo album which I keep beside my bed and most days I have a look at it and it's got little poems and photos of her and things. That's my memory of Ruby.

Rosemary had a nice verse, at the funeral, by Rudyard Kipling<sup>16</sup> of all people! I couldn't believe it was him. I was a fan of him when I was much younger and I've got some of his poetry books and some of them were pretty rough, weren't they? That he could show such tender feeling really struck me and it helped me a lot reading what he wrote, *"That God lent a child for a little while because there were lessons to be learnt down there and he had searched for good parents to help the child learn it and if, if I take her before you're ready forgive me"*. You know, I thought that was lovely and that was one of the things that helped me a lot to think that. I also heard a verse on the radio last night. I listen to Radio Pacific and between midnight and dawn a different type of people ring up and lot of things come out of that that they wouldn't say in the daytime. There was a verse read and it said *"Don't weep for me I'm not dead, I'm the wind that blows."*

Not having known Ruby as a person meant that I hadn't the same feeling of loss so my grief, which is still so much a part of me, had not been as intense as that of Rosemary. The pain is still there and I still have sudden tears, though I am a person who rarely shows emotions, and I mostly cry only when alone. I had previously been aware of the normal stages of grieving but in this book [by Margaret Gerner] I learned of some of the physical effects. I hadn't connected my loss of appetite or my inability to concentrate with my loss nor did I think of the necessity to ensure that I should watch my own health.

### Memories

I can talk easily with my daughter about Ruby, but I find it difficult to give her all the comfort she needs. Really, the only things I have to remember Ruby by are photos of her in her coffin, and, strangely, an umbrella. During the graveside ceremony, the rain was pouring down and I held this umbrella over the girls and me. This umbrella I will

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<sup>16</sup> We have had no success in locating the source (to provide a reference) of the various excerpts, which Rose had at the funeral.



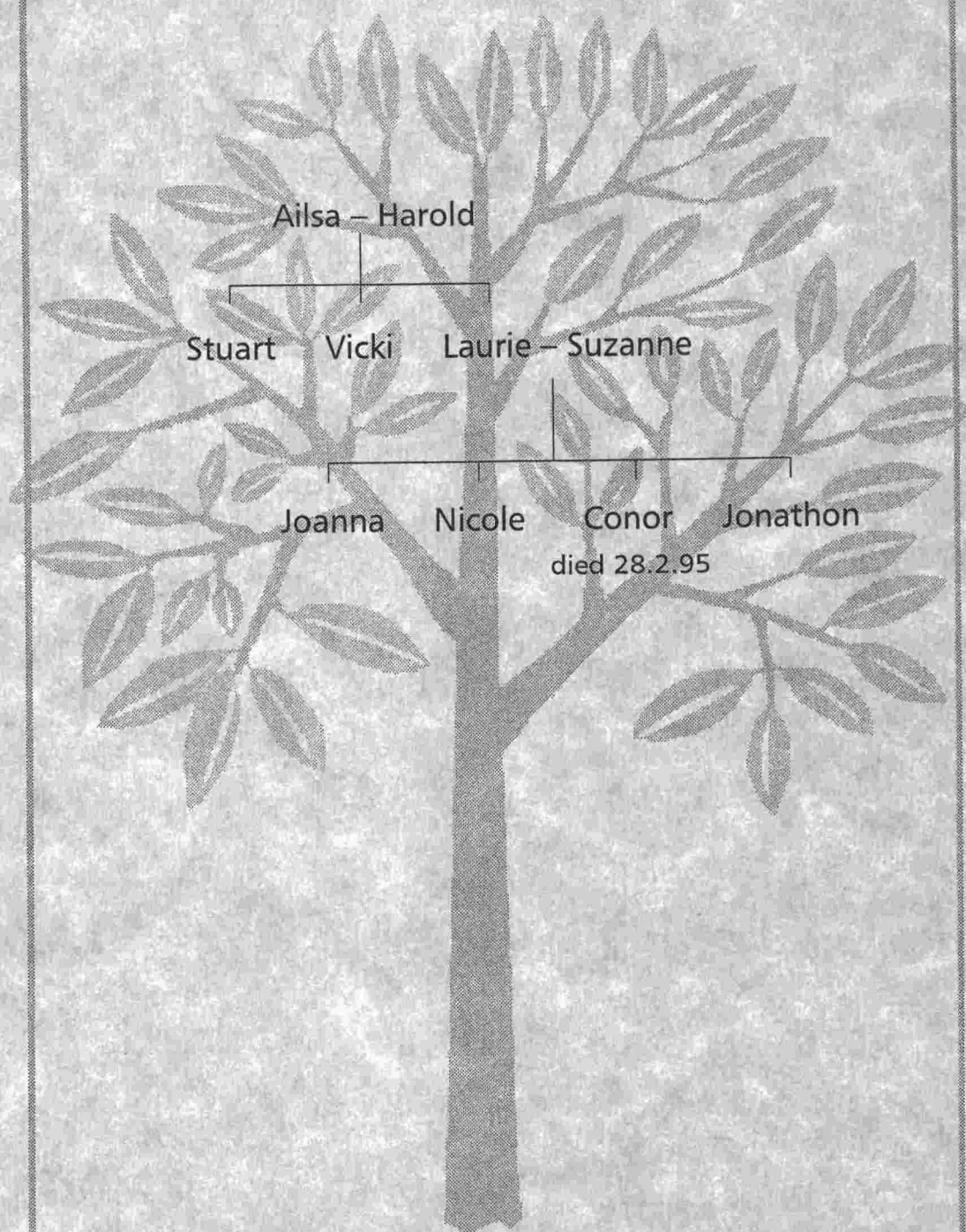
never use again but I have put it in a place I pass by most days, and I touch it and remember. I'm just leaving it there - that's "Ruby's umbrella". Today I came across a folder of Rosemary's poems about Ruby and her own feelings and that helped Rosemary a lot, to be able to express herself. She is going to publish them. It is a good way to be able to handle grief, to be able to put it into words and words that help other people too.

*For Marie, the umbrella she used at Ruby's funeral is a symbol of Ruby*



## Conor died aged four and a half months

This is the story of his grandmother, Ailsa



## AILSA'S STORY

### About me

I was born in Dunedin in 1936 and grew up in North East Valley and have lived all my life in the North End of Dunedin, apart from approximately four years when I was first married. I have three children named Stuart, Vikki and Laurie and nine grandchildren named Marcus, Kristy, Gemma, Stephanie, Liam, Joanna, Nicole, Conor and Jonathon. My husband died eight years ago, after 14 months illness of lung cancer, so now my life revolves around my children and grandchildren. My interests are sewing and knitting which I have done since reaching my teens. I retired from New Zealand Post in 1990 after almost 20 years and previously worked with my husband in self employment for six years.

### When Conor died

Suzanne rang me up on the night that Conor died and the absolute disbelief I felt with Conor's death was indescribable. My husband had died four and a half years before Conor was born and I knew that Conor was going to be the last grandchild and I felt as though life was complete again with Conor. I had always wanted Suzanne and Laurie to have a son. That would have been three grandsons, one in each family. I had always said that if I had a one sex family I would like to have boys rather than girls, not that I like boys more, there is just something about wee boys. When Conor was born I felt as though my life was complete again, as though I had finally come to accept losing my husband. When Suzanne rang me that night I just couldn't believe it. I thought, if anything, it just had to happen to someone else - not to us. It was absolute devastation. Laurie being my youngest, he was always the baby so it was very, very difficult.

After Suzanne had rung I actually went to pieces. I think Suzanne was sorry then that she had rung, she thought perhaps she shouldn't have. I stayed here until they got in touch with my eldest son who came and picked me up and we went over to Suzanne and Laurie's house. My daughter lives in Cromwell and in between Suzanne ringing and Stuart coming, I had got in touch with my sister, I was just a complete mess, so she came up. Stuart and I went over to Laurie and Suzanne's place. My daughter and her family came down that night and they didn't arrive until about one o'clock. They just packed up and came straight away. I mean, everyone was just absolutely devastated. We all thought Conor was absolutely wonderful and knowing he was the

last grandchild, too - I think you are going to enjoy it more. I had been looking after him on the Monday before he died and I had just hugged him to pieces. I'm very, very fond of all my grandchildren and have lots of hugging and loving with them. I had just done that on the Monday and I just couldn't believe it, that he had gone just like that. The wee boy that was there was not the baby I had cuddled on the Monday - he was so different. His life was just over. He didn't even look like Conor - so totally different. It was just the start of a few days of not knowing what you are doing.

Laurie was very upset at the start. When we went over to the house he was sitting on the end of his bed with Conor in his arms and just looking at him I don't think he believed - trying to imagine that that was his baby. I know that I couldn't hold Conor because I felt that he wasn't... it was just a shell and I couldn't hold him. I wish now I hadn't felt that way - I wish I had held on to him longer. Whereas Laurie had held on to him all the time sitting there. I wish that I had held him and cuddled him. That's the trouble, if you go back and think about things you can wish that you had done things differently. But [at the time] I just felt that he didn't seem anything like the little boy that I had nursed the day before. His whole being - you wouldn't believe that it could be the same child - his face and features were so totally different. If you believe in the spirit then obviously the spirit wasn't there any longer and just the shell was left and the shell wasn't anything like what Conor had been.

I think for **me**, one of the hardest parts was seeing my children so devastated and not being able to do anything for them. Because when your children are little you can fix all their aches or all their problems but as they get older their problems get bigger and you can do less about them. And there is nothing you can do to make it better for them. And this is worse than anything else, because you would give anything to get that baby back for them. Yet there is nothing that you can do about it, I found that just seeing the grief in them was harder than for myself. The family and my other children were very supportive. Laurie and his sister are very close and she was very supportive of him and also my eldest son and his wife were really good. They were there and I didn't have to be there. I could just be myself.

In the next few days before Conor's funeral I think we went over to their house each day and we saw them some part of the days. Suzanne's mother came from

Christchurch. We are very good friends and it is just like we are all the same family, it's not like mothers-in-law. I go and stay with them and that sort of thing so we were all together. They had plenty of support and they weren't left on their own. Suzanne's mum is very practical and she coped by taking over. She didn't want anyone to see her cry, although we knew she was really upset about it, that's her way of coping. So we saw a lot of them, but as I say, we are a very close family.

The day Conor died was the 28<sup>th</sup> of February. The strange thing was when my daughter rang me back that night - I had forgotten the date for some reason, she said, "Mum, it's Nana's anniversary". It was 28 years to the day that my mother died, when Conor died and it was a Tuesday again **and** it was night. It was the most strange feeling. I never, ever, forgot my mother's anniversary and that was the first time that I ever had. It wasn't until my daughter mentioned it, I hadn't thought of it in the day that really pulled me up. I said to myself, "What do you want him for? What do you need him for?" As though there was a sign in it. As I say, I'm not a religious person in the least and I don't know if there is anything in the after life or not but it just made me feel it was a sign.

### **Why not me?**

When we went to Suzanne's and Laurie's place I said, "It should have been me". I remember them telling me off about it. What I meant was that I had had a life and I would have willingly given my life for him to have had a life. I felt that my life was over and that would have been my ultimate sacrifice to have given my life for him. After you have lost your partner you go through all of those stages where you feel that life is not really worth living. I think I coped well. I felt that I coped but I know when you get past it and you look back you think, "I must have been a bit down" but no one ever said to me that they thought I was. No one ever felt that I had had to have help or anything like that but I think, until you get past a certain stage you don't really realise you are in it. Once you get past it you think, "Oh well I was a bit down at that stage" but I certainly had those feelings. I used to say to the doctor, "It doesn't really matter whether I live or die" but then I said, "I don't really think that I want to die". You have a guilt feeling about still being alive, why are you still alive when your partner is gone? Feeling guilty that it wasn't you and it was him. Apart from the start, right at the beginning, when I said I would have given my life so that Conor could have had one, I

don't really feel that I have thought about my own death since then. You certainly look at death in a different perspective.

### **Conor's funeral**

When you are a grandparent you are more helpless than when you are a parent, because when you are the parent you have got the responsibility and you have got the decisions. When you are a grandparent you have to be there to help but you can't make the decisions. Whether it is the right or wrong decision you can't make the decision; you have got to be there just as a support or if you are asked to give advice. But that is not your decision when you are a grandparent, is it? You have to just stand back. As far as Conor's funeral went, I didn't have any input into it really, I didn't try to make any decisions about it at all. I thought, "Well it is their child's funeral". They sorted all their music out and I said, "Yes I liked that" but I would never have said, "I don't think you should have that" - that was their decision not mine. I just floated along behind them. I was quite happy not to have any decision making. I don't think I could have coped with having to do that, it was enough to be there.

Suzanne doesn't show a lot of emotion. She shows a lot of strength but inside she's feeling it. I think it was the Sunday after, either a week or two weeks after, we went out for a picnic to Brighton. There was a very good friend of Suzanne's, her husband and family, with Laurie, Suzanne, the girls and myself. We were just walking along the beach with the little ones and I can remember looking at Suzanne and thinking I have never ever seen someone who just looked as though sorrow oozed out of all her pores. I have never seen anyone look so desolate in all my life. I just was really worried about her that day.

### **My husband and Conor**

My husband is never far from my thoughts and even as a family we talk about him. We are not one of these families that push them aside once they've gone. We still talk about him. I don't know whether I even believe in the after-life but we talk about this as "Granddad will be looking after Conor" and those sorts of things. But I think that is to help yourself; you do those things because you think it's going to help you. You feel it's consoling each other and you are consoled by the thought that everyone you love is together.



I felt anger when my husband was sick. He died of cancer. I can remember sitting in the bus one morning going to work and a car pulled up beside the bus with people sitting in the car and feeling the anger "Why couldn't it be that person? Why did it have to be my husband?" I mean, I didn't know the person at all, it was just another person. I had that same feeling for a while walking around the supermarket and seeing a baby in the supermarket "Why couldn't Conor be here and not that baby?" Not that I meant any harm to that child at all but it was just anger that it happened. But not spitting anger just that sorrow, more that sad feeling, "Why did it have to be Conor?" That's life and you have to accept it, regardless of who it is or what it is. I've always had that sort of philosophy; "If you can't change it, accept it". So, you have to accept things.

Funnily enough I think I've been reduced to tears more often over Conor than I was over my husband, Harold. Whether it was because we knew my husband was sick and was going to die, whereas Conor was sudden. I think that was probably part of it. I did think it would not have affected me as much because it is not really a change in my life. Like my husband dying has changed my life completely, whereas losing your grandchild doesn't change your life the same. It's the same as I have said to my children time and time again, their father dying, or even if I die, their life still goes on - they have grief but it doesn't change their life. If you lose your partner your whole life is so totally different. So I really thought I would not have the same feelings about Conor, but I have had. Whether that has been brought back and I was more tearful with Conor because I didn't cry before [when Harold died]. I was always a person that showed my emotions easily and I used to say I could be an official mourner - I could go to any funeral and cry. If I saw somebody else cry then I would cry but when it seemed to matter most, like my husband dying, I didn't. So whether Conor's death has helped me release that, I don't know.

### **Grief takes time**

I feel it gets worse before it gets better. At the start, I'm thinking more of my husband's death rather than Conor's death. At the start you think, "Right, that's over now, this is what it is going to be like - you are going to be on your own". And then a year or 18 months or two years down the track when it doesn't seem to be any better than it was at the start, you feel as though you were stronger at the start than you are at that stage. But now it is six years since my husband died and I feel "I'm past all the

grieving" - this is my life. So it does get worse before it gets better. It does get better, it becomes the norm. It is just like going into a marriage really. At one stage you are on your own and that is your normal life and then your life changes as you learn to live with another person and that life becomes the norm. You can't imagine any way of living except being in that life and children come along and they just gradually increase the life. It is like a door opening and shutting. It is like, each part of your life is like a different part of the house, going from one room to the next and becoming used to living in that room. So bereavement or change is a long passage between the two rooms.

The lady next door died just over two years ago and her husband was talking to me over the fence one day and said, "You know how people say time makes it better? I don't believe that at all. I think time makes it harder". I was pleased to hear that someone else felt the same way, that it really does get worse before it gets better. My daughter bought me a book by Beryl Te Wiata called "Widowed" which she started writing after her husband died. Not straight away, it took her quite a number of years. She used to jot down these feelings because she said there was nothing available at that time for her in a book. I found that book very, very good to read and it can fit into any sort of bereavement really - hers was definitely for a partner but a lot of the situations could fit in too. When you are sitting reading, you think, "That is exactly how it was, that's how I felt at that particular time". The undertakers gave Suzanne and Laurie a booklet which said that grandparents grieve twice. Grieve for the grandchild and for their own children and I really believe those were the feelings I had. I couldn't make it better for them and I just wanted to make it better for them. It's terribly, terribly hard to see your child in such agony and you can't do anything to help them, they have to get through it themselves. Just putting your arms around them and loving them is all you can do. You feel that it is not enough. You want to do something else, you want to blot it all out for them. I still feel like that. I still have that feeling that I wish I could do something to help, wish I had the right words to say something to help.

Conor's death, it was something that you had to accept. Something that you can't change so you just have to accept it. I know a lot of people say, "Oh, you have to get on with your lives" but your life can never be the same. Even for Laurie and Suzanne. Sure, you get on with life and do things. You can't stop doing things, but their life can

never be the same as when that wee boy was there. It's a complete change so you just have to accept it. I know that there are times when you feel depressed and life isn't worth living but time is the only thing that changes that. Some people might get over it very quickly and others take a long time but time will eventually give you a new life or make things seem more normal. I know, at the time, that you feel as though you are the only one it has ever happened to and then you realise that you are not. It happens to somebody every day of the year and every year of life somebody is feeling grief at that particular time and obviously some people are feeling it worse than others.

### **Talking about Conor**

We often talk about Conor. Not every day conversation, every day of the week but we all do talk about Conor. In fact, I was at Laurie and Suzanne's for tea last night and we were talking with Joanna about it. The children were saying how they spelt his name and I said "What was Conor's other name?" just in conversation. I think it is important for children, too, to bring that up now and again not just to push it away to the back and forget about it. They need to have it brought up. I always talk to Suzanne about "Conor's room", you don't think about it as the spare room it is "Conor's room" as though he is still part of them.

Nicole was probably too small - too young - but Joanna had a few problems with accepting Conor's death, I think. When it came round to October and it would have been his first birthday she told the headmaster, who was a new headmaster at the school, that it was her brother's birthday and he said, "Oh did you give him a present?" and she said, "Yes we gave him a teddy bear". They had bought a little concrete teddy bear and taken it out to the cemetery and cemented it to the grave but she didn't tell the headmaster that Conor was dead. She told him that it was his birthday and that they had given him a teddy bear but the death was never mentioned. She's just turned seven, so she was six at the time. She wouldn't tell the children at school about Conor being dead - she'd talk about Conor but she wouldn't tell them about him being dead. It was her little brother. Possibly it's not so much like that now, I don't know whether she still talks that way. She went to the Bereaved Kids group<sup>17</sup> and that probably helped her.

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<sup>17</sup> A group run by the paediatric nurses for children who have siblings die, using play and drama to help them explore their feelings.

I know when Conor died, I remember going to the bank one or two days after he had died and saying to the girl at the bank that Conor had died. She told me she had lost a child from cot death. There were a number of people that I found when you mentioned it, you never even knew that they had lost children and it would come out because of the similarity of the cot death thing. Those people seem to feel that it gives you a closeness to them, because you have joined their club.

When people ask "How many grandchildren?" I say, "Nine counting Conor". You think of what you have got and you think you can't really exclude him. Even if he's not here he's still a grandchild. If anyone asks, I usually say, "Nine but eight living" I like to include him but you have got to make the distinction I think.

### **Memories**

The photos of Conor are important, to know that he was here in the world and that he will never be forgotten, that I can always show that he was here. I like to show them to people, that he was a beautiful baby who didn't die because he had something wrong with him, just that it is proof that he lived on the earth. I think Suzanne feels like that because she has always had quite a few photos around although perhaps now that Jonathon is here [Jonathon was born after Conor] the photos might not have so much importance. There will always be photos of Conor but perhaps not quite so many. And I think that was trying to keep him there - his place in the family.

### **Other Grandchildren**

Nothing will bring Conor back - I think that's the hardest part. Suzanne's had miscarriages since and that makes it harder and each time you just feel that it's so unfair. You see other children that have been abused or beaten and you think there is no justice in life that some people have so many problems, and people who can't have children at all, and yet other ones have them and can't even treat them properly. You feel it more when you have lost your grandchild. Well, a person probably feels it more when they have lost their child. You think, why do people behave like that? Why do they treat children like that? Throw them against the wall and things like that. I can't understand it, I really can't.

And so now with Jonathon being born, Conor's room has become Jonathon's room. We had always just talked about it all the time as "Conor's room". I said that it was

going to be very hard to realise that it is "Jonathon's room"; it was not "Conor's room". You can't talk about it as "Conor's room" anymore. When Conor was born, a friend gave him the letters, carved in wood, of Conor's name and it had always sat on the sideboard in his room. Then, a few weeks before Jonathon was born, Suzanne shifted it out. They have a little window at the top of the staircase that lets light into the hallway and there is a windowsill and Conor's name sits there now so it was almost shifting him out of the room. The name was the symbol. Yet it was a sad feeling to have had to have done it. I think they felt it too, it was almost like pushing him out. I suppose that it is that you are having to get on with life and realising that is like a little mausoleum to Conor, that little room, and you couldn't keep it that way because life is not going to stay there at that point. It has got to go on and now Jonathon is taking that place. Not replacing Conor by any means, but it is filling a gap isn't it? But at this stage I think it is still terribly hard not to think of it as replacing Conor. Once Jonathon gets past Conor's age perhaps it might be different because we still keep looking for Conor in Jonathon and I think once he gets past that stage where we haven't got memories of Conor, Jonathon will become his own identity. It won't happen until that time.

### **Looking back**

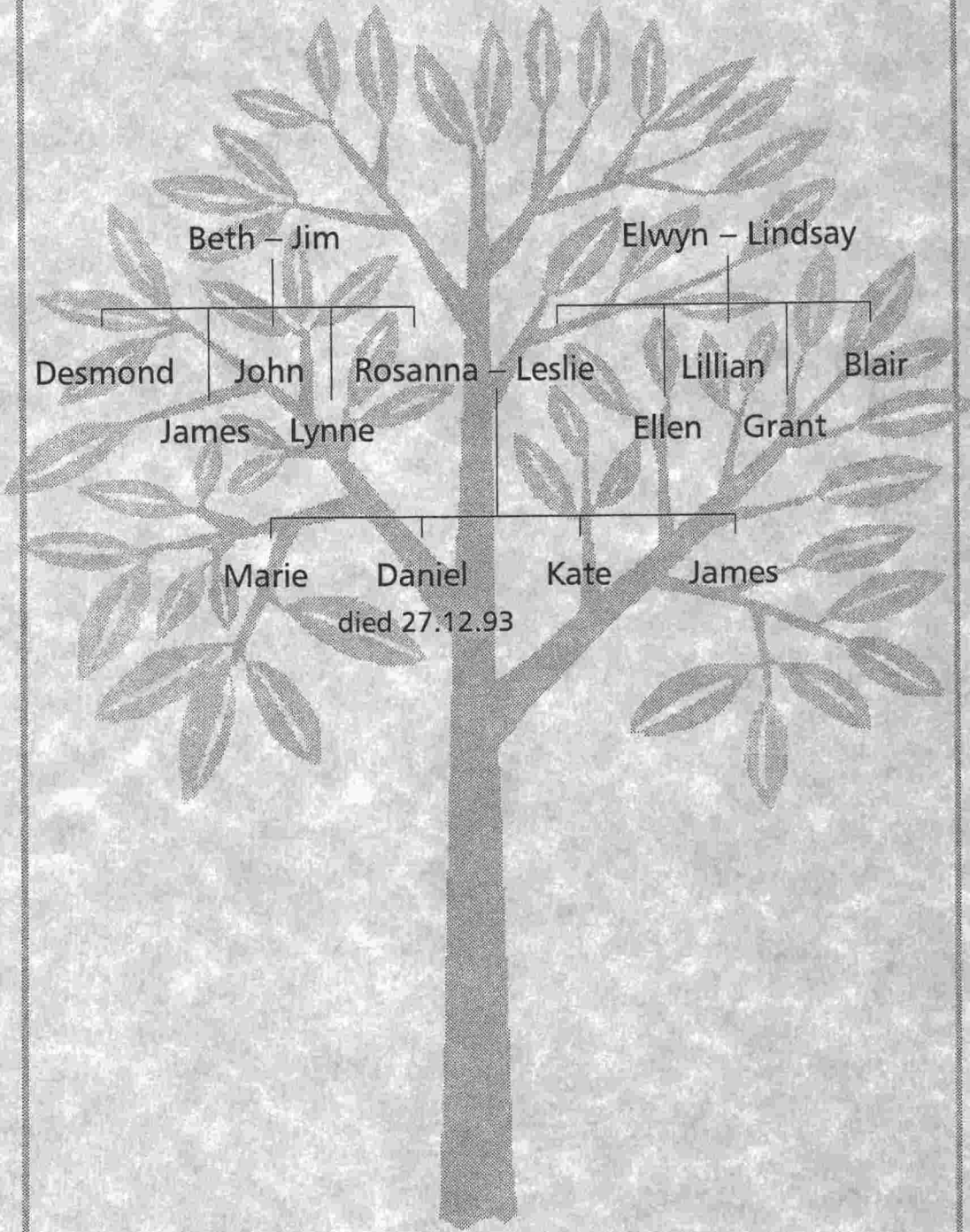
It is 2 years now since Conor died. There are still times where I have this great feeling of sadness, momentarily perhaps. It doesn't last all day but you just feel very sad and think, "Why does it have to be? Why did it have to happen?" There is always that IF ONLY. If only we could have done something differently but there was nothing that you could do, it just happened. When I see articles, magazines or things on TV where a child has been saved or a person has been saved and they are expressing what a miracle these things are, I think, "Why couldn't we have had a miracle?" But death is so final, isn't it? There is absolutely nothing you can do when it happens, just that finality of it.



# Daniel died aged seven and a half months

These are the stories of:

- Elwyn, who is his paternal grandmother
- Beth, who is his maternal grandmother





## ELWYN'S STORY

### About us

I grew up in South Otago. I was born here in Balclutha and when I was nine years old, that was during the War, Mum and Dad shifted to Edievale. At 15 years old I left school and I was at home because there was nowhere to work. However, people would ring up and say, "They were going into the maternity home and having a baby and could they have Elwyn for a fortnight or so, to help them when they came home?". I went on to work in a knitwear factory before marrying Lindsay - he was working on a farm at Dunrobin - so I had all my children there. We had five children, two girls and three boys. Soon after our 25<sup>th</sup> wedding anniversary Lindsay died. My eldest girl lives across the road and they have three daughters so you can imagine the thrill with my first grandson and then my second grandson - Daniel. Daniel was the second child of my son Leslie and his wife, Rosanna. Their first child, Marie, was 18 months old when Daniel was born. He was born prematurely at 24 weeks. He was cared for in the Neonatal Intensive Care Unit where he fought respiratory problems and infections. Eventually, at the age of seven and a half months, when plans were being made for him to go home- he died suddenly. Two years after Daniel died Rosanna and Leslie had Kate and then 18 months later James was born.

### When Daniel was born

It was a traumatic time when Daniel was born, all the time that Rosanna and Leslie spent with him. But I admired them terribly the time that they gave to Daniel and the time that they made sure that Marie got to make up. I sometimes wondered how they ever did it, but Rosanna is a great wee mother. Leslie surprised me too, when I saw him caring for Daniel. It really quite amazed me what he was doing and quite capably and he learnt to know exactly what was needed to care for Daniel. It must have been dreadfully hard for them - to cope with all that. I have had one or two traumatic times with my own children but not like that. When I first saw Daniel I didn't know how such a tiny little person could survive.

Daniel was such a lovely baby and that was the hardest part for me, for me to understand. Because at times I used to look at him and think, "You look such a healthy baby". There was another thing, too, one day when I went to visit him and Leslie was nursing him in the wee room where we used to go, as I walked to the door I

thought "Oh". The way he was holding the baby Daniel looked so much like Lindsay's sister and it was then that I realised how much like his grandfather, Lindsay, he was. That was, special to me, too, and I think that was another thing I was sad about when he died because I suppose, in a way, he was bringing Lindsay back for me. I'm sure he was you know. Just the same colouring and his chin the same.

Running a business here [80km from Daniel's hospital] it was hard to visit too often. I certainly made the effort to go when I could. When I could not go to see him I was hungry for any little thing that was improving and then you would hear that something wasn't quite right and your feelings would plummet. I just felt that the longer he lived, the better his chances were. It seemed to me, I couldn't believe it when he had lived for so long, and it was just a week before he was going home when he died. I couldn't believe it when Leslie rang and said, "We think he is not going to make it". I really couldn't believe it that we had gone through all that time and that happened. All we had been through and look at the devotion and, you know, it really was hard.

#### **At the time Daniel died**

I maybe felt, "Why did it have to happen?" and probably, "Why it needed to happen after so long?" and of course the loss and what the loss meant to Leslie and Rosanna and just the general sadness of knowing that Daniel wasn't going to grow up. Babies like Daniel really haven't had a fair chance at life, I guess, but I still can never get over that feeling that it is God's will.

#### **Daniel's funeral**

After Daniel died, Leslie rang me up to see about whether Daniel could be buried with Lindsay. That overwhelmed me but I was so thrilled by it and I think that meant an awful lot to Leslie that Daniel could be buried down with Lindsay in Balclutha. I had to find out about whether Daniel could be buried there, because the plot is for Lindsay and me, where I am to be buried when I die. I was so thrilled to find out that Daniel could be buried there, really I was. The funeral service itself was a totally new experience for me. Rosanna and Leslie had Daniel at home after he died and that was totally new, totally new, but so different, but so nice really. At the service, the casket was open and I have never ever experienced that before and everybody who wanted to, were able to say good-bye to him. When I think about it, probably that service did an awful lot for me, you know the way it was done. It did help my grief for Daniel and

Lindsay and it was tremendous really. And I think, too, that having Daniel buried in Balclutha made Daniel that wee bit more special in a way because he'd been in hospital for so long, that you know so few people had really seen him. One of the things for me was that, whilst I did actually get to hold Daniel, I wasn't really ever involved. Whereas even if he had been a little bit older and if he had got home and I'd been there I think that would have had more impact on me.

In terms of organising the funeral I'm pretty sure that Leslie, and Rosanna too, would have asked if there was anything that I could do. I know there was one or two things that I offered for Rosanna at the time of Daniel's death but it was all organised and in that situation you have to leave it for a parent to do, because often that is helping them to deal with it.

### **My feelings**

I guess my feelings about Daniel are still that sadness for Leslie and Rosanna would be my strongest feelings. Probably because that gap is there, and it will always be, there in their family. While Rosanna has had another baby, Kate, since Daniel and has another baby in her arms that gap will always be there for them. Nothing can change that. I guess that is true for me - I was aware of that from my own miscarriage. I don't think about my miscarriage very often; but I have wondered what sex it might have been or how the family would have been changed if that baby had been born. But once again, you can't change anything. You can't think too much about what might have been. I think in the long run you might end up making yourself unhappier.

When I am trying to help somebody I like to do practical things. But at the times like Daniel's death, you really want to do something that's going to help to take their pain away, yet there is nothing that you can do except be there. Be there when you can and be as supportive as you can. You just feel as though you wish there was so much more that you could do to take away Leslie and Rosanna's pain but you can't.

I often think, when things are inevitable, I just usually bear up. I just buck myself up and go forward and I try not to cry. I suppose because I tend to feel that you make it harder if you dwell on things, so probably, in some ways, I push things aside, which maybe isn't right but I guess it's my way of coping. I think I learnt this after my husband died. He died so suddenly that I really had no time to think about him. We had

a wee farm, my younger son was only 12, Leslie was an older teenager, my older daughter was married. I was working full-time as well as trying to run the farm. So I probably didn't have any time to think too much about Lindsay's death. Although, I remember one Saturday morning when I was up in the bedroom making my bed and the radio was on and a particular song came on and it was an older song and I just burst into tears and it was just the song itself and the words. I suppose those sorts of things happen and they're probably good for you.

### **Counting Daniel in the family**

When some-one asks me, "How many grandchildren do you have?" I count Daniel now. It was actually something Rosanna said that made me stop and think. I just became a member of Probus<sup>18</sup> about mid-year and I had to give my profile and I went quickly through my life and I said I had seven grandchildren. I gave it to Rosanna to read and she actually pulled it up that I had missed Daniel out. Underneath it was probably because I didn't really know how to treat something like that and probably felt, "Well, I've got seven". And I understood how Rosanna felt and I felt bad about it because it was almost like when she was reading she'd be thinking, "Oh, he meant nothing". That was how I felt she might be feeling. So, I think of him still as a grandchild now - but it just took that to make me think about that and realise. Since then when someone says, "Oh how many?" I say, "I've got seven grandchildren and I lost a little grandson at seven and a half months". That sounds normal - good explanation. They might say, "That was sad" or something, and I would say, "Very". You can make it sound OK.

### **Reflections on Daniel's death.**

Sometimes you think about what might have been and I know that I think if Leslie never has another son, what it will mean for him, because I know how I'd love another grandson and I know what Daniel meant to Leslie as being his first son. I know how much he'd love another son. So I feel for him. [**Postscript**- Rosanna and Leslie had a son, James, the next year after this interview]. But I guess that there are different times since Daniel's death that something will occur and you think "I wonder what he would be like". Or with James being born and you think about their ages and you automatically think about Daniel in between and you can't help but think about, "What if?" or, "What would he be like?" I think that we do get to accept it.

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<sup>18</sup> Retired professional and business women's group.

**Lindsay and Daniel's deaths**

People used to talk about working through your grief and there have been times when I wondered if I actually worked through my grief when Lindsay went. I know that I just threw myself into work and I wonder if I pushed it aside and didn't really deal with it. And of course, that would be my most traumatic loss. I guess with Daniel, I was more able to accept it. If I had never had lost anybody before maybe I wouldn't have been able to accept it as well but probably, when you have been through it before you do learn to accept it more easily.

*For Elwyn, an angel symbolises Daniel.*



## BETH'S STORY

### About us

Having married and had our family at a young age, family life is important to me. Now, five children and nine grandchildren later, we assume we can sit back and enjoy the pleasures of being grandparents. But life is not that simple. Rosanna, our daughter, and Leslie, her husband, were looking forward to the birth of their second child to be born in 4 months time but Daniel was delivered prematurely at 24 weeks and cared for in a Neonatal Intensive Care Unit (NICU). Rosanna and Leslie were preparing for Daniel to come home from NICU, when he died suddenly.

### When Daniel was born

Daniel was born just before we were due to go overseas to work for three months and it was very difficult having to leave, but we were very hopeful that everything would be fine. Rosanna was able to nurse Daniel in hospital, but it was very difficult for her having to be a wife and mother at home and nursing Daniel at the hospital. Not being there to help and support was very hard, as you feel very strongly for your own child and I knew Rosanna was suffering so much. I knew that, because of Rosanna, Daniel was getting the best care he could ever get. I felt very strongly for Rosanna as I could see the stress and pain she was going through, trying to ease the rest of her family's pain and keep day to day things running as smoothly as possible. While at the same time spending as much time as possible helping with Daniel's care in hospital. Daniel was a dear little person to us and he had Rosanna there looking out for him, making sure he had everything he needed. I guess not being there to support them when there was a need was how I felt about my situation. When we got back from overseas we would spend time with Daniel. He loved being nursed and he loved being sung to. That was special to me. Short as it was, that is how I remember Daniel. Because Daniel was in hospital all of his life, the family probably didn't get to know him as much as if he had been at home and in the family environment. There are lots of lovely little memories, like photos and Rosanna has given us a video of his life in hospital and, because we didn't see him a lot, that is really special. It is because of Rosanna that there are so many memories for such a short life. She is pretty special. I think I have probably told her that as, a while after Daniel died, she said she didn't feel that she was special.



### **After Daniel died**

Rosanna organised the funeral the way she needed to and that for me was good, because I knew she was doing what she needed to do to work through her grief. I just tried to support her in what she wanted, and she had lots of loving friends and the medical profession who were very supportive. Being there with the family, I took the role of looking after the family so that Rosanna was free to do what she needed. My role was supporting Rosanna and Leslie. I felt that the parents of Daniel were going through enough, I didn't want to add to that burden by talking about my feelings. Leslie is a quiet guy and he is somebody who I felt needed a bit more support than he allowed people to give. Rosanna often said to me she used to get really upset with people saying, "Oh you are coping so well" and she said, "I'm not".

### **Memories**

Mechanical things symbolise Daniel for me. Seeing Daniel at home after he died, dressed up in his little suit with his little spanner in his pocket and a little car. Daniel's Dad is a mechanic and I always thought Daniel looked very much like his Dad.

### **Changes in the family**

I think if anything Daniel's death brought us closer together. We are a pretty close family anyway but I think anyone living through something as traumatic as that is drawn closer together.

### **Other grandchildren**

One thing I do feel is hard, is that we have another grandson born virtually about the same time that Daniel should have been born and so he is now the age that Daniel would have been had he not been premature. I think that must bring up feelings for Rosanna of what Daniel would have been like had he lived. For me, as Rosanna's mother, it is just the long-term thing of seeing Rosanna and her family through. Now they also have Kate and James, both born after Daniel. A lovely, little family.

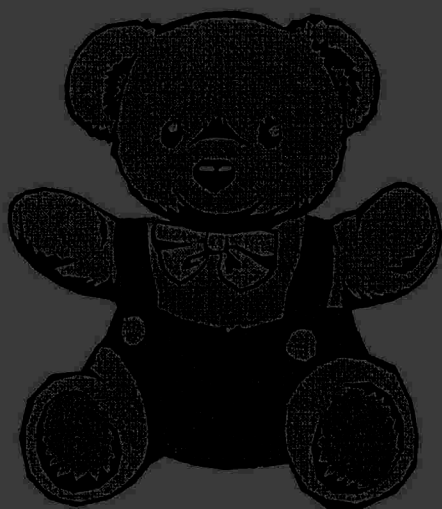
### **Reflections**

I think it makes it more difficult for nurses like Rosanna, who have an ill child, because they feel that, because they are a nurse and it is a medical problem, "I'm here to win this battle". But of course there are things in this life that no matter how hard you try- they are not meant to be. That, for me, made it really hard. I guess every Mum is the same, it is a very personal battle for them.

I often wonder WHY Daniel died but that is a very normal thing. Definitely you do grow from these things because you learn probably when someone else is in a similar situation like that you learn a lot of what to do and say. Being there is most important. It is a learning curve, trying to help other people. Like Rosanna said, there are some people who are quite close friends but didn't get in touch because they didn't know what to say. So that is a major part of what I have learnt. It doesn't matter what you say, you need to be just there for them. I feel now if someone close to me lost a child I wouldn't think, "Should I go and see them or shouldn't I?" I would just go. Saying, "I understand" to someone who has had a child die is not something I would ever say because there is no way I can understand. The closest I could come to 'understanding' is that I feel losing a child is the greatest loss that anyone could have and if you haven't lost a child you cannot know what it feels like - you can only know it must be totally devastating.

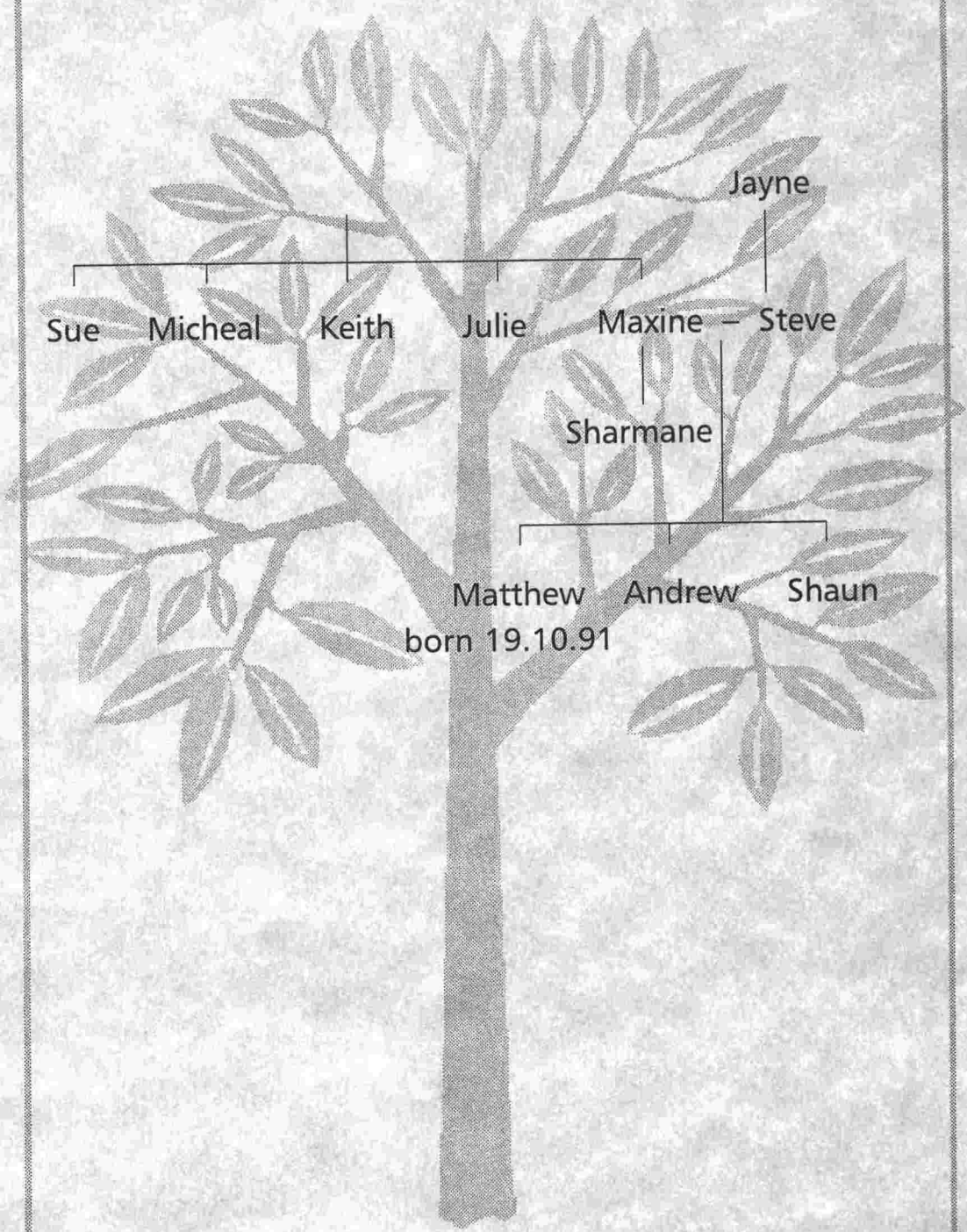
I realised after Daniel's death, that grief is a very personal thing. Individually different for everyone, with the common bond of loss and emptiness. When I think about Daniel now, 5 years after his death, I am comfortable with the memories. He has had his little life. He lived his little life, short as it was and that is how I remember him.

*For Beth, a teddy bear and a spanner are what she thinks of in relation to Daniel.*



**Matthew died aged eight and a half months**

This is the story of his mother, Maxine



## MAXINE'S STORY

### About us

After surviving a first marriage breakdown - bringing up my daughter by myself - living by my rules - I felt confident and secure with myself. Two years later, I met my second husband, Steve, who had been married also. We fitted the look, of being a family. I became pregnant and we were overjoyed. I had a good pregnancy - natural birth this time with Matthew, last one, with Sharmane, was a "C" section<sup>19</sup>. I breastfed for only three weeks then Matthew went on the bottle - I felt tired but I felt I was the luckiest person alive. I remember saying to myself once:

" I have a wonderful husband/partner

A beautiful, lovely daughter

Our own house/transport

**PLUS** A cherished, beautiful baby boy

I AM the luckiest person out

Surely it can't last, it's too good to be true.

AND IT WAS!!!

### My parents and Matthew

Well, they were really good when Matthew was born. Dad would hold him, which sometimes he hesitated to with the other grandchildren. Mum had always said to me, she wouldn't babysit any of her grandchildren until they were over a year old, so you knew not to even ask her. She was always worried that something would happen to one of the other kids because of her son, my half-brother, Micheal, who died as a cot death. You see, after my father died my mother met up with my step-father and they had their first son, Micheal [he died at 9 months of age as cot death], then my other brother Keith and then my younger sister Sue were born.

### Matthew's death

When Matthew died I remember having to ring my parents up and I was so pleased that Mum didn't answer the phone, though I wouldn't have spoken to her, I would have asked to talk to Dad. And I remember just thinking, "Gee, I've got to tell them". Because after what had happened to their own son, Micheal, it seemed awful that Matthew had died. When I look back, it was a bit unfair for me, because I sort of had to worry about what Mum felt so I had to be a brave girl not to upset Mum but then, at

the same time, she was worried, she wanted to make everything better for me and didn't know what to say. So it was a bit of a scene really. I remember, I blurted out and I said to Dad, "Matthew's dead" and I remember he said, "Oh hell". Then because Sharmane, that's my six year old, was staying with Mum and Dad, we had to go out to collect her and I said to them not to tell her until I got there. And I think Mum sort of freaked out when Dad told her and it's a wonder that Sharmane didn't hear it. When we got out there, Mum just rushed out and wanted to cuddle me. I remember having to tell Sharmane and that was sad. Seeing her trying to understand what it all meant and that sort of really broke your heart having to, trying to, explain to a wee kid, "Well, you know when you left him yesterday that was the last day you saw him". I remember Dad said to me, "Come and sit on my knee" and I felt like this wee girl again who had to be cuddled by Dad and it was really nice he actually showed affection and put his arm and cuddled me in and gave me a pat. It's the first time I've seen him show affection which was really nice and I think it sort of made us a little bit closer because I knew that he was really hurting.

### **When my brother died**

Actually I was probably not quite four and my other two sisters, they were about seven or eight I think, or maybe just a wee bit older. My older sister, Julie, she actually found Micheal. She went in and he was down under the blankets face down and as she found him Dad actually came in and he sort of, "What the hell have you done?" type of thing - you know blaming her. But he never told Mum that the kids had actually found him because it really freaked them out. Mum always thought she did something wrong because Micheal had vomited so many hours or whatever before he died and she'd always held this guilt. After he died, apparently Mum just lost it; she went hysterical I've heard. Just people, since Matthew died, they let me know little things. Actually I reckon if my parents had talked about him, Micheal, I probably would have remembered him because it was a closed book, apart from as a four year old you say what you think and you say "Where's the baby?" all the time. But like my younger brother Keith, who was Micheal's real brother, he didn't know he even had a brother. He only found out since Matthew died that he had a brother. Even though it was open knowledge we just didn't talk about it - the rest of us knew and so he was quite upset

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<sup>19</sup> Caesarean section delivery.

that his brother had died, "Why didn't someone tell me?" He was 24 before he knew.

After Micheal died, apparently Mum screamed and they actually drugged her up so she lost a couple of days along the way. People got rid of everything for the baby, everything went to the Salvation Army so when she actually came round his stuff wasn't there and you just didn't talk about it. When she had other children she was always very protective - she is, even now, of the grandchildren.

#### **After Matthew's death**

I didn't really want to be round Steve's parents after Matthew died. When I came back after seeing Matthew at the undertaker's, I just stayed in my room and Steve stayed out in the lounge with his family. I think because I smoked I felt this tremendous guilt that I'd killed Matthew maybe. And I just didn't even want to look at them. I remember people made me cups of tea. I didn't want anything to drink. I was just sitting there with a few friends having a smoke and not knowing what the hell to do. Mum was bringing a cup of tea and it was foul; she used half a cup of whisky in it. She kept trying to fill me up with whisky and she said it wasn't her and that it was Steve's mum, Jayne, who was making the tea. I actually said to Jayne a wee while ago, "Did you keep putting whisky in my tea? She said, "No I didn't". So it was my mum trying to drug me up to try and make me feel better. She didn't like the fact that that's what had happened to her so why was she trying to do it to me? She obviously thought she couldn't offer support so have some more whisky instead.

We actually got Matthew christened the day before he got buried and Sharmane, she'd never been christened herself, as well. So, Sharmane and Matthew got christened at the funeral parlour, which was really different. Not many kids get christened there. And Mum and Dad came along. Dad didn't hold Matthew but the fact that he was there all the time was really good. Mum held Matthew heaps of times, and I've got the photos. I've got photos of everyone holding him. I think that really helped Mum therapy-wise because she wasn't able to do that with her own son. And just being able to hold him and cuddle him, you could see like three griefs there for her; for her own son, her grandson and for me as well. I remember looking at Dad. They have nice photos of pictures down at the undertaker's and he was just sitting there staring at this one picture for over an hour, with hands in his pockets just looking at it and crying. He was just bubbling looking at this picture and I went up and he cuddled me. Whether it was just



because, at the time, we had both been through the same thing and he was hurting so much and he knew how I was hurting and it clicked maybe. It sort of brought us quite close and I finally really knew what Mum and Dad had been through in a sense. But at least we, Steve and I, were able to be a lot more open about it than they were and do what we wanted.

### **Talking about Micheal and Matthew**

Because I knew that Mum and Dad didn't talk about Micheal I thought, "Well nobody is going to stop me talking about him". I wanted to know as much as possible about what they knew so that I could compare it. I actually made them talk. I'd go and see them and I'd ask them how they found Micheal and how he'd been and actually got them talking together. They didn't know but it was a wee bit of therapy there, too. When I left, Dad wouldn't talk to Mum about it. It was only when I was there. So that's why whenever I was there I thought, "Well I had a right to talk about it now" so they couldn't shut up when I was there and keep me in the dark. I made sure that I asked questions that Mum wanted to ask Dad. So that way Dad would have to answer me, he felt obliged to and that way Mum actually found out information about Micheal or the autopsy or stuff like that, that she wasn't able to ask. I don't know whether asking the questions was healing for me. It was inquisitive basically to see what we had in common. It might have been healing back then but you look at it now and you are trying to help everyone except for yourself really.

Mum talks about it a lot now and she's pulled out Micheal's baby book and things and Mum and Dad actually went and saw him (his grave), I think it was last year, in Christchurch. When we shifted away [after Micheal's death], they never went back, so that was quite good. Mum goes out to the cemetery to see Matthew, because it is on the way to where they live. She goes more than I do probably. Like she said, going to Matthew's funeral was also like saying good-bye to her own son.

A lot of things have come to the surface that Mum sort of kept behind and I'll say things quite friendly to her like, "You can't keep it back and we have to talk about things". It took her ages to try to come to terms with things. She talks about things a lot but I still find that she doesn't listen any more, whether that's just because she's so involved in what's going on in herself. She'll listen to some things but if you want to

have a good decent talk she'll always relate that to her own feelings or she'll cut you off and change the subject without even knowing it. So that's quite hard, I think.

### **Going to meetings**

Well, Mum came along to some of our Cot Death group meetings and then, when I got involved in The Compassionate Friends, I got Mum to come along as well. Dad wasn't into that but because of Mum going there and talking, she'd go home and have to talk to him, which let them open to talk to each other about thing. So I think that helped a wee bit. Mum's been to a few of the group meetings and Dad goes along to all the Candlelight Services. Having Mum at The Compassionate Friend meetings has been a wee part hard, because it's quite hard for me to talk in the group if I want to talk about her and she's there. Or even talking about certain things that you don't think she might be able to cope with. It would be different if she heard someone else talking about it, but her own daughter saying it.

It has just been in the last two years that Jayne, Thom's mum, has come to the Candelight Service. To start off with I didn't want any one there. I just wanted it for myself. The first year I was a blubbering mess and I was just about hyperventilating. I hadn't cried for such a long time and I hadn't cried like that at all and it all came out. Then the next couple of years Mum started to come. That was quite hard because I wanted it all for myself, as something that was precious to me. Then at the same time I was feeling selfish because Mum should have something like that as well. So Mum would come along and then I would feel like I had to be big and brave. I didn't want her to see me upset because then it would get her upset - oh, it was stupid. The last two times Jayne has come and I sat with her, not Mum and Dad, because Steve couldn't come. Jayne and I, both, went up together to light the candles and she also lit one for her father. We got talking afterwards and she really enjoyed it. I sort of never told her that we had been before - I never said, "Would you like to come?" It was like my time because I had given out to everyone else and I needed something of mine. But it is still hard to cry in front of them, just breaking down the barriers I suppose.

### **"Being Strong" - my feelings**

I had it at the back of my head - I was a wee bit paranoid - that Steve's parents would blame us that we had failed, that is how I felt. You see them as a perfect family! Every family is not perfect and they have their squabbles. I just felt that I had failed being a

good parent and so did Steve. We actually talked about this a couple of weeks ago and he, too, felt the same that we had failed to give them their grandson. I always thought that they would blame me because I smoked. That was why, when we came back here from the funeral directors and they were all out here, his family, I didn't want to look at them - I just stayed in my bedroom. Steve's family have never really had anyone close in the family die. They just all come together - that's family. It was really hard to actually handle because in our family, they will always be there - but it is hard to explain, the support is not built the same. Like me having to worry about my mother and my father whereas Steve's family's building blocks are actually stronger. That's how I see it. It was only just a couple of weeks ago that I had Steve's mother and father here for drinks and we were talking. It has only been in the last half year that we actually talked about things [to do with Matthew] and how I felt. Now, Jayne is actually game enough to ask questions because, before, she always thought it would upset me. And I was always upset that she didn't care enough to ask anything. Jayne wanted to ask a question and that question led to a lot of other questions. She asked me really interesting questions, quite important ones because she was just trying to understand and because she wanted to know why I didn't cry. They always said to me they admired how strong I was. That makes it really hard on me now because, if I do feel upset, I feel like I have to keep up with what they think I am. I had to be strong back when Matthew died because of my mother; if I went to pieces she wouldn't have handled it, she wouldn't have coped. So my in-laws saw that side of me and thought I was so brave and didn't cry at the funeral at all. Now, when Jayne wants to ask something she'll just come straight out and ask it. I always feel better when people do that because then there are no barriers and you know that you can be honest and straightforward. I said a few things to her that I've never said to anyone else and it made me feel really good to say how I felt. And she said, "I can understand that - well understand why you want to feel that way." That actually felt quite good.

### **Remembering Matthew**

I remember the second or third year after Matthew died, I wrote a poem about him dying and put in the first couple of sentences about how "No one mentions your name". I only put it in there, not to offend Steve's family or my friends, just to give a nudge to people who possibly it did concern. The ones that it did concern and upset are the ones that it should have. You know what I mean, if people talked about Matthew then that part of the poem wasn't going to upset them. It really upset Steve's parents

and they actually rung up and said they didn't like the start of it and I said to Steve, "Oh well, they must have taken a lot more meaning into that". So obviously that sent waves through the family but Steve didn't mind he thought, "Well this has got them thinking" because they never mentioned Matthew's name.

### **Andrew**

Andrew was born a year after Matthew died. My parents are close to Andrew. Actually my mother even babysat Andrew after he was born. He had a monitor<sup>20</sup> and she babysat him and he was under a year old; at seven or eight months she looked after him. And I think that having a monitor she felt safe and she liked to have it beeping which I couldn't stand but she felt safe having it beeping and even Dad would come and babysat with him. So, if anything happened he knows how to resuscitate and you know my mum made Andrew really special. She'd lost her son and I'd lost mine. It was a wee bit scary actually because to her it was like getting her son back. Quite strange. And that "specialness", she didn't do that to Keith, her own son. Even my Dad, he's quite close to Andrew too. They're still quite firm and fair but it's different.

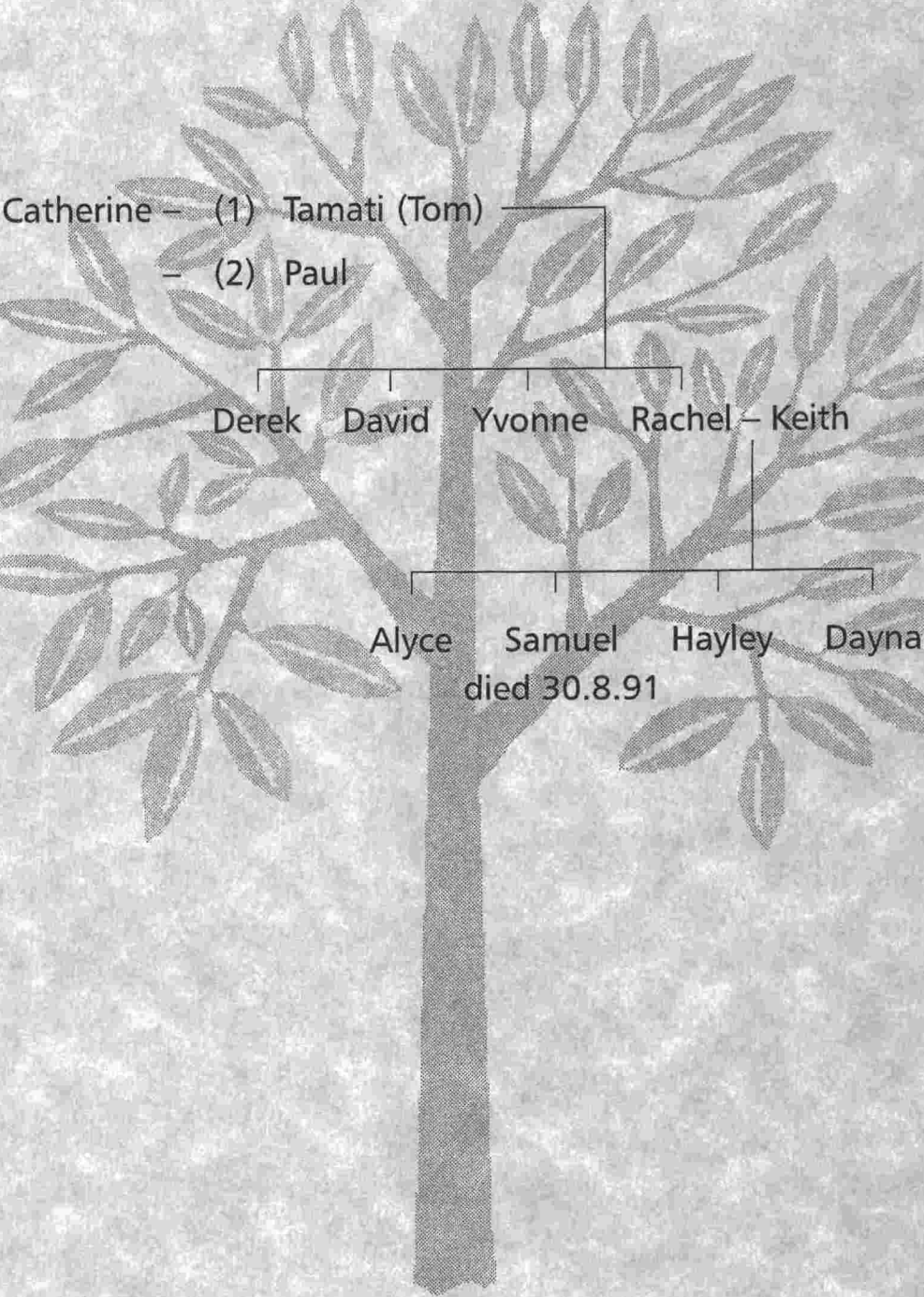
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<sup>20</sup> Apnoea monitor which makes an alarm noise if a baby stops breathing for more than about 20 seconds.

# Samuel died aged nine months

This is the story of his family:

- of Rachel, his mother
- of Catherine, his grandmother and Rachel's mother





## RACHEL'S STORY

### About us

Keith and I have been married for ten years and have four children; Alyce, Samuel, Hayley and Dayna. Samuel, our second child, died of SIDS at the age of nine months in 1991. We have had two subsequent children and this was a very stressful time for us. Six years after the death of Samuel life has become bearable again. I am now in my second year of a midwifery degree and am thoroughly enjoying it. I chose this career in the hope of making a difference to the lives of our babies.

### Samuel's death

Samuel had been crawling after me with the lux<sup>21</sup> in the day and he had a good feed in the afternoon. Keith had got home a bit later that night. Samuel had his tea and we hadn't had our tea so we popped him off to bed. And, "No, that didn't work" so we had our tea and got him back up and gave him his bath. We put him back to bed, that must have been about half past seven, and he didn't want to go to bed so we got him back up again. It wasn't unusual for him to do that. He was quite happy when he was crawling round the floor and I remember he was chasing after a red balloon. It was about nine o'clock I think that we put him back to bed and he still grizzled. I can remember that I was reading my book and it was very exciting. So I said to Keith, "You go back up to him" and so he went up and tucked him all back in again. We had an intercom and it wasn't going all the time, we just switched it on to see if he was sleeping, and he was, so that was about quarter past nine.

It was about ten that we went to bed and I went into check Samuel, Keith went in to check Alyce. I called out to Keith to come and have a look at Samuel because he was on his stomach up in the corner and it was the first time that he had done that. I thought "Wow, he's gone to sleep like that" so I said to Keith, "Come and have a look". But he took too long and I thought, "Oh well, I'll just turn him over". So I went to pick him up and went to turn him over and he was just very floppy and didn't wake up and I remember I put him on the bed. I must have yelled for Keith before he came. There was probably lots of yelling or whatever and I think I might have said to him, "He's dead" or whatever. Keith grabbed Samuel and I just went straight to ring the

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<sup>21</sup> Vacuum cleaner.



ambulance. I hung up from the ambulance and after that rung up Mum. I thought about it afterwards, "I wonder why I did that?" but I did and that was good.

I went back in there and did CPR<sup>22</sup>, Keith had started it already. I did mouth to mouth and he did the compressions and he was blue around his mouth but he was warm and he didn't really feel like he could be dead. He had been sick. There was just a bit of a brown coloured sick, so I knew that wasn't right. We tried to find the pulse but we couldn't because he was dead. It was really hard to think that maybe if he wasn't dead then I had actually killed him by doing the CPR. So Mum and Paul [her partner] arrived, and Mum rubbed Samuel's feet. He must have had cold feet or something. It seemed ages before the ambulance arrived and as soon as they arrived there was a man in the ambulance car and he [the ambulance officer] came in and I said, "Hurry up, hurry up". I sort of thought once I stopped doing the CPR he should go straight in and continue CPR. Then he asked me to leave the room, which I am really annoyed about because I don't know what happened. I wasn't really hysterical, I know I said, "Hurry up" to them but I wasn't really that bad. I don't know if Mum stayed in there but I know that Paul did and Keith had walked out as soon as they arrived. Mum came back out and said that he had died. That was the start of our nightmare. It was hard to believe. I couldn't cry. I hyperventilated and I'd never done that before. While I was doing the breathing I could feel my hands, legs and feet go all pins and needles. I think Keith started phoning people and saying he had passed away. I was annoyed about that because he didn't "pass away" - he died.

They were trying to get hold of my doctor but they couldn't because he was away so the ambulance men got hold of the police and they told us the police were going to come. They arrived, I wasn't really very happy with them either. The man was just a young guy who stood in the corner of the bedroom. I can remember him saying, "Has anybody moved that baby?" Stupid man. I know now that he was probably nervous but at the time, it wasn't really very good. There was a police lady and she asked me what position he was in and I sort of felt really guilty that maybe I had done something and I wasn't sure whether to show them where the sick was, but I did. It was a feeling, "What are they doing here?". I thought, "Oh my God, what have I done?" and I went out. Then they asked for somebody to identify the body; Keith's brother was there at that time so he went down and did that.

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<sup>22</sup> Cardiopulmonary resuscitation – commonly known as mouth-to-mouth & heart massage.

Suddenly, this yukky man in a black suit with a beard was standing in the doorway. He didn't introduce himself, I mean, I didn't know who the heck he was. He was actually an undertaker, come to take Samuel's body to the hospital for postmortem. And it seemed not long after that the police were called away to something else, so they had to go. So they put Samuel in that blue yukky bag and they wanted it buttoned up at the top before it went outside and I felt, "Why couldn't the man do it out there?" That was really distressing. We had a baby one minute and then he was gone. I didn't know where he was. I imagined Samuel on one of those metal slab things and it was also that he was alone, all by himself. That was really hard.

### **Samuel's funeral**

Samuel came home on the Monday after the postmortem and I'm really pleased about that. The funeral was on the Wednesday and lots of people came. Keith and I carried him into the chapel and carried him out again. I remember we carried him in head first and I wanted him to go out head first - I don't know why I did that. So we turned him around and so he went out head first. He was buried with Keith's mother. That was quite nice and Keith thought that was quite good.

### **Feelings for my mother**

Initially I was worried about her and I was really pleased that her sister said that she would come down from the North Island. That was really good, even though my mother would have Paul there. Of course my mother was all busy. I don't know what time she left the night Samuel died but they drove back early next morning, and were busy doing all sorts of things like cleaning and cooking. At that stage she told me she wished she could take the pain away. She did talk to me about her pain - that she felt for me. I can remember her saying, "If something was broken, when you were little, I could always fix it and I wish I could fix this for you". I didn't want her to feel like it was her fault - when it wasn't. She didn't need to feel like that.

After Samuel died I did not want to be parented or protected. But I did want to be with Mum. I used to go to Mum's house a lot after Samuel died. She wasn't working quite full-time, so I used to go there quite often. I felt, "Where will we go? - To Mum". That was where I felt comfortable - she'd talk about it whereas other people didn't.

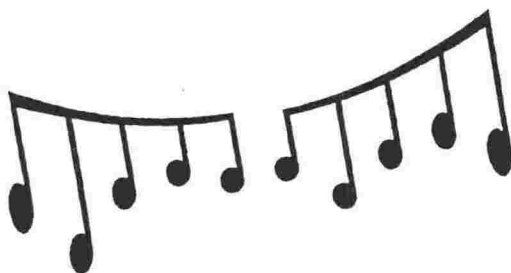
### Memories of Samuel

Clannad music definitely reminds me of Samuel. We played one of their songs at his funeral and I think afterwards I played that music quite a bit. It was really nice to listen to then but now when I listen to it, it is terrible. Even though I still like it, it brings back how I was feeling at that time, listening to it. And we also played a kid's song at the funeral. One which you hear quite a bit at kindy that Samuel used to clap his hands to. I think it wasn't really the best choice of music - it was "If you're happy and you know it clap your hands".

### Children after Samuel

When I was pregnant with Hayley, seven months after Samuel died, we wanted to have another boy and we had scans and found that she wasn't going to be a boy. Mum wanted me to have another little boy, too. We had good support when Hayley was born. Mum and Paul lived in their caravan on our drive whilst their house was being built, so that was really, really good. We came home with Hayley and Mum was there cooking things for us to eat and that was really good. I think Hayley was about two months old when they moved into their house, so they were really good support for us. With Dayna, we were a bit more used to having another baby.

*For Rachel, music played at Samuel's funeral brings back the feelings of that time.*



## CATHERINE'S STORY

### About us

I was born in 1941 I grew up in the North Island, had four children and now have 11 grandchildren. I work now as a counsellor. My daughter, Rachel, and her husband, Keith, had a daughter Alyce and then Samuel was born. He was a lively, active boy and then suddenly at the age of nine months died as a cot death.

### When Samuel died

It was four years ago that Samuel died. I had gone to bed, just almost dozing off to sleep and the phone went. I got out of bed and rushed to the phone. Rachel was on the other end and she said, "Mum, Samuel's not breathing what am I going to do?" I said, "Phone the ambulance". She said, "I have. Mum, I'm terrified". I said, "We'll be there". Now we live about ten minutes away, maybe less than ten minutes. So it was like, get up and throw clothes on. Paul and myself took off and broke all the speed limits getting there. We went in there and Rachel and Keith were doing mouth to mouth. I went to help them but I knew as soon as I saw him that he'd gone. You could see that he had gone. But it was like we all got busy there, Paul took turns doing CPR and I was rubbing his wee feet. And his little feet were lovely and warm and it was like rubbing them and thinking, "Yes, yes - please breathe". You could really see he had his wee eyes shut like he was sleeping but you could tell that he had gone. It was the fear, I guess, the fear that was in the air was so strong. It was so frightening but they were doing what they were doing and hoping until the ambulance came and the man [from the ambulance] came rushing in and he put a thing in Samuel's mouth which I think is for breathing. I think he could see that Samuel had died. So then he said, "Would you go out and I'll see what I can do". So we all went out and Rachel and Keith were just holding each other. It was like for me, as a mother I think, you want to make things right for your children and comfort them and make things better. And I couldn't do that.

A little time passed, it was probably only a minute or so, but I went back up and the ambulance man said, "He has gone". I knew that and he said, "Do you want to tell them or will I?" And I said, "Well, I will. But first of all, we'll pick him up off the floor and put him back in his cot." So we did that. That was the hardest thing, was the reaction when I told them - just so agonised. The call, the noise that each of them

made. I guess maybe they knew, but they didn't want to know and, "Hey, someone had come and Samuel was going to be alright" and that was really hard. In one way I wanted to tell them, but it was a dreadful thing to have to tell them - I didn't want the ambulance man to tell them. It was probably the most dreadful thing that they have ever heard and it came from mother. I wasn't so much feeling for myself, even though I was feeling dreadful, but it was the feelings that I had for my daughter and son-in-law because I love them and we're very close. So that was a really hard thing to do to pass on such a painful message to them. I think the police most probably arrived very shortly after that but first, Rachel and Keith, they went up into the bedroom and they had a bit of time there but it was like not really knowing what to do. And for Rachel I think she was in a state of shock and so it was just looking and I guess holding Keith and crying. So then the police arrived. The policeman was just a boy, but I resented him being there. It was like, "What was he doing there in a place when there was grieving and loss?" and, "This is no place for a policeman". Yet I knew that this was procedure and that he didn't want to be there either and he was very uncomfortable. There was a policewoman as well and she seemed to be a little bit more comfortable, probably more competent than him. Keith was on the phone to his family to phone his sister and brothers.

Then Rachel and I went up to the room. Keith didn't really want to. He didn't want to be there very much at that stage. Rachel and I went in and I said, "Pick him up" and she said, "Do you think I can?" I said, "Of course you can" so we picked him out and we sat on the bed and we had a cuddle and a look at him and a feel of him. And it was like he was asleep and "Why didn't he open his eyes?" But for me it was like he'd flown, he really was not there. His little body was there but he wasn't there. So we had a cuddle and then by this time, probably, more family were arriving. Then it didn't seem that long and the undertaker came with his little bag. We thought about it later with hindsight. We shouldn't have let him go so soon - it had only just happened. I think it must have only been an hour or an hour and a half and he was gone. It is no time. If we had thought about it I would have suggested, I'm sure, or Rachel would have said, "We'll leave it till the morning" or, "Come back in a few hours" but we didn't. We allowed it to happen! It's like you don't know and I think the shock makes you a bit meek or you do what you're told. This man [the undertaker], who is probably a very nice man but he looked sort of evil, he wasn't the undertaker that we ended up

having. He was there with his bag waiting, and then he went outside and waited, but it was like he was wanting to be away. After Samuel had gone we suggested that Rachel and Keith just get away to bed and that probably they wouldn't sleep but they could be together. They did and we went home.

We were back there first thing and found that their little girl, my granddaughter, Alyce, was up and it was all very exciting for her. She was only three and it was all quite exciting and she was quite enjoying herself. It was, "Mummy don't cry, it's alright you've got me" and for Rachel most probably thinking, "Well yes I do, I love you to bits but I want both of you". Rachel had sore breasts because she was breastfeeding so she phoned up and made an appointment to see her doctor and he wasn't there. So they went into the Emergency Doctor that was in town and she got some pills to dry up her milk.

### **Waiting for Samuel to come home**

The waiting for Samuel was the dreadful thing. Samuel died on the Friday night and the postmortem wasn't going to be done until Monday. Rachel talked to the funeral director and said, "I'd like to go and see him and I need to know where he is". And he strongly suggested that we didn't go. He said, "It's not a very nice place to go - it's down in the dungeons". So that was a hard thing. I thought surely, it could have been arranged that they brought him out and put him in a nice little room somewhere that they could have gone and seen him on the Saturday because he hadn't had his postmortem then. That was really very cruel and we did some things about that later - I did. We were angry as well; a lot of anger was directed at the system. We phoned and we tried to arranged a postmortem for the Saturday morning but, "No, they couldn't do that". Apparently on some occasions it does happen, and we realised later if we had really pushed for it a little harder - Samuel had a little bit of Maori blood in him - if we had pushed that, it could have happened. Again it's like you do what you can and you don't know and no-one was really there to say, "You could do this or you could do that". Come the Monday he was going to come home about 2:30 pm. That was a really long wait and long weekend and a long day and I guess seeing my daughter and son-in-law without their baby. That was so cruel really. Everyone was quite stuck and it was like a month those two and half days and you didn't really know what to do.



**Samuel's funeral**

Samuel wasn't home very long really; the next day was the funeral so he was home for that night. He was in his cot, all tucked up in his cot, wrapped up in a shawl and the funeral director had said we can lift him out if we were very careful and just treat him like a newborn baby and watch his head. Rachel she wanted to do that but Keith didn't really want to be there. It was Rachel and I that picked him out of the cot but she didn't look at what they might have done with the autopsy and I didn't suggest it. I thought, "If she wants to, then we'll look" but she didn't ask. Then she talked about how she would like some hair, a curl. He didn't have that much hair but he had some curls down the back. So I said, "Well, I'll take them for you". She didn't want to because she knew there would be some stitching on the back of his head from the postmortem. Keith's sister and myself, we did that. We turned him over gently and it was sad to see all of the stitching on the back of his wee head. I don't think I would have wanted Rachel to see that. Liz [Keith's sister] and myself, we just nervously chatted to each other while we were doing it, but it was a very fearful time, I was quite frightened.

And then there was the dressing of him. We didn't dress him. I think, because when he had the postmortem the mortuary staff dressed him. I guess again we could have asked to be there but we weren't. Rachel found him the clothes and there were the little booties that I had knitted him. They were red and blue ones, real little boy's boot booties and so she had those put on him. I remember her saying, that the girl who was going to be looking after him at the mortuary said, "Do you want any of the clothes back?" and Rachel said, "No she didn't". Whether she regretted that I don't know, we didn't talk about that. And the shawl, he was buried in a beautiful knitted shawl that was given to Yvonne for her babies and she gave it to Rachel and said "Would you like to use that?" I guess she felt as a sister there wasn't anything that she could do but this was something that she could do. I guess we all thought that we were not doing anything - but just by being there you are. And I gave him a special earring. The death that had affected me most in my life before Samuel was when I was a teenager and my grandmother died. When she died I was given this lovely pair of gold earrings that I treasured and then I lost one. And for me it was like I needed to give Samuel something to take with him and so it was the other earring - from the person that I had lost and loved. I think I had been very lucky that my all family was still alive at that

time and so I just popped it down the side [of the coffin] somewhere and felt something needed to go that was mine. I was happy for the wee booties to go too - that was nice.

We had a Maori minister come because of that little bit of Maori blood that was there. It was more Keith really, he wanted some Maori words said. We had this Maori minister. He was lovely and he spoke the Maori words and farewelled him. And a song that Rachel and Keith chose at the end was really quite heartbreaking. It was one that Samuel had liked "Clap your hands when you're happy" and it was quite hard to sing. I don't know that many people could sing it really. I think probably what tore me apart too was Rachel and Keith carrying out the wee coffin themselves. They didn't want anyone else to do that, understandably. They wanted to do all they could for their baby themselves.

The day before Samuel's funeral Rachel, myself and my sister and Yvonne, my oldest daughter, had gone up to a really big, beautiful garden which was full of daffodils. The owner was a friend of my sister's and she phoned him and he said to come up and pick some daffodils. So we took up a lovely big wood basket and we picked the daffodils and that was a healing thing too, to be picking the daffodils and doing something. Samuel wasn't home, this was on the weekend and he wasn't there, so it was a purpose and doing something, picking all these beautiful daffodils. We had the basket by the graveside and you could throw in a daffodil or a snowdrop. It was lovely - before the earth went on there were all the beautiful flowers sitting on top.

### **Blessing the house**

Keith phoned me one night and said, "It's not really nice down here. It's a bit scary. I keep thinking I hear Samuel and things like that." I said, "Well, do you know what the Maori people do? They bless the house and they go about the house and they bless it. If his little spirit is still about maybe it will go fly away where it is meant to." Keith straight away said, "Yes, that sounds lovely we will do that". We phoned up the Maori minister who had conducted the funeral and he would be only too happy. There was Paul and myself and Rachel and Keith and Keith's sister and David, my youngest son. The minister came out and it was beautiful, really. For me, it was quite a healing thing and I think it was for Rachel and Keith, they really felt at peace. We started at the front gate. He was an Anglican minister and he had his Holy water and the Bible and he said, "You just follow me and you touch things as you go along". And he was saying

prayers in Maori right from the front gate and so we walked along and touched the gate and the fence and walked in the door. He opened up all the windows and blessed each room and went through the rooms, went through Samuel's bed and threw the holy water, went out and went up to the swing and the sandpit and all around just sprinkling the Holy Water. Then afterwards he took Rachel and Keith up to Samuel's room and really, he was the only person that could have done that, I couldn't have done it. It was like "He's not here any more" and he pulled the bed all to bits and he said "Make up the bed again, but wash all these things [Samuel had been sick before he died] wash all these things. You can make up the bed again if you want to and one day you will take it down. But he's not here." I don't think anyone else could have done that, because I think Rachel would have been really angry, but it needed to be done.

### **In the days after**

There were lots of visitings and phone calls and for me, in one way, wanting to be there a lot and yet feeling, "I can't be, they need to get on and they don't really want mother sitting there". So, lots of talking, lots and lots of talking about Samuel and "the remembers" and "the angries". Being angry with the system and what happened and it shouldn't have happened. I said to Rachel, "Well, what I want to do, if that's alright, I want to write some letters because I would hate this to happen to anyone else, it should never have happened. I need to write some letters". So Rachel said, "Yes, that would be fine and show me the letter before you send it". We did it sort of together. I sent three copies of the letter, one to the Coroner, and one to the hospital, which would have been the Chief Executive, and one to the head of the Police Department. I have a copy of the letter somewhere. Just expressing my grief and anger that what did happen was so distressing for my daughter and son-in-law and for the family; that it should never have happened. Then I had a letter back. The three people had a meeting and one person, the Coroner, replied on behalf of everyone that in the future they would see that on Saturdays there would be a change, with postmortems being done then.

### **Another grandchild after Samuel**

Well, we were living with Rachel and Keith at the time. Our house was being built and our caravan was in their driveway. Really, I think by the time we moved into our house it was "Phew" for them. But it was, I believe, good. We kept to our caravan and cooked our own meals and every now and then we would share meals and pool our food and either one of us would cook and have a meal. Again, it was like a sharing and

a family time and a supporting time. Rachel was pregnant and, for her, she was thrilled to be pregnant and yet maybe it wasn't quite real and maybe she was betraying little Samuel – because here she was pregnant again. We were living there when she went into the hospital and Keith phoned and told us that they had had a wee girl. We all knew it was a wee girl. That was lovely for me; it was so beautiful having a little baby but again it was quite strange with this apnoea monitor and not wanting her ever to be out of sight. I bonded straight away with the little Hayley; she is a dear wee soul. But I worried and if the phone ever went at night that just made me sick in the stomach and I would never let the phone ring at night.

### Feelings

I remember wanting to make things right for your child and not being able to and really feeling, I suppose, quite helpless and I was going to say isolated, but it was not isolated. It was really feeling like you are out on a limb because there was not much you could do except make the right noises and cuddles. At the time Samuel died I felt, not necessarily useful, that I was able to be of some help and I think that helped that feeling of helplessness. It was a little highlight when I was able to do something for Rachel and Keith, like a phone call. So again, it is like the parents wanting to help their children. When they are little that is what you want - to do things for them and see their happiness and pleasure in the things that you give them - so maybe it was even something like that but it wasn't about happiness and pleasure when Samuel died.

I remember that sense of shock and unexpectedness when Samuel died. I can remember the next day the milkman was coming and the paper was delivered and it was, "Why were all these things still happening?". Because the world had stopped for us, yet everybody was going off to work and just doing all of these things. And the really strange feeling of following the hearse while all the other cars and people were busily going about their business.

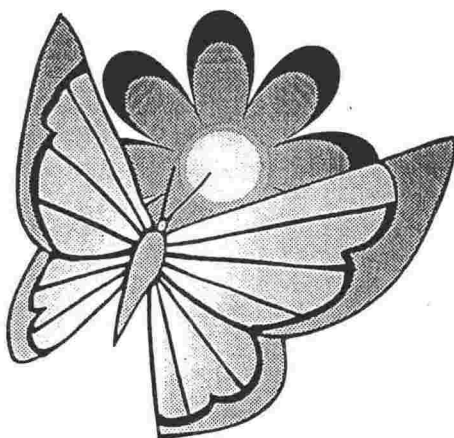
In my grief, I feel the loss of a little boy coming here to see me. The loss that he is not here to share the birthdays and the Christmases and the Mother's Days. But then the grief for Rachel and Keith when his birthday comes around and when the day he died comes around. And I guess Rachel looks at photographs, we have never said that, but I guess she looks at photographs and there is a space there for him – I must have a chat about that and see if she does - I am sure she does. But we talk about the table, that

there is a place missing and when we have them here for a meal, there is a place there for Samuel. Not actually there, but it is in our minds. Acceptance comes. The moving on, that life goes on. I think that it comes and goes in waves and that there are days when probably I don't think about him at all. I think they become further and further apart - there might be quite a long time whereas before that it was every day and several times in the day. So the time does heal and maybe before when the anniversary day was coming of thinking, "It's coming, it's coming, it's next week, it's a couple of days" and now it is like, "Oh yes it is here". I think about grief as I have heard some of my clients talking about it, that at first it is just so painful - it is like a knife turning - but as time goes on it is like a dull ache and not like the knife turning.

### Memories and mementos

I think that mementos are very precious, and precious because the memories are there. You can't take away the memories, so the mementos, like the photographs and the toys, are special because they help keep the memories alive. Or make them rounder or clearer because, at times, little faces can fade and you can think, "Am I forgetting what he looks like?" And then I think, for me, it is more memories than things. It is remembering the little things he did and the things we laughed about and the little adorable things more than the mementos. When I think of Samuel, I think of him as a baby. There are times, like when I look at the pictures and there is someone missing and I sort of put him in there in my fantasy or imagination. When I see the little family together and he is not there I put him in, as I think, as his age would be now. That has been from way back and so now he is the six-year-old instead of the three-year-old or the two-year-old. But, when I consciously just think of him it is as a baby.

*For Catherine, the blue-mauve scabious flower, often called the butterfly flower, with butterflies hovering above it, is a symbol of Samuel.*





## **Health / Bereavement Professionals working with parents and grandparents when a child dies**

These are the reflections of:

- Diane – a grief support coordinator with a funeral director
- Barry – a paediatrician
- Jane – a paediatric nurse specialist



## REFLECTIONS OF DIANE – GRIEF SUPPORT CO-ORDINATOR

My main observation from contact with grandparents who have experienced the death of a grandchild is the overwhelming sadness and concern that they feel for their own child - the parent.

### **Support for bereaved families and grandparents**

As grief support co-ordinator for a funeral director. I usually make contact with the bereaved family about 6 weeks after the funeral. About this time friends and the wider family have resumed their normal activities and the full impact of their loss is beginning to be realised. The support we offer depends on the needs of the family. Initially it is to affirm their need to grieve for their loss, to help them understand the grief journey they have begun and the effect this will have on their own lives and the lives of those they love. I often offer information about local support groups to contact when they feel ready and how to access professional help if this is required.

It is not usual for me to contact grandparents directly. I have literature written for grandparents and offer it to the parents to pass it on to them. However, grandparents who have family living elsewhere have contacted us because of their concern at not being able to be physically present for their child when a grandchild has died. They want to know how they can best help their child at this time and they also need to have their own loss acknowledged. Grandparents who have been caring for their grandchild at the time of death have made contact because of the great burden of grief and responsibility they carried for the child they loved so dearly. There are grandparents who have borne their pain alone because they wanted to "be strong" for their child and there have been times when a grandfather was reluctant to talk about his feelings and so his wife remained silent. In other families grandparents have been involved in the funeral arrangements and I have met them in our office at that time.

### **Different experiences of grandparent bereavement**

It may happen that the parents of the child withdraw from the grandparents for a while and this can bring feelings of abandonment and bewilderment for the grandparents as they struggle with the double grief they have. Or the parents can turn to their parents for solace and support, rather than sharing this need with a spouse or partner, which

can also cause resentment and hurt if the parent's parent is not discerning and diplomatic. Families often link together or move away emotionally after the death of a child; this happens in other bereavements too. "I should have been the one taken. I've lived my life" is a feeling expressed by some bereaved grandparents. However, in my experience this has been when an older child or young adult grandchild has died and the grandparents were older. With babies and younger children the grandparents are usually younger.

Nowadays when families are so mobile it can be hard for grandparents trying to cope with the death of a grandchild when friends and neighbours haven't met either the parents or the child. Then, it isn't easy for the friend or neighbour to comprehend the loss. They don't know the child who has died and it can be difficult for them to offer support and accept the struggle that the grandparents are having as they try to adjust to what has happened in their family.

It is heartening to see that the nature of grief, and the need for people to grieve for what has been lost, is now better understood by the wider community. An understanding of the process of grief allows family and friends to give their love and encouragement without being disconcerted by the many faces of grief that can be shown until healing begins.

### **My own personal experience**

In October 1966, in Invercargill, our fourth son was stillborn. The impact of such a loss on a young family wasn't realised or acknowledged at that time and I rejoice that there is such understanding and support for families now. The opportunity to share the feelings and the concerns that such a loss brings is so important. A significant number of elderly people – women as well as men – I have spoken to when their spouse died, have shared with me their experience about when they lost a young child many years before. They spoke of not being encouraged to talk about what had happened and in many cases were actively discouraged from asking questions or showing any emotion. Grief doesn't go away because you try to ignore the pain of the loss! When our son died it was the old people who helped me the most – who had been there, themselves, and had a child die. They understood and we could talk together. Friends and family were supportive in practical ways but they avoided mentioning what was foremost in my thoughts at that time.

## REFLECTIONS OF BARRY

### – CONSULTANT PAEDIATRICIAN

#### **Roles of grandparents**

In my experience, the role of grandparents when a grandchild dies is very, very dependent on what the relationship is between the mother and the grandmother particularly and the grandfather, depending on whether it is a matriarchal or patriarchal family. Clearly where the grandmother is seen positively then the grandmother can be very supportive. Partners will often be very supportive, the grandfathers will often be as much support in that situation depending on whether they are comfortable with their feelings or not. So, some grandfathers are brilliant in that situation in terms of supporting their children. The traditional NZ male doesn't do that very well - but there's just a lot of variability. Then, in reality, a lot of the role of grandparents is physically looking after other children – they see it clearly as their role to look after the other children, while the parents deal with their acute grief. To do that, grandparents see that they must deal with their own grief in another way or at another time.

#### **Meeting grandparents whose grandchild died suddenly**

I see most families about 6 weeks after the baby has died. It wouldn't be uncommon for some of the grandparents to come as well. But it would be a minority of families, about 30%, where the grandparents come. The roles which grandparents take in the interviews varies. It depends a bit on the parent. I mean if you've got a 16-year-old mother who's still very shy, the grandmother may come and talk as the mother effectively, in terms of asking the questions, and responding almost for the real mother. Sometimes it's the opposite, the parents really control the interview and the grandparents sit there and then towards the end they focus on what they have experienced and what they are thinking and feeling. Then they will sometimes ask the questions and occasionally they will actually, if there's a lot of angry feelings in the family, be the ones who will express that. That can vary as well. So, the roles are multitudinous depending on what role they have with the mother and father. Sometimes they can be supportive and sometimes they very clearly have their own angry, or otherwise, feelings that they want to discuss as well. I offer ongoing contact with families. Not many take it up. My attitude is that we [as health professionals] come into this really to be with the family as it exists. Sometimes the grandparents are an important part of the family and of the support structure for the couple [bereaved

parents] that you're talking to. But often they're not. I mean, NZ society has examples where parents have been rejected and are considered to be the enemy, rather than as a support. In that situation then obviously grandparent involvement is inappropriate.

What usually happens when a family comes to see me is that I go over the events leading up to the death, I go through the postmortem report in detail explaining some terms that they may not understand. I then go over the sort of mechanisms that may lead to a baby dying, because the postmortem doesn't usually tell you very much about that. We then deal with any questions that come up at that sort of stage. Most of the actual emotion is shown when the parents go through the sequence of events leading up to the death. Then we usually talk about how it's been for them, what support they've had or not had, what happened at the funeral, how they are getting on with each other—especially if it's a couple. If the grandparents are there we would then also focus on them. I specifically ask the grandparents what happened for them and how they are feeling. Then towards the end (and this usually takes up to an hour and a half) we talk about the future and if they were ever to want to have another child what facilities we have for support during pregnancy and afterwards. I say, "Look if there's anything else you need to come up with or want to discuss then I'm happy to do that". I also say, "One of the ways to get through this is to use the Cot Death Society and then in turn support the Cot Death society when other people join". There's quite a lot of talk about grandparents at the Cot Death Society and occasionally grandparents are brought along to the meetings. They don't consistently come but there have certainly been people attend once or twice to see what is happening.

### **Double grief and survivor guilt**

Double grief is the thing for most of the grandparents, I have talked to, identify as the most important issue and the most painful part of grandparent bereavement.

I'm not so sure about survivor guilt. I can't remember any grandparent saying that really it was their turn to die rather than the child's. I think it has happened in one other context where grandparents have said, "Well, you know I'm old and maybe I should have died". It's not been said as a serious issue, more as a slight joke, and that's where it made more sense to me rather than someone who's racked with guilt.

## REFLECTIONS OF JANE

### – PAEDIATRIC CLINICAL NURSE SPECIALIST

#### **A family where a grandchild was dying**

I was involved with bereaved grandparents when working with a family where a child was dying at home. The family lived quite a distance from the hospital and local support was provided by district nursing services and the family's GP.

The mother of the child had not seen her father for many years (he was separated from her mother) but she thought she would make contact with him to let him know what was happening to his grandchild so he could be there if he wanted to. He had never met his grandchild before and decided to come and visit. I went into the situation where, visiting the family at home now included the grandfather's presence, however he was not included in any interaction or conversation with the rest of the family. He was very much "in the corner of the room", present but not part of anything. When the grandmother was there and they were all in the same room together, there was a certain tension. I found it much easier to talk to the grandmother because she was a lot more conversant and involved in the dying child's care. Whereas the grandfather was quite removed- his role was not so clear. Because the mother got on well with her mother (Grandma) it was easier to talk with her and explain things. I knew that the grandfather was also listening which kept him informed but was in no way meeting his need to talk and be involved. I felt my prime concern was for the child and parents and then the grandmother who was providing a lot of support. I took my cues from them.

#### **Grandparents' role**

The role that the grandmother took was a support role; doing what she could to help - such as the cooking, cleaning and spending time with the older siblings. She became the practical support person. She didn't outwardly show much emotion, being the strong support person for the family, particularly for her daughter in caring for her child and keeping the place functioning. The child was oxygen dependent requiring CPAP<sup>23</sup> at home. It was difficult for the mother to go out for a while or have any sort of break. The grandmother tried really hard to learn about this when I was teaching the district nurses how to use the equipment safely. She felt quite nervous, naturally, and I

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<sup>23</sup> A form of ventilation.

don't think in the end that she ever felt confident to remain solely responsible. However, she was doing her best to learn. I remember her constantly making cups of tea, cooking, picking up the other siblings from school and keeping it all together really.

#### **After the grandchild died**

After the child died I continued contact with the immediate family. I never thought to make contact with the grandparents. I rang the mother fortnightly for a while and then when passing through the town, three months after the child died, I made a visit. Christmas time was about a month after the child died and so we sent a card from the ward and telephoned. The parents had the strength to come and visit the Children's Ward one day. The first anniversary of the child's death was last November when I again contacted the family and sent a card to the parents and another one to the siblings and since that time I haven't rung, so the support is lessening. I've never seen the grandparents since the child's funeral and I have never thought to contact them. I'm not even sure where they live.

#### **Thoughts on grandparent bereavement**

I do think it is a very important, often overlooked issue. When a child dies, naturally everything is focused on the parents and siblings. However, grandparents are always so involved, giving and just being there for the family. They are not just helping out with the meals; they are helping their children grieve. They are the ones left after a child dies providing support, listening and grieving themselves, for the death of their grandchild and for the loss in their own children's lives.

There would definitely be times where we could have, or should have, made contact with grandparents. We usually meet the extended family when a child is chronically ill and it would be important to continue that relationship in bereavement. However, it is difficult to know what the parents would view as appropriate contact and what is appropriate in each situation. Perhaps, even just to spend time with them to discuss bereavement issues and acknowledge that they, too, are grieving.



## AND TO CLOSE

I believe that the stories in Part 2 offer a window into the worlds of bereaved grandparents, as constructed by grandparents and those around them. The question then, is what happens after that glimpse through the window? During the development of these stories I read Arthur Frank's (1995) "The Wounded Storyteller". He was writing about narrative ethics and the use of story as testimony, and noted that, "the first lesson with thinking with stories is not to move on once the story has been heard, but to continue to live in the story, becoming in it, reflecting on who one is becoming" (p. 159). I believe that the glimpse through the window offers an opportunity to "become" through the stories and to gain new insights and perspectives. In particular, the stories highlight both the unique and the shared aspects of grandparent bereavement, which sets the scene for the next part of the thesis. Part 3 presents a joint construction of grandparent bereavement, which developed from the different perspectives of individuals in the three participant groups. Whilst the joint construction is grounded in the diversity of the contexts of these stories, it is framed as a conceptualisation of how grandparent bereavement can be. The remainder of Part 3 explores the joint construction in relation to existing literature and the possibilities that this research holds for the future becomings of people, and of practice, with bereaved grandparents.

## **PART 3**

# **THE JOINT CONSTRUCTION, THE SURROUNDING CONTEXT AND THE IMPLICATIONS FOR PEOPLE AND PRACTICE**

## CHAPTER 6

# THE JOINT CONSTRUCTION OF "WHEN AN INFANT GRANDCHILD DIES"

### INTRODUCTION

This chapter is a story of grandparent bereavement presented, not as one individual's experience told in the stories in Part 2, but as a construction from a group of grandparents, parents, health/bereavement professionals. This chapter has two parts. The first is the joint construction, which reads as a story of the ways that grandparent bereavement can be. It is written in a group voice and where individuals have commented on, or articulated parts, of the construction these are presented as separate voices. At the end of the chapter is the second part, the theoretical framework which I have proposed, with participants' agreement, as a way of visualising the interrelated parts of the construction.

In setting the context of this chapter I note three points. First, this construction recognises the context of people's lives and the many roles<sup>1</sup>, which contribute to the self-identity of people called "grandparents" in this chapter. As Colston wrote,

*My definition of myself seems to change according to circumstances.... So, I am Colston, Philip's wife, mother of Keith and Christine, mother-in-law of Martin and, as important as any of these roles, grandmother of two well beloved grandsons. I also see myself as a Christian minister, well known in the parish. (Colston 9:3)*

However, the focus of the study and construction is grandparent bereavement in the context of the family, which means the construction largely focuses on the loss for two roles that a grandparent has within the family: as a parent of the parents and as a grandparent of the grandchild. Second, the construction is bound to the context from which it emerged. It is grounded in the individual

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<sup>1</sup> The term "role" is used not in the sociological sense e.g. role theory, but as used in conversations as an umbrella term encompassing different aspects of being a parent or grandparent.

constructions, their critique and negotiation of differences between 16 grandparents, 6 parents, 3 health/bereavement professionals and myself to become, in its final form, a synthesis of these discussions. Therefore, it is not a theory of grandparent bereavement and it cannot be assumed to generalise beyond the context from which it has come. This joint construction has developed with discussions about other worldviews of bereavement, including ideas from other researchers and clinicians, but these are not discussed specifically in this chapter. The construction is presented as a whole, the debate about where the construction sits in the wider context of the existing literature is explored in the next chapter. Third, a note about the presentation of this chapter in terms of referencing time-point and sources. Bereavement is time dependent in that feelings, thoughts and interpretations of the experience do alter. However, I believe time becomes unique to the individual and is not a reference point to be at a certain place in the construction. So, only when time is important to the context of the construction have I indicated the actual time-point. As much of the construction is based on a synthesis of numerous texts across participants, it is not possible to reference parts of the construction to specific sources. Therefore, only quotations that come from one text source are referenced.

## THE JOINT CONSTRUCTION

As I explained in Chapter 4, the way in which grandparent bereavement can be constructed starts with the view that the grandchild's death creates a situation of challenge and change. This has three parts: **"Facing the challenge"**; **"Responding to the challenge"**; and **"Managing changes from the challenge"**. "Challenge" is used in the sense of a difficult situation that tests resources and abilities to cope. Individual grandparents perceive the challenge differently; for some it is a personal challenge, and for others it is a challenge to the bereaved parents and the family as a whole.

## **FACING THE CHALLENGE**

The challenge which faces grandparents when a grandchild unexpectedly dies is that of being taken out of a comfortable space and time in their lives and thrown into a difficult situation. It is, in effect, "*When the world turns upside down*"<sup>2</sup>. Faced with an upside down world grandparents have a whole range of feelings which reflect having two roles in the family, as parents and as grandparents. This brings the different forms of grief or pain which Marie described as "*You have all those extra ones when you are a grandmother*" Marie 1(9).

### ***When the world turns upside down***

The death of a grandchild impacts on grandparents in their roles both as parents and grandparents. It affects the whole family including the other children, grandchildren and siblings of the grandparents. "*When the world turns upside down*" reflects the perspective that in the world of the grandchild's family all was going well; life was as expected and looked set to continue that way. Then, suddenly, things went wrong - either before the birth, or afterwards, which resulted in the grandchild dying unexpectedly. The sense, for many grandparents, that the world has changed, even if not physically turned upside down, is grounded on all, or some, of the following; the fact that "*The death of the grandchild is unexpected*", combined with the belief that it happens to other families can lead to a sense of "*Being unprepared*" to respond to this situation.

### **➤ *The death of a grandchild is unexpected***

The reason the death and loss of the grandchild is so unexpected seems to be because it is the opposite of what grandparents thought was happening. The challenge grandparents face is being suddenly thrown, through no choice or action of their own, from a state of something such as enjoyment, anticipation, excitement, comfort or confidence to a state of pain and loss. The shock and enormity of this unexpected and unbelievable event can create the sense of being the "only grandparent that this has happened to". Whilst, at the same time,

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<sup>2</sup> The names of categories and subcategories in the construction are distinguished using this font.

knowing that there are many other bereaved grandparents. It is, for a brief moment, two different views of the same event: the wider comparative picture and the narrower picture of what it personally means. The other bewildering aspect of the shock is appreciating that, outside the family, the world is still the right way up. Catherine reflected, "I can remember the next day [after Samuel's death] the milkman was coming and the paper was delivered and "Why were all these things still happening?" Because the world had stopped for us" (Catherine 3:6). It is a momentary experience of such hugeness which some grandparents can equate to other major transitions or crises in life, such as giving birth to their first child and feeling that one is the only mother in the world.

Yet, why is it so unexpected when a previously well grandchild dies? One of the consequences of widespread media coverage of a whole range of human issues is that society, families and grandparents know the "facts" that young children do die unexpectedly, even in the 1990s with all the available medical technology. In particular, the high NZ and UK cot death in the 1980s is something which grandparents know about. However, there seems to be a distinction between knowing about it, and believing that it can touch one's own family. There is a belief, and perhaps a hope, that it will happen to "other people". As Ailsa said, "it's something you think will happen to somebody else and not you or your family that will be affected" (Ailsa 1:12). An unvoiced part of this belief can be an unwillingness to tempt fate by even thinking about it as a possibility for a member of one's own family. Benita described her premonition of Matthew's death and how she dismissed it given that all seemed well (see p. 247). In addition, evidence for many grandparents' belief that unexpected death happens to other families and not their own family, is the tangible proof that existing children and grandchildren in the family are all alive and well.

So, what happens if grandparents believe, or know from their own experience, that young children do die unexpectedly? Does it offset the shock and sense that it is unexpected when their grandchild dies? The answer seems to be "No". There is still a distinction between knowing that such as death is a potential risk and believing that it could "really" happen. Given their professions as hospital chaplain



and nurse, both Alex & Benita were aware, and believed, that young children die unexpectedly. It was a fear they had had for their own children when they were young, but neither had expected that it would happen to Matthew because everything had gone well during the pregnancy and his birth. Colston explained in her story that, although she had personal experience of her own child, David, dying a few days after he was born, she did not consider the possibility of it happening to her grandchildren.

The other element of the unexpected shock which death of a grandchild brings is the way in which grandparents hear the news. The majority received a phone call, out of the blue, from the parents of the grandchild. It is not a situation grandparents ever anticipate will happen and, for many, remains an imprinted memory. Betty remembered when Donald phoned, early in the morning, with the news of her granddaughter, Gracie's, death, "Well, it was the shock - on the day - in the morning. And I was still in bed at half past four and I lay there thinking 'What on earth will I do?' A helpless feeling. And then I thought I would get up and have a jolly good bath" (Betty 2:2). Betty's description of her feelings are described by other grandparents as "*being unprepared*" or "*feeling your way*".

### ➤ *Being unprepared and feeling your way*

The unexpected shock of having a grandchild die can, understandably, create the sense of being unprepared for what is happening. Parents, grandparents and the whole family are often moved into an unknown world. Even if it is a world "known" as part of the grandparents' work environment, it is still different to be personally touched by this. The death can bring into action the combined involvement of a number of systems and professionals, including emergency responders, doctors, nurses, midwives - in the health system; police, pathologist, coroner - in the judicial system. In the case of a sudden infant death, which was the reason that Conor, Matthew and Samuel died, the legal requirements to have a sudden death investigated mean that police arrive at the place where the baby died. Statements are taken and the baby is taken away for a pathologist to complete a postmortem, which is then reported at the coroner's inquest. All this takes place before a death certificate is issued and the funeral can happen. As

Catherine described, in the face of such processes and professional involvement, grandparents and parents often do not feel prepared to question, challenge, or even make requests. Terese still regrets that when Bernadette died, 17 years ago, no-one offered to take a photograph and, in her shock, she did not think, or know, to ask for one. Another aspect of *"being unprepared"* is that it contravenes expectations that grandparents have generally experienced most family events that their children are likely to encounter, such as having children. There is a notion that they are one step head of their children in family related experiences and can often support their children, as parents of their grandchildren, with practical advice and the experience of having survived as a parent. The death of a grandchild means that the grandparent's child, the parent, is now experiencing something that most grandparents have not experienced. At the same time, this is exactly the time when grandparents want to be able to do their best to support and help the parents of their grandchild. Catherine described it as, "not knowing what is right and what needs to be done and it is like feeling your way and everybody communicating and talking and finding" (Catherine 3:4). Not knowing what to expect can mean that grandparents are surprised, even shocked, by things never previously experienced, like the cost of headstones or the appearance of a dead body. After the immediate shock of *"When the world turns upside down"* come a range of feelings which reflect what the loss of a grandchild means for grandparents.

### ***You have all those extra ones when you are a grandparent***

When Marie talked about this she was explaining that being a bereaved grandparent is not just about being a grandparent. Having all those "extra ones", apart from oneself, is the context which frames the bereavement and which impinges on the *"Feelings and concerns of grandparents"*, the *"Meaning or nature of the loss"* and the *"Individuality of the loss"*.

### **➤ *Feelings and concerns of grandparents***

There is no set sequence, in this construction, of the feelings that grandparents have. What is accepted is that feelings go round and round and the raw intensity of feelings at the beginning does become less intense as time moves on.

Grandparents differentiate the pain they feel at the death of a grandchild with respect to the different relationships they have within a family. They make a distinction between pain felt for the parents and pain felt for self. "Pain" is the word that is used in this construction, often more than "sadness" or "sorrow" because it describes what can be felt as both an emotional pain and a physical pain. The focus of the pain is for those still living, in particular the parents because, as Margaret & Keith explained, they are still here. The outstanding feeling which continues over time is sorrow and pain for the parents' loss. The enormity of that loss is seen but also appreciated as not being fully understood. Beth explained that she could not know what her daughter, Rosanna, was feeling, "And if you haven't lost a child you cannot know, what it feels like, you can only know it is totally devastating" (Beth 2:7). The intensity and duration of sorrow and pain for many grandparents is unexpected and, at times, uncontrollable as Elisabeth wrote 3 years after Martin died,

Grief took on a whole new meaning after Martin died, the double grief was almost unbearable- watching your own child and her husband. And feeling the loss of our grandson. It seemed so enormous and as a person who was usually in control of my public emotions I suddenly found I would weep in the most unexpected places and with the most unexpected people - this was difficult and quite hard to accept. (Elisabeth 7:5)

The extent of grandparents' pain may never be fully perceived outside the family because everyone's attention, including that of the grandparents, is focused on the parents. Where grandparents' pain is perceived outside the family, it is the pain which grandparents have for their child, the parent of the grandchild, not their own grief as a grandparent which stands out to people such as health/bereavement professionals. However, in time that pain can form a new bond of understanding between grandparent and parents, as Maxine described (see p. 304). Rose felt that she appreciated her parents, differently, after Ruby's death.

Because grandparents get completely forgotten in a grieving process when a family loses a child and nobody realises. I mean it took me a while to realise just the depth of feeling that Mum and Dad have. Because not only are they grieving for their grandchild, they're grieving for their child's pain. And being a parent myself, now, I understand. (Rose 1:32)

Undirected anger may be a response to the feeling that a grandchild's death was unfair and "Why did it happen?" Or anger may be directed towards someone or

something. Colston was encouraged by local clergy to "be angry and shout at God, quoting the Psalms" (Colston 3:6). Catherine and her family were angry with the medico-judicial system which had kept Samuel in the hospital mortuary, from when he died on Friday night until Monday morning when the postmortem was conducted; a system which had discouraged the family from going to see him. With her daughter and son-in-law's support, Catherine wrote to the pathologist, coroner and police questioning the practice of not providing postmortems at the weekend. The response was a change in practice, which to Catherine, Rachel and Keith was a good outcome to the anger they all felt.

Feelings of guilt and responsibility for the death are not a strong part of this construction. This is mainly because grandparents are not involved in the everyday care of their grandchildren, which means there are fewer opportunities to feel as though something one did, or did not do, contributed to the death. However, as Ailsa explained in her story (see p. 279), there can be a momentary sense of "Why them? Why not me?"

A consequence of feeling unprepared "*When the world turns upside down*" can be a feeling of helplessness; experienced by many grandparents around the time that the grandchild dies. This is largely centred on grandparents' role as parents of bereaved parents. Ailsa described it.

I think, for me, one of the hardest parts was seeing my children so devastated and not being able to do anything for them. Because when your children are little you can fix all their aches, or all their problems. And as they get older their problems get bigger and you can do less about them. And there is nothing you can do to make it better for them and this is worse than anything else. You would give anything to get that baby back for them.  
(Ailsa 1:4)

Helplessness is a feeling which expresses the love, care and hurt which grandparents hold for their children. It is about never wanting this to happen to their children. There is also a recurrent feeling of concern for the parents of the grandchild. Concerns are about a whole range of things including: the parents' pain; how other people behave towards the parents; how the parents feel about another child in the family of the same age as the child who died; whether the parents talk to each other; and whether the parents "need" to talk to a counsellor.

And so the concerns continue. Feelings of concern are an expression of care, and most grandparents are careful not to act on those feelings until given permission by the parents. As the next section "*Helping out as parents of adult parents*" explores, whilst grandparents feel helpless, they neither expect, nor try, to fix the situation, because to do so would not be consistent with respecting their children as adults.

Feelings of relief in bereavement can also be an expression of care; this time for the grandchild. Relief is a feeling grandparents may have if the grandchild's quality of life seems limited. Matthew, Ruby and Daniel all died unexpectedly. Things had been going well for them and then suddenly they were terminally ill and died within a few days. The stories of their families uncover the balance of relief and sorrow at their deaths. For grandparents, the physical pain of the grandchild, the pain of watching their grandchild in pain, and the pain of the parent's pain can mean that the death is both a relief and a sadness.

Feelings are also expressed for other family members apart from self and the parents of the child. They can include; pain and sorrow for the grandchild who died, for other grandchildren, for the loss of how the family might have been, for one's partner as another grandparent, for other children who may feel fear and discomfort because their children are still alive, and for own parents, the great-grandparents. Feelings for all these "extra ones" reflects the relationships which grandparents hold in the family and their view that these people are important to them.

Many grandparents experience feelings of extreme tiredness after a grandchild's death, but few identify these as physical consequences of grief. This may be because the signs are not recognised at a time when so much is happening. It may also be due to grandparents' lack of knowledge of commonly experienced physical changes of bereavement such as sleeplessness, loss of appetite, weight loss, tiredness and being run-down. Marie commented, after reading Margaret Gerner's (1990) booklet "*For Bereaved Grandparents*", "in this book I learned of some of the physical effects [of grief]. I hadn't connected my loss of appetite or my inability to concentrate with my loss. Nor did I think of the necessity to ensure

that I watch my own health" (Marie 3:1). In addition, pre-existing health conditions may be exacerbated, such as Colston's arthritis which worsened after Christopher's death.

### ➤ *The meaning or nature of the loss*

Grandparents' feelings reflect what the loss means to them as individuals and as members of the family. The death has two compounding aspects of loss. It is about loss of a grandchild and what this means in terms of lost opportunities to be a grandparent to them, and it is also about the meaning of this particular grandchild's death. Alex' eulogy sums up many of these losses (see p. 256). The lost opportunities to be a grandparent to this grandchild are constructed by individual grandparents according to the importance that they place on being a grandparent, and how they construct the role of "*Being a grandparent*". Entangled within this role are the other meanings of loss which are constructed in relation to particular characteristics of the grandchild such as age, gender, and birth order of the grandchild.

### *Being a grandparent*

The importance attached to having grandchildren includes some, or all, of the following: a desire to be able to have "fun" with grandchildren; the importance placed by own child on having a child; the extension of the family with further members continuing the name; and grandparenthood as part of the expected sequence of events in life. The death of a grandchild challenges these expectations. At an everyday level, the death of a grandchild removes the opportunities to be a grandparent to this child. Being a grandparent holds a shared meaning which is characterised by the voluntary nature of the role. It involves choices about spending time with grandchildren and being able to have "fun" with them. In contrast, parents are seen to have the responsibilities of instilling values, principles, boundaries and providing everyday care. The relationship of grandparent-grandchild is viewed as having mutual benefits because it is two way - both giving and receiving. The activities of grandparents with grandchildren include talking, playing, caring for, telling stories, providing a sense of family history, introducing them to new experiences, and integrating them into activities which grandparents



do, such as going to church. Grandparenting is not identified as strongly modelled on grandparents' own experiences of their grandparents, although some activities are a direct response to what did not happen in grandparents' own childhood. However, the principles of valuing and caring for the family are seen as being carried forward across the generations. It is these opportunities to care for family members and contribute to their growth and development, which are challenged when a grandchild dies.

Extending beyond what the death of a grandchild means is what the death of **this** grandchild means to grandparents, and again this is constructed individually. The shared areas of meaning in this construction are "*Death of a young grandchild*", "*Birth order*", "*Gendered loss*", and "*Non-personhood*".

#### *Death of a young grandchild*

Having a young grandchild die, before the age of one year, brings the sense of the loss of potential. The loss of what that grandchild might have been; as a grandchild, as a member of the family and as a member of society. Spontaneously contrasting the grandchild's death with other deaths may be one way of clarifying the unfulfilled nature of that potential. The reference point of other deaths, generally includes a death that grandparents have personally experienced. So, a teenager or young adult's death is seen as tragic, but they are seen to have lived a part of their life and, in so doing, fulfilled part of their potential. Whereas, a person dying in their 70s or 80s, as many of the parents of grandparents have done, is perceived as having lived a full life and there may be few regrets about their death. In contrasting the ages at which people die, grandparents make an assessment of the death in terms of fulfilment of potential and fairness/ injustice. Thus the death of a young grandchild is unfair because it means that the child did not fulfil his/her potential. This creates a sense, for Jenny, of having been "cheated by something that can't be expressed" (Jenny 5:6). In this respect, some grandparents construct a hierarchy of injustice or potential where the grandchild's death is seen as "most unfair" or "most loss of potential". Similarly, a hierarchy of grief within infancy may be constructed where others' experiences are perceived as "worse" than one's own experience, which implies that the pain is not as bad as it

might be. In contrast to the age of death, the reason for death, such as stillbirth or SIDS, is not used to construct a hierarchy of "worse" or "better" deaths.

### *Birth order of the grandchild*

The position in which a child is born into the family can have a large impact on grandparent bereavement. When a grandparent's first grandchild dies, especially around the time of birth, grandparents are in the process of role transition. They are claiming for themselves, within their family and the wider community, the role of grandparents based on tangible evidence of a grandchild. So, what happens when the grandchild dies? Grandparents may pose the question to themselves. Jenny expressed her confusion when she wrote, 8 months after Jordan's death, "I call myself Jordan's nanny, but then a voice in my head says "You're not really a nanny, yet" - but part of me says I am - so what am I? Where do we go from here?" (Jenny 1:3). Other people identify the same confusion. Elisabeth wrote, 3 months after Martin died, "One friend said she was sorry as she wanted me to be a grandmother and hoped I would be one in the future. I felt angry and hurt and told her I WAS Martin's grandmother" (Elisabeth 1:6). The answer to the question "Are you really a grandparent?" may never be satisfactorily answered, or may be superseded by the arrival of a future grandchild which then legitimates the role and removes the doubts. In contrast, grandparents who already have living grandchildren and are established in the role, do not experience this aspect to their loss. At the opposite end of the continuum, grandparents who have many grandchildren, for example eight or more, still experience the loss of a grandchild as special and valuable. The grandchild is no less valued even when there are many other grandchildren.

### *Gendered loss*

The meaning a grandchild holds is often a combination of birth order and gender. The hopes that grandparents hold for a grandchild of a particular gender to balance, or complete, the family composition may contribute to grandparent bereavement. For Alex & Benita, Matthew's gender had two meanings and two losses. He was their first grandson following the births of two grand-daughters, so he balanced Frazer & Sarah's family. Matthew also broke the pattern established

by Alex & Benita's three children who were all the same gender (male). This aspect of bereavement was not a feature of Matthew's other grandparents, Margaret & Keith's, loss because they had four children, Sarah and three brothers. Conversely, there may be the sense that the bereavement may have been tempered, precisely, because the grandchild who died was of the same gender as existing grandchildren. Again, the grandchild is still valued and mourned but their gender contributes to the meaning of the bereavement. Colston wrote about the death of Christopher, "I don't know quite how to say this - the fact that he was the third boy may have taken some of the edge off, we all [as a family] longed for a daughter/grand-daughter" (Colston 6:4). The importance of loss that recognises the particular gendered expectations of a grandchild is not solely a feature of grandchildren who die around the time of birth. It might be assumed to be more important at this time, because there has been little opportunity to know the grandchild as an individual, and gender provides a meaning of their potential as a granddaughter or grandson. However, Elwyn keenly felt the loss of her eighth grandchild and second grandson, Daniel, at the age of over 7 months. To Elwyn, Daniel's death meant the loss of her grandson and also the loss for Leslie, Elwyn's son, of his only son. In addition, Daniel's face reminded Elwyn of Lindsay, her dead husband, and Daniel, in part, represented Lindsay living on.

### Non-personhood

An aspect of many grandparents' bereavement, to a greater or lesser extent, is the lack of opportunity to "know" their grandchild – particularly when they have died around the time of their birth. To have a sense of the individual identity of the grandchild, and therefore the loss of this, requires knowing the grandchild, which generally includes having spent time with them and appreciating their individuality. Time together is something that many bereaved grandparents do not have and, therefore, part of their bereavement may be trying to establish the identity of the grandchild to be able to mourn for the loss. Marie explained in her story that she felt Ruby was a "no person" (see p. 272) and that she only knew her through Rose, Ruby's mother. For Marie, not "knowing" her grandchild led to a range of activities such as frequently looking at photographs in an effort to make the presence, and hence the loss, of Ruby "real". Making Gracie a "known" person was the reason that Donald and Pip felt having Gracie home, before her funeral,

was important. It provided a chance for her grandparents, Betty, Diana & Rupert, and other friends, to get to know what she was like.

### ➤ *Individuality of feelings*

It is apparent, from both the individual stories in Part 2 and from this construction, that a grandchild's death can hold shared and individual meanings for grandparents. The individual nature of grandparents' bereavement is the main thrust of this construction. Grandparents' feelings are expressed in a variety of ways including crying, hugging, and silence, depending on the "normal" behaviour for each individual grandparent. The expression of feelings, or not, is determined by what individual grandparents feel comfortable with. This individuality is clearly seen as outweighing gender differences associated with the expression of feelings. Whilst all grandparents feel the pain, some grandmothers and grandfathers will share this pain, as Alex did in his eulogy to Matthew and as Ailsa did by talking extensively with her son and daughter-in-law. Other grandmothers and grandfathers hold their pain to themselves, which is evidenced in Frazer's description of Keith as a man of few words and Beth, who describes herself as controlling her emotions.

Grandparents choose carefully **where** and **with whom** they share their feelings. Often it is with living spouses, generally with grandmothers talking more about their feelings than grandfathers. Sometimes it is with other family members, close friends and, occasionally, with another person who has had a child or grandchild die. It is with the parents of their dead grandchild that grandparents are most cautious about sharing their feelings, especially in the time soon after the death. This is motivated by being the parent of the bereaved parents, and as Elisabeth explained, "I could share some feelings with Lorna and Geoff, but often I felt I must be strong for them and hide my feelings as they were struggling" (Elisabeth 3:6).

People outside the family also identify that grandparents put their feelings second. Barry, a paediatrician, described that, in his experience of meeting bereaved grandparents, they "see it clearly as their role to look after the other children

while the parents deal with their own acute grief. And see that they [grandparents] must deal with their own grief in another way or at another time" (Barry 1:11). The individual nature of bereavement can also explain what might be called a hierarchy of grief based on degree of relationship to the deceased. Most grandparents perceive that the parents of their dead grandchild have a deeper or more extreme grief than themselves, as they are one step removed from the grandchild. However, this can vary according to the individual. Frazer perceived that his mother, Benita, experienced the grief as though it was the loss of her own child; this reinforces the importance of recognising the meaning of the loss as deeply individual. Having explored the ways in which the challenge that grandparents face is constructed, the question then remains "How do they respond to this challenge?"

## **RESPONDING TO THE CHALLENGE**

Despite being unprepared for their grandchild's unexpected death grandparents do their best, use the knowledge and the resources that they have, and consider, "What would be the best thing to do for the parents?" This activity constitutes three aspects of the construction "*Being with*", "*Helping out as parents of the parents*" and "*Coping as knowing, caring and doing*".

### ***Being with***

A central and continuing part of grandparent bereavement is the importance of "*Being with*" the parents, dead grandchild and other family, both around the time of the grandchild's death and on an ongoing basis. Going to be with the parents reflects a range of motivation – from an instinct, to a need, to a wish – all of which have a strength and an urgency attached to them. Benita, in explaining why she and Alex wanted to be with Sarah & Frazer when they took Matthew home to die, said, "there was a strong instinct to stay with them and if we left it would be, to me, it would be like abandoning Frazer, Sarah and Matthew. For all the pain it would cause we just had to see the whole thing through together" (Alex & Benita 1:7). The importance of "*Being with*" cannot be underestimated, either from the perspective of grandparents who make the effort to be with the parents of the

grandchild, or from the perspective of the parents who value this highly as an expression of support and care. Donald felt that the most important thing his mother, Betty, did after Gracie died was,

Coming down from Christchurch and being present at the funeral. We aren't a very close family and Betty was the only member of my immediate family who was at the funeral. It makes talking about Gracie, to Betty, easy now.

Whereas it is a topic I would find hard to discuss with my brother and sister as they weren't at the funeral. (Donald 2 :1)

The nature of "*Being with*" is, in many ways, similar to the Middle English meaning of "midwife" – which is "with woman" during labour and delivery. The midwife's role includes both physical support (practical care) and emotional support (encouragement and listening). There is also an element which is less tangible and involves an attitude of watchful expectancy which is "Other" focused. It is about being quietly around, available and at times part of the background of the woman's experience of labour, which is in the foreground. This aspect of support is part of grandparents "*Being with*" parents, dead grandchild and other family. It involves "*Sharing time*", "*Sharing humour*", "*Sharing feelings*" and "*Sharing the doing*" which make up the fabric of memories and acknowledgement of the grandchild's place in the family as time goes on. The care that grandparents give to bereaved parents by being there, is appreciated by health professionals as a commitment to the family. Jane, a paediatric clinical nurse specialist, held a strong impression of bereaved grandparents as "*Grandparents, I see, always giving [support to parents] and being there*" (Jane 1:7).

### ➤ *Sharing time.*

The time shared by grandparents with parents represents an expression of support and care, and it provides the memories which grandparents think about and talk about afterwards. Betty's memory of Gracie's funeral was very vivid, 9 months after Gracie died.

We had our service in the garden and the trees - that was the laburnum and the crab-apple tree - absolutely in full blossom. We stood under these trees and sometimes you could hardly hear what the minister was saying for the buzz of the bees around. (Betty 1:20)

All of the stories in Part 2, illustrate the amount of time which grandparents share with the parents of their grandchild. This may involve cancelling or re-organising



other commitments such as employed work or running farms to drop everything to go. "*Sharing time*" clearly takes precedence around the time when their grandchild dies, and it continues to be of importance to grandparents as time goes on. Over the following weeks and months, grandparents make the effort to spend extra time with the parents and their children, where "extra time" is more than the amount, which was spent with the family, prior to the grandchild's death. The reason for doing this is grandparents' wish to continue supporting the parents in a bereavement which does not go away. Particular events make sharing time together especially important, such as the funeral. The funeral represents time to acknowledge the infant's life and death, and to say good-bye. By sharing in this time together parents and grandparents have memories to discuss in the future. In addition, by sharing in the funeral, there can be consequences for how grandparents re-view other losses in their lives, such as Elwyn's reflections about her feelings for her dead husband, Lindsay (see p. 290). Another event where sharing time together is important is the next pregnancy which can be especially stressful for the parents, and the grandparents. The time families spend together may be one way of coping with the strain. When Rachel was pregnant with Hayley, she valued the time and support that she had with Catherine and Paul, who were living in a caravan on Rachel and Keith's driveway whilst they were building a house.

"*Sharing time*" is finely balanced between enough time and too much time. Elisabeth explained it as being, "sensitive to their [the parents] feelings - when they wanted to be alone or needed company and when to talk and when to stay silent" (Elisabeth 6:3). Jenny explained that she put her own needs of sharing time second. "I needed to be with Sue and Charlie every day, or to speak to them on the phone. But I knew, deep down, they craved time alone, to try to begin their new life without their cherished baby" (Jenny 1:2). Again, it depends on the individual relationship between grandparents and parents. For many parents the amount of time that grandparents share with them is "just right". "*Sharing time*" depends on how and where the time together is shared. Elisabeth and her daughter, Lorna, were happy to spend time together at a SANDS meeting and for each to talk in the group about their loss. Whereas, for Maxine, time at The Compassionate

Friends' meetings was **her** time, and when her mother, or mother-in-law, went with her, she felt constrained by their presence because she did not want to say anything which would upset them; an issue which is discussed further in "*Sharing feelings*".

### ➤ *Sharing humour*

Occasions of humour arise as part of being together as a family and these, too, contribute to the shared memories of events associated with the grandchild. This seems to particularly occur around the time of the grandchild's death and funeral. Alex & Benita and Sarah & Frazer shared the story of the toilet seat-lid which was closed down when Sarah rushed in just after Matthew had died. The value of sharing humour can act as a release of tension and is also about contrast. Alex & Benita summed this up, when reflecting on something which Frazer had said that made them all laugh at Matthew's funeral.

Alex:        The contrast, the sadness and the laughter, switch backwards and forwards.

Benita:     And I realised then, that this is life. You are right in the middle of it, this is the grief and this is the death. This is the grief but all around us is life. (Alex & Benita 1:39)

As Benita describes, humour can bring fresh insights and can also help people to share feelings, which is a central part of this construction.

### ➤ *Sharing feelings*

There are choices to be made about the sharing of feelings which rest on the following questions. How much to share? How much to listen? When to listen and when to share? For most parents, having the opportunity to talk about their feelings with their parents is part of what gets them through the experience. Five months after Ruby's death Rose valued her parents for being there, to listen to her, representing a place,

... where you can go and talk and not feel that you've exceeded your time or anything like that. Which is protected space really, to go and be who you are at the time. Whether it is a raving lunatic or whatever emotions you're feeling at the time, you can express them to your parents and they won't criticise and they won't say "You can't feel like this". (Rose 1:38)

It is particularly around the time when a grandchild dies that grandparents choose not to share much of their distress with parents. As time moves on some grandparents increasingly share their feelings, perhaps reaching the point where there is little which is not openly discussed. Parents, too, are sensitive about sharing their feelings and are sometimes cautious of sharing their pain; they do not want to distress grandparents further. As Sarah explained, 4 years after Matthew died,

... sometimes I don't like to talk to Alex and Benita about the way I felt when Matthew died, because I don't want to cause them any further pain. Benita finds it hard to talk about him without tears in her eyes, and then I have tears in my eyes too. (Sarah & Frazer 2:10)

This, and the picture from the individual stories, shows the mutuality of caring between grandparents and parents in relation to how, and when, they share their feelings with each other. Most parents and grandparents make the decision not to share their feelings with the other based on a rationale of caring about the other. The decision is based on an assessment of how the other family member might feel and respond at the time, and the decision is revised as the situation changes. Such a decision is not based on protecting the other by trying to cocoon them away from the pain. Woven into this decision-making is the individuality of families and family members. Some families are caring and supportive but share their feelings very little and that can suit everyone concerned. Other families talk about their feelings at length and each member values the feelings shared by the other members.

Sometimes there is a mismatch between what grandparents **do** and what parents **want** in terms of "*Sharing feelings*" and vice versa, as Jenny explained in Chapter 5, when she described her distress at Sue's request for Jenny not to visit her (see p. 159). Equally parents may want grandparents to share their feelings to hear acknowledgement of their child. Maxine talked about the spiral of reactions which came from her mother-in-law not sharing her feelings about Matthew's death.

It's been nearly 5 years [since Matthew died] and now she [Maxine's mother-in-law] starts to talk. Because she's always been too scared to talk to me about how I'm feeling in case it upsets me. I've always told her I'd sooner talk about things and at least you know what I'm thinking. (Maxine 1:20)

That silence meant that Maxine felt Matthew was not acknowledged and that there was no opportunity to share, and hear about, her mother-in-law's feelings.

### ➤ *Sharing the doing*

Whilst not all grandparents may be comfortable sharing their feelings extensively, a common emphasis is placed on "*Sharing the doing*" of activities associated with the death of the grandchild. This includes assisting with the practical decisions related to the funeral, providing cups of tea for visitors, making suggestions or writing a death notice, caring for other grandchildren, or cleaning the house. By being with their child and family, many grandparents share some of these activities. How and what they do this is explored in the next aspect of the construction section on "*Helping out as parents of the parents*". In the wider picture of the family long-term, part of sharing the doing returns to the mutuality between parents and grandparents. Benita explained, "I guess I feel our relationship [with Sarah & Frazer] is a mutual one, where it comes and flows; backwards and forwards. They do things for us and we do things for them" (Alex & Benita 3:20). Grandparents share in the activities to help the parents knowing that, at some time in the future, or in the past, the parents, too, help the grandparents.

### **A note on "Being with-out"**

The individual stories and sections above emphasise the positive aspects of sharing as part of "*Being with*" the family. When grandparents are unable to be with the parents, this constitutes "*Being with-out*". The words "with-out" reflect being outside of the sharing and it can be distressing for both grandparents and parents. Within this construction, the situation of "*Being with-out*" arose from force of circumstance. This may be because geographical distance precludes grandparents from being able to physically be with their child, grandchild and other family. It can result in pain because grandparents want to be with the parents' family. Marie talked about trying to compensate for the distance between herself, in Dunedin, and Rose, with Ruby in Auckland, by having regular phone calls and by sending strong energy feelings to Rose. Sometimes "*Being with-out*" is, as Diane, a bereavement support co-ordinator, described, a choice made by parents to withdraw from grandparents. This can be the only way the parent feels that they

can cope in the short-term (see Terese, p. 200). The pain for a grandparent, respecting their child's wishes, can be enormous as Jenny described when she wrote about her feelings of Sue's withdrawal (see p. 159).

### *Helping out as parents of the parents*

The nature, and extent, of help which grandparents give to the parents of their grandchild varies according to individuals and circumstances, but it is one of the strongest parts of the construction. Both grandparents and parents identify that the grandparents have a role as "*Parent of adult parents*" that is important in framing the ways in which grandparents help out the parents. In the role as "*Parent of the adult parents*" the emphasis is on the word "adult", which means "*Helping out but not taking over*", particularly in relation to the giving of "*Advice or information*" and "*Practical help*".

#### ➤ *Parent of Adult Parents*

The stated emphasis of bereaved grandparents is on being a parent of adult parents, which is clearly defined and appreciated by grandparents as **not** parenting a young child. Every individual grandparent, in their role as a parent, has their own particular style of parenting but the common features of being a parent of adult parents relate to autonomy of, and respect for, the adult parent. These common features include: loving and lifelong care; giving advice only when asked; supporting and encouraging; being available when needed; respecting parents' decisions and wishes. Colston described parenting as, "a life long changing relationship. Moving from total dependence through the stages to letting go and allowing them [the child] the space to continue developing in their own way" (Colston 8:2). Evidence of these features, as part of what grandparents think, feel and do, exists throughout this construction. It is about grieving for their child, caring about what happens to them, deferring to their wishes, supporting but not deciding, and helping but not taking over.

#### ➤ *Helping out but not taking over*

The areas where grandparents help out the parents of their dead grandchild include the giving of advice or information, and practical help such as financial

assistance, housework or funeral preparations. The extent of helping out peaks around the time the grandchild dies and then reduces to an ongoing level of help, which may be higher than the level preceding the death. As in all aspects of the construction there are large variations within families, and between families, as to the nature and extent to which grandparents help parents. Opportunities to be able to help are related to grandparents' health, activity levels, closeness of relationship with child and grandchildren, accessibility in terms of transport and distance, and availability of money. Wanting to help out is a wish that all grandparents have, but the opportunities may not exist. Marie wanted to give Rose and her family a hand after Ruby's death but had to rely on Colin, her husband to drive her there and, with arthritis and ongoing memory loss, so the extent to which she could help Rose was very limited. Marie, therefore, relied more on telephoning and talking with Rose.

The important issue in relation to help is, when and how the help is given to parents. As Keith explained, sensitivity is needed to balance helping the parents without taking over from them.

You are trying to help them [the parents of the grandchild] and you really have to be very careful. They have to be left to do what they want to do. But you can see things that you think you could probably help with - but check it with them. (Margaret & Keith 2:12).

Similarly, Gracie's family explained in their stories, how Pip knew what she wanted to do for Gracie, which meant the grandparents fitted their help around what she wanted.

Gender differences play a part in "*helping out*". Women are traditionally seen as the nurturers within the family. So, is it grandmothers who take on the active role in being with and helping out the parents of their dead grandchild? Grandmothers do take a very active role which may, in many instances, be more active than that of their partners. However, as the stories of Alex, Keith and Rupert illustrate, individual grandfathers can be very involved in helping their children. Some grandfathers may be constrained by other commitments. Whilst Alex was able to organise to spend time and help Sarah & Frazer, the farming commitments of Rupert and Keith limited the time that they could spend away from the farm. However, in a clearly defined division of responsibility, Rupert and Keith both took



on more home commitments to enable Diana and Margaret to spend time with, and help out, their daughters, Pip and Sarah. Helping out does not always require grandparents to go and spend time with the parents, many grandparents offered advice or information which could be shared in person or at a distance, by telephone.

### Advice and Information

As parents of the parents, grandparents are often involved in discussions about what to do, particularly in relation to the funeral arrangements. Questions arise such as which funeral director to go to, how to word the death notice, whether to leave the coffin lid off or on at the funeral service, and where to bury the grandchild or scatter the ashes. Grandparents are both asked for advice and make suggestions of their own volition. Suggestions are based on a combination of previous life experience, relevant professional experience and insights. When Keith said the house still felt "odd" several months after Samuel's death, then Catherine, his mother-in-law suggested asking the Maori minister, who conducted Samuel's funeral service, to come and bless the house. It was a suggestion that felt like "a good idea at the time" and was greatly appreciated by Rachel and Keith.

Grandparents hold a belief that, whether they make suggestions or not, they should support the parents' decisions, whatever they are. Both Betty and Rupert acknowledged that they had grown up in an era when death was not discussed in their families. Pip and Donald's decision to take Gracie home for several days, and to take her in the Toyota to see different parts of the farm, was not the choice Betty or Rupert would have made. However, both supported these actions because they could see how important it was to Pip and Donald, and both could see benefits in being more open about death in the family. One of the consequences of being available to help the parents, but not actually making the decisions, can be a feeling of helplessness. This can almost be an uncomfortable form of powerlessness, as Ailsa remembered,

When you are a grandparent you are more helpless than when you are a parent. Because when you are the parent you have got the responsibility and you have got the decisions. When you are a grandparent you have to be there to help but you can't make any decisions.... You have to just stand back.  
(Ailsa 3:6)

The willingness of grandparents to support the choices of parents, and to take a secondary role, reflects their commitment to putting the wishes and needs of the bereaved parents first.

### Practical help

Aside from offering advice and spending time with the parents, many grandparents, in particular grandmothers, provide practical help around the house at the time of a grandchild's death, such as catering for the funeral, attending to visitors, and making cups of tea. Grandparents often help out with childcare for other children of the bereaved parents. This includes caring for them, either in the parents' home, or taking the grandchild to be with the grandparents in their home. In some instances where a grandchild becomes ill for a short time before their death, the grandparents may become the primary carers for the other grandchildren. This may involve telling the grandchildren that their sibling has died. By caring for other grandchildren, grandparents try to provide parents with the opportunity to spend time with their dead child or to attend to making the arrangements for the funeral.

Helping out also extends to subsequent grandchildren born after the grandchild who died. However, parents often do not ask grandparents to babysit in the first few months after the baby is born because, as Rachel said "for it [another grandchild to die] to happen to anyone else would be really bad - I think it was our responsibility to do that" (Rachel 1:14). This reflects the fears, which are shared by parents and grandparents, that the next child, too, might die. The certainty that all will go well, has often gone forever "*When the world turns upside down*". Financial help is another part of the practical help which grandparents offer. Having young children often means that only one parent of the grandchild is a wage-earner, so money is limited. If the money is available, grandparents offer financial assistance, when needed, to enable the parents of the grandchild to have some choices about planning the funeral or having a burial plot. Offering financial assistance requires a sensitive appreciation both of family relationships and of not taking over, since paying for their child's funeral is often important to parents as one of their last responsibilities to their child.

### ***Coping as knowing, caring and doing***

Part of responding to the challenge of a grandchild's death involves coping with feelings, thoughts and activities which result from the death. Individual grandparents cope in different ways, where "cope" is used to mean carrying on or surviving the challenge. Coping is perceived as fluctuating between times of "being strong" and times of "being less strong". It is about the shift from facing the challenge of raw feelings of loss, to eventually managing changes from the challenge where one begins to be able to live with these feelings, ideas and they become manageable. In the process of coping, grandparents draw on personal resources and strategies from life experience. All grandparents have varying levels of support **within** the family and some have support and information from **outside** the family. The three aspects of coping within this construction are: "*Coping as knowing*"; "*Coping as caring*"; and "*Coping as doing*". The latter is distinct from the earlier section on "*Helping out but not taking over*" where grandparents are seeking to help the parents. "*Coping as doing*" reflects the need of many grandparents to keep busy in order to distract from, and cope with, the pain.

#### ➤ ***Coping as knowing***

"*Coping as knowing*" includes: knowing what is happening; knowing what needs to be done, knowing what choices there are and knowing what is important in life. All of these give some sense of control within the unexpected situation. This contrasts to the period, "*When the world turns upside down*" which often has a shortlived sense of not coping, of not being prepared and of not knowing what to do. "*Coping as knowing*" draws on previous experience of death, crisis, or simply life. Previous experiences of death, such as the death of a spouse can give self knowledge of coping strategies. Ailsa believed, from her experience of her husband dying, that grief gets worse before it gets better. This helped her to be prepared for this response in relation to Conor's death. Similarly, some grandparents, like Diana, felt that previous family deaths, all of which have totally different circumstances, provided only the advantage of increasing confidence to cope with whatever occurs. Such a perspective does not provide short-cuts or panaceas to the situation but can give insights which help. Some of the training

and experience which grandparents gain within their work-place provides knowledge which is useful when a grandchild dies. Having experience in spending time with distressed and bereaved people may mean that grandparents are not overwhelmed by the pain of the parents. Whilst grandparents having this knowledge may be an advantage to the parents, it may not necessarily be to the advantage of the grandparents themselves. As Frazer pointed out, Alex was both a minister and a grandfather and around the time of Matthew's death Alex "had to be there to say the right thing and be supportive" (Sarah & Frazer 1:25).

There is little information available to provide grandparents with knowledge of how to cope with what is happening. It tends to be limited to pamphlets which funeral directors may give to bereaved parents to pass on to grandparents. Whether grandparents actively source and read written information about bereavement is related to their preferences as individuals for reading material in the form of books, magazines or the Internet. Grandparents who source such material find that it is usually general in nature or about other forms of bereavement. No-one had previously heard of the two booklets for bereaved grandparents which I sourced (Gerner, 1990; Leininger & Ilse, 1985). After reading these booklets most grandparents in the study found the booklets provided insights which would have helped them cope with the death at the time. Beth commented on the chapter on "Grandparents and Holidays" by Margaret Gerner.

[it] touched a chord as Christmas came not long after Daniel's death. We floundered through. This book would have been helpful at the time. It has helped me now with Daniel receiving a gift at Christmas time, as does everyone else. It is a decoration for the tree to remember him by. It is much appreciated by Rosanna and Leslie [Daniel's parents] and it will continue.  
(Beth 3:1)

"*Coping as knowing*" can include holding beliefs or a worldview that offers a philosophy of life. Sarah said about her son, Matthew's, death, "I don't know how people manage without faith. My faith is very important to me and has given me the strength to carry on.... Having Alex and Benita being Christians as well, was great" (Sarah & Frazer 2:13). Believing that the grandchild's spirit is with other dead family members can help both grandparents and parents to cope with the pain of

imagining a small child alone, and separated from the care of its close family. Ailsa talked about her husband and grandson being together.

My husband is never far from my thoughts... We [the family] still talk about him. I don't know whether I even believe in the after life, but we talk about this as "Granddad will be looking after Conor" and those sorts of things. But I think that is to help yourself.... You feel its consoling each other and you are consoled by the thought that everyone you love is together. (Ailsa 1:14-15)

Another aspect of "*Coping as knowing*" is discussed on page 371, as part of "*Putting loss in life in place*", where particular beliefs contribute not just to coping with, but learning to live with, or accept, the grandchild's death.

Knowing that other deaths, tragedies and disasters exist, and continue to happen, can provide a way for some grandparents to cope. It is a strategy with which we are all familiar having been told to "Count our blessings". Elwyn explained,

I guess you have to think that some people are worse off. I always remember a Minister telling me ... I was pretty down, I had a miscarriage with my first baby and my husband had a bad accident with his lime sower and we hadn't even been married a year. I remember he called, when Ministers used to, and I remember he said, "It doesn't matter how bad things are, if you look around you, you'll always find somebody who is worse off than you are." I thought it was a bit unfeeling at the time, but I have thought about those words so often since. It is true, you know, there are some very, very sad things around. (Elwyn 2:10-11).

### ➤ *Coping as caring*

Another aspect of coping is caring for, and being cared for, which is, in effect, about emotional support. Most grandparents cope by being able to care for parents and their children by being with them, or helping out, particularly in the early days. Some grandparents find that keeping busy by cleaning their child's house or looking after visitors can be a distraction to the pain. Catherine reflected that even being able to do something small, like a phone call for the parents, helped to cope with the feelings of helplessness.

Coping is also about feeling valued, and cared for, oneself. Much of the support and care for grandparents comes from within the wider family such as their other children. The amount of support grandparents seek, and/or accept from the

parents of the grandchild varies. For Alex & Benita, both giving and receiving support is about the mutuality of the family. In contrast, Maxine's concern, at the time that Matthew died, was to help her mother cope because she perceived that a range of experiences and losses in her mother's life made it hard for her mother to cope. Support, which helps grandparents cope, also comes from outside the family. In particular, friends and people who are part of the local church, or rural communities. It ranges from expressions of support such as cards, baking and phone calls, to people sitting down and talking. Such support is often appreciated by grandparents, but does depend on what individual grandparents want for themselves. Some do not want a lot of fuss and want to be able to choose when they talk about their feelings. Expressions of support for grandparents are not widespread. Grandparents are much more frequently asked how the parents of their grandchild are. There is no question or acknowledgement of how the grandparents are coping, which may socially reinforce the role of being a grandparent as secondary to the primary role of the bereaved parents. Jenny wrote that the main issue for her, as a bereaved grandparent, is,

[I want] to be acknowledged by "society and the media" to be suffering a great loss. Not just be accepted as the "tower of strength" for everyone else and as the 'bottomless pit of experience' to be drawn on at will. But to be in need of a hug or a friendly ear, or just someone to sit and walk with in companionable silence. (Jenny 4:1)

Supporting people to help them cope is often the goal of health/bereavement professionals and self-help groups. However, few grandparents receive support or acknowledgement from health professionals such as their own GP, or those



“No” because grandparents, and parents, perceive that grandparents cope with the resources they have. The “but perhaps” is because most grandparents appreciated that, in the process of this research, they had gained new insights and some wondered if this would have helped earlier in their bereavement. However, the research process has not been about helping grandparents to cope, because they were coping, or had coped, before they took part in this research. Instead, the research conversations have enabled grandparents to explore the next two aspects of grandparent bereavement – “*Placing the grandchild in the family*” and “*Putting loss in life in place*”.

### ➤ *Coping as doing*

Keeping busy at the time the grandchild dies is the way in which many grandparents cope; as Ailsa described Suzanne’s mother’s busyness (see p.279). Grandparents have a range of activities in their lives that assist in both expressing and distracting from feelings and thoughts. These activities are specific to each individual’s interests and circumstances, ranging between gardening, writing, knitting and sitting on a tractor.

This section of the construction has explored the different ways in which grandparents responded to the challenge in terms of activities and coping strategies. Interwoven amongst these responses are the situations where grandparents manage the changes which arise from the death of a grandchild.

## **MANAGING CHANGES FROM CHALLENGE**

From the time a grandchild dies, grandparents are involved in managing the changes which result for the family and for themselves as individuals. In this context managing the changes is a life-long activity since the death brings permanent changes. “Managing” refers to the thinking and the talking which goes on to make sense of or live with what has happened. This involves “*Placing the grandchild in the family*” and “*Putting loss in life in place*”.

### *Placing the grandchild in the family*

After a grandchild dies there is an ongoing process that involves creating, maintaining and redefining the grandchild's position in the family. The acknowledgement of the grandchild's place in the family occurs in two worlds – within the family and outside the family. For grandparents, this process of acknowledgement is important to them, as grandparents, to claim their loss. Acknowledgement is also important in their role as parents of the parents of the grandchild, because of the value that the bereaved parents place on marking the life and death of their child. To parents, the activities of grandparents in doing this are of particular importance when a young baby dies, since the baby has not had an established place in the outside-family world. The grandparents are, therefore, among the few people who may have seen the baby or acknowledged his/her existence in the world. This is part of the role which grandparents hold in the family as “family keepers”. From the perspectives of both grandparents and parents this role includes; keeping different branches of the family in touch, keeping the sense of continuity across generations with stories of family members (live and dead), and keeping a count of family members with new additions to the family.

Creating the grandchild's individual position in the family may not be necessary. The position may have been well established over a period of weeks or months, as the family came to know the grandchild before their death. However, where a baby dies around the time of birth there is a need to make their death concrete. “Concrete” is used to imply making something rock solid, as a foundation for their place in the family which, in effect, is the psychological process that occurs. It involves first making the life (presence in the family) and then the death (which is the loss of presence) of the grandchild identifiable and tangible. It is about responding to the non-personhood, discussed earlier. Ways and means of making the loss of the grandchild concrete include using memories, mementos, symbols and memorials. All of these assist with the process of “bonding” to the child and establishing the permanent gap, or place, for that grandchild in the family.

Maintaining the position of the grandchild in the family, is about keeping their place as time goes on ... and on ... and on... It is about grandparents revisiting

memories, talking about memories, visiting memorials, looking again at mementos, and remembering anniversaries. It also includes making a conscious decision to count the grandchild, or not, when asked "How many grandchildren do you have?"

Redefining the position of the grandchild in the family occurs as time moves on. As the family grows older, does the grandchild keep their place of importance in the family? What happens when another grandchild is born to the same parents? In the midst of all the excitement about a new grandchild is the paradoxical awareness that this new child might not have existed if the grandchild, who died, had lived. Subsequent births mean re-appraising the loss of the dead grandchild. Redefining the grandchild's position includes grandparents sharing memories and looking at mementos with the parents, other existing grandchildren and new grandchildren.

The sections below explore six parts of the process of creating, maintaining and redefining the position of the grandchild in the family; *"Memories"*, *"Mementos"*, *"Memorials"*, *"Symbols"*, *"Counting the grandchild"*, and *"Anniversaries, meaningful dates and milestones"*.

### ➤ *Memories*

As grandparents talk about their dead grandchild to themselves, their partner, the parents and other grandchildren, this forms a large part of marking the life and death of the grandchild as both a part of, and a gap within, the family. Margaret said, 4 years after Matthew died, "I think it is awfully good to talk about him a lot. Just include him as ... Just talking makes it easier" (Margaret & Keith 2:8).

Grandparents' role in talking about, and remembering, their grandchild is highly prized by parents. As time goes on, the amount of talking and remembering tends to diminish, yet has ongoing importance for the parents. Remembering what happened, who said what, how the grandchild was, how the funeral went, forms the fabric of memories, which largely depend on having shared in the life and death of the grandchild by being with the parents and their family. Terese's memory of holding Bernadette is deeply treasured **because** there are no

photographs or mementos of her. A range of things can trigger memories for grandparents and parents – music, smells, places, words –all acting as a reminder which brings back memories and with them, come the strength of emotion attached to the memory. Pip feels that what is important to her, as Gracie's mother, is what she calls the "spontaneous remembering" (Pip 2:26). This is talking about a memory that has been triggered as part of everyday life, as opposed to creating an artificial situation to talk about Gracie. For her, the important role that grandparents hold is "remembering to remember" (Pip 2:21) and to talk about their memories spontaneously.

For some grandparents there can be a fear that, with aging, the memories fade and that they do not always remain fresh. The issue is not that their grandchildren will be forgotten but that some of the details will be less clear. For Marie, in her mid-70s, with slow memory loss occurring, her concern stemmed from a sense that, for both herself and for her daughter, it was important that she held on to the few memories she has of Ruby's life.

Grandparents join with parents to keep and share memories with existing, and subsequent, grandchildren in the family where a grandchild died. Naming, talking about memories and looking at photographs, all help to keep the dead grandchild's place for existing grandchildren who, if young, may only dimly remember what happened. Ailsa explained,

We often talk about him. Not everyday conversation every day of the week, but we all do talk about Conor. In fact I was at Laurie and Suzanne's for tea last night and were were talking with Joanne [Conor's older sister] about it. The children were saying how they spelt his name and I said 'What was Conor's other name?' just in conversation. I think it is important for children, too, to bring that up now and again. Not just to push it away to the back.  
(Ailsa 2:6)

Sharing memories with subsequent grandchildren helps them to place themselves in the family. This means grandparents, and parents, have a responsibility to look at how memories are interpreted, in order to be realistic about, and not to romanticise, the role of the grandchild who died. Otherwise, as Benita pointed out, there is a danger that a living grandchild could grow up in the shadow of its idealised sibling, feeling an inferior replacement.

### ➤ *Mementos*

These are tangible items that were part of, and therefore reminders of, the grandchild's life and death. They tend to be portable and are able to be touched, taken out and re-viewed. The range of items includes photographs, videotapes, hospital identity bracelets, foot and hand prints, locks of hair, clothes and toys planned for, or used by, the child. The number of mementos a family has can vary from none to many. It depends on the age at which the grandchild died, since with age there is more opportunity to accrue mementos, and having the opportunity to collect mementos. Elisabeth regretted that when Martin was born and died, only two polaroid photographs were taken by hospital, and only one of these was of reasonable quality. Lorna keeps this framed and Elisabeth looks at it when she visits. Nowadays, the hospital has a camera and takes a whole roll of film for families, but it is too late for Martin and his family.

Grandparents feel it is the parents' prerogative to hold or to distribute any mementos of their child. This particularly applies when the memento is unique, such as a lock of hair. Respecting the parents' "right" to own mementos was the reason that Colston did not ask Christine for copies of photographs of Christopher, even though, as a grandparent, she keenly felt the loss of a photograph amongst the photographs her other living grandchildren (see pp.191-192). The mementos which grandparents do have, are generally copies of those which the parents have, such as photographs, birth/death notices and the funeral order of service. The way in which grandparents treasure or interact with mementos by re-visiting, looking at and talking about them, is valued and appreciated by parents. It represents an acknowledgement of, and an opportunity to talk about, their child. As time goes on after the grandchild's death mementos do not diminish in value, but are visited less often. When there is an opportunity for parents and grandparents to jointly view mementos, this is a moment treasured by all, as a time to focus on the child.

When looking at the way in which grandparents use the photographs of their grandchildren it is clear that they become a form of memorial. Some choose to frame, hang on the wall and publicly display photographs. Where the photographs are placed can be a symbolic display of keeping the place of the grandchild in the

family. Alex & Benita placed Matthew's photograph on the stairs between the photographs of his living sisters. This symbolises his place in the birth order of the children - between Rose and Jessica.

### ➤ *Memorials*

These are tangible things used as a statement to remind people about the life, death, and importance of the grandchild to parents, grandparents and the family. Often these are solid structures publicly marking a place where the child was buried or ashes were placed, such as gravestones and plaques. They mark a physical place identified with the child - a place to take flowers to or to go and talk to the child. Grandparents perceive it to be the parents' right to organise and decide the form of these memorials, although they may offer ideas for parents to consider. In contrast to personal memorials for the grandchild, there are also publically owned memorials, which can represent the grandchild to individual grandparents and families. The decision to scatter Christopher's ashes was later regretted by his mother and family because there was no geographical place to visit which could be identified as "his place". Some time after Christopher's death, "George", a concrete teddy bear, was erected in the nearby cemetery by the local SANDS group. George is a public memorial to all the children who have died. He has now become the place where Colston and Christine go to put flowers for Christopher.

The importance of structural memorials, to grandparents, varies according to the meaning that the memorial has for them in relation to their grandchild. Marie did not visit Ruby's grave and headstone because, as Rose understands, Marie does not feel that Ruby's spirit is there. Other grandparents visit memorials both for themselves to spend time thinking about their grandchild and to show the parents that, by going and placing flowers there, the grandchild continues to be of importance to them.

Written memorials include birth and death notices in the newspaper and entries in books of remembrance. These are a public acknowledgement of the family's loss, generally naming as mourners, the parents, then grandparents and other siblings. Another kind of written memorial, created by the grandparents in consultation



with the parents, is a story about their grandchild. In developing her story for this research Elisabeth confided that she liked writing Martin's name, it was a memorial to him. Her story has been included in the SANDS Aberdeen booklet available to bereaved families and health professionals.

### ➤ *Symbols*

Many grandparents identify a symbol which has a story or reason attached, as to why it re-presents their grandchild. The symbols provide an ongoing tangible link to the grandchild. Beth told her story of the spanner.

Leslie [Daniel's father] is a mechanic and wee Daniel, after he died, was at home all dressed up in a little suit and he had this spanner in his pocket and a little car. I guess because Daniel's dad is a mechanic you relate the two. I always thought that Daniel look very much like his dad. So, I think of him as this little boy with a spanner in his pocket. (Beth 2:19)

Symbols can be private to the grandparent, or shared with family and/or with other people. Many symbols are not created consciously. It appears that they emerge by standing out as a memory or an image of a situation, which has a meaningful link to the grandchild. The symbols which participants have chosen to share publicly, are represented at the end of their stories. Symbols may have an ongoing meaning or may have particular meaning at certain times, such as anniversaries or special times. So, Colston lights a candle to Christopher in her study at Christmas, and Jenny released a blue balloon with streamers to take her love up to Jordan on the anniversary of his death. Symbolic links can have a deep personal or spiritual meaning particularly related to the place where the grandchild is buried, or where their ashes are placed. Some families carefully choose the location for burial to represent a family place, and taking the grandchild to this chosen place represents keeping the child within the arms of the family. Terese explained, the importance of having Bernadette was buried with Terese's grandparents. Similarly, Alex & Benita explained that Matthew was buried in the burial plot reserved for them and that Matthew was a "trail-blazer" going ahead of them, which represented the family staying together and being re-united in death.

### ➤ *Counting their grandchild*

This can be a matter of large, or small, moment to grandparents and parents. Social interactions with new people often require us to define ourselves by roles in

relation to work and family. Consequently, grandparents are often asked "How many grandchildren do you have?" This can create a challenge as to whether to acknowledge, in a public setting, a loss which is painfully felt. In response to this question there are a number of replies:

- the total number of grandchildren- with no differentiation between living and dead;
- the total number of grandchildren but differentiated e.g "I have four living grandchildren and one grandchild, "Zoe", who died";
- the number of living grandchildren only.

Grandparents respond to the question individually. Some grandparents always state the total number of grandchildren to whoever asks, because it is about keeping the gap in the family visible to the world. Elisabeth wrote, "I always say 'Two, but we lost the first grandchild, Martin, who was born too early and did not survive'. I like to mention his name. Then I go on to talk about Eilidh [Elisabeth's second grandchild] and bore the pants off them!" (Elisabeth 6:4). Other grandparents never include their dead grandchild in the answer, as they wish to avoid other people's discomfort. After all, it can be a conversation stopper to say that one has a dead grandchild, since the inquirer is often unsure how to respond. Some grandparents assess the situation and make a decision about the most suitable reply in the circumstances. When a grandchild is not counted in the reply grandparents are, generally, comfortable with their decision. This may be because they are convinced there is no purpose to sharing the information with a stranger **or** they avoid feeling disloyal to the grandchild, and to the parents, by mentally, or physically under their breath, adding "and Zoe."

The public acknowledgement by grandparents counting the child who has died is important to parents, and can be sorely missed if they do not do so. Whilst many thoughts, ideas and feelings are discussed between parents and grandparents, the decision to "count or not count" is an area where many grandparents and parents do not discuss *how* and *why* they each respond to the same question "How many .... do you have?". This means that parents may not always appreciate grandparents' rationale for managing the situation and grandparents may not appreciate how important the counting is to parents. Elwyn explained that she

counts Daniel now, 4 years after his death. She made the decision to count him when she realised how her daughter-in-law might feel when he was not counted (see p. 292).

### ➤ *Anniversaries or meaningful dates and milestones*

"Anniversaries" is the word commonly used, but it does not accurately denote that meaningful dates/times may occur more or less frequently than every year. The obvious ones are personal dates of importance to the whole family, such as birth or death days. Then there are the public dates perceived as "family times" such as Christmas, Mother's Day and Father's Day. Knowing how to deal with meaningful dates as a grandparent can be difficult. What to say? What to do? Aside from grandparents' own feelings about the dates, there is the perspective of being the parents of the parents and a wish to support them. But how to do this? This can lead back again to "*feeling your way*". Should one mark, or celebrate, the occasion by phoning or "*Being with*" the parents? Or should one try and follow their lead? Or should one say nothing, because it will bring up painful memories? From the perspective of the parents of the grandchild, grandparents have an important role in marking "*meaningful dates*" by a phone call, a visit, or flowers. To some families it is also important to mark less obvious, but nonetheless, "*meaningful dates*". Rose treasured her mother phoning her on dates like one month after Ruby's death. To Rose, it was an expression of how much her mother thought about Rose and Ruby.

As time moves on, "*meaningful dates*" extend to include "*meaningful milestones*". Many grandparents hold two images of their grandchild, which we have called "dual age images". One is the memory of their grandchild as they were alive and dead, as an infant. The other is an image of how they might be at the time a meaningful milestone is reached – like being a toddler, going to school at the age of five, or in the future reaching aged 21 years. Sometimes the image is not a clear picture of what the grandchild might look like, but a thought, "What would they look like at this age or stage?" Grandparents and parents perceive the times when these thoughts are talked about, as a joint family activity that redefines the place of the grandchild as the family, itself, is growing older. For grandparents, dual age images only seem to occur for young grandchildren who die. Even where

a close relative has died in their twenties the memory image of them has stayed at the age they died. Jenny tried to account for why she imagines Jordan as he gets older.

I can only guess at why this is so. It is probably because we have no memories to fall back on. And, also, the fear of leaving Jordan behind as a newborn baby. So, we bring him forward always as though he was growing along with us and our other grandchildren. (Jenny 5:5)

The activities involved in placing, and keeping the place of, the grandchild in the family are paralleled in a similar range of activities which involve the grandparents "*Putting loss in life in place*".

### ***Putting loss in life in place***

This aspect of the construction "*When an infant grandchild dies*" represents the psychological and spiritual re-organisation which grandparents undertake when a grandchild dies. It includes: "*Re-visiting other losses*"; "*Living with the grandchild's death*"; "*Re-viewing self*"; and "*Re-viewing the family*". In a metaphoric sense, it is like re-organising the wardrobe although clearly of a vastly different magnitude and importance. This re-organisation may involve a complete overhaul with everything taken out and checked over before some clothes are replaced and others are discarded, or it may just involve a little brushing of existing clothes or switching the order of a few hangers around.

#### **➤ *Re-visiting other losses***

By the time a young grandchild dies most grandparents have experienced the deaths of other family members or close friends, and there have been innumerable other changes and losses in life, ranging from children leaving home, new jobs, to divorce. Grandparents do not see losses as discrete sections of life; they become part of the whole and are interrelated. Contrasting previous loss(es) with the new loss of a grandchild involves: developing knowledge and insights on coping with death (see p. 357); identifying the particular nature of bereavement when a young grandchild dies (see p. 343); and re-visiting or re-viewing the earlier losses in the light of feelings, experience and hindsight gained from the experience of their grandchild's death. Revisiting other losses can change the feelings about the earlier loss or even result in activity about redefining the place of that family member. It is

in the area of childbearing loss that such redefinition of the place of a dead family member appears to be particularly meaningful. Both Colston and Maxine's mother had children of their own die unexpectedly. After the death of their grandchildren, both undertook activities, such as revisiting memories and visiting special places associated with the dead child, which created and strengthened the the place of their own child in the family. Similarly, the husbands of Elwyn and Ailsa had died before their grandchildren died and both experienced feelings about their husband's deaths which were interlinked with their grandson's deaths. It appears that re-visiting the loss can include re-interpreting the loss from the position of a different stage in life, as Colston described (see p. 9), and also re-interpreting the loss in what may be a different socio-cultural context. For both Colston and Maxine's mother, ideas about infant death have changed extensively in the 30 years since the death of their children. Other deaths may be much closer than 30 years ago. For Keith, and his family, Keith's mother's death is entangled with Matthew who was born on the day she died and died on the day she was buried.

### ➤ *Living with the grandchild's death*

Being able to move from the shock of "*When the world turns upside down*" to a point where the world has settled into its changed form is managed in different ways by individual grandparents. Within this construction the "point" of settling is not necessarily an endpoint, because bereavement is not viewed as a finite state where grandparents "get over" or "recover" from the grandchild's death. Instead, bereavement is seen as lifelong, and as permanent, as the death of the grandchild. However, the feelings change and, for most grandparents, a point is reached of living with, or accepting the grandchild's death. "Acceptance" does not mean willing acceptance – it is an acceptance of an event that has happened, and over which grandparents have had no choice. Alex viewed it, 4 years after Matthew's death, in the following way.

I don't think you ever completely get over it, but a major resolution has taken place. But there will always be occasions when it seems you go back into a space of coping with it, like anniversaries and that sort of thing.  
(Alex & Benita 2:36).

Pip was talking about both herself, as a parent, and about grandparents when she said "people say time heals- it doesn't heal, it changes it [grief]. It makes it

different" (Pip 1:23). Ailsa explained this "difference" and change as a result of her grandchild, Conor's, death in the following metaphor.

It does get better, it becomes the norm.... It is like a door opening and shutting. It is like a different room of the house. Each part of your life is like a different part of the house. Going from one room to the next and becoming used to living in that room. (Ailsa 2:16)

Ailsa also believes that sometimes, in moving between the rooms of our lives, there is a **long** passageway to get there. In describing "the norm" Ailsa meant that life continues to go on; routines and functioning return to the family. It is the loss of the grandchild that does not go away; it is a permanent change.

So, how do grandparents reach their individual points where they accept, or live with, their grandchild's death? For some grandparents, parents and families, their Christian beliefs frame the context of the grandchild's death with a clear structure that there is life after death. Here the focus is on the wider picture and not on the purpose or reason for the grandchild's death. For grandparents without such beliefs, there are other ways of making sense of a the death, such as holding the view that if one cannot change something in life then one has to learn to live with it. Rupert drew on his farming experience, "I suppose all my life dealing with animals and livestock you accept that things die for no reason at all [... and you] think 'Well, it happens. It's part of the way Nature has got things organised.'" (Diana & Rupert 1:6). Another way of responding to the question, "Why did he/she die?" is to try and find a medical answer from the postmortem results. However, these results rarely provide an answer which then leaves the question of "Why, when he/she was perfectly formed, did he/she die at the beginning of life?" Finding a way of living with those questions may be hard or may never happen. It involves wanting a structure for understanding why events like this happen, and not feeling comfortable with a world of chaos and random events. Grandparents, who want an answer to the question WHY?, can perceive two benefits of having the question answered. It may be possible for medical technology to prevent future grandchildren dying, and it might provide a purpose, or a meaning, to the pain.

With, or without, a medical answer or particular beliefs, grandparents and parents can mutually identify positive outcomes to the grandchild's death. These include



self growth (see next section), helping others in the community, and strengthening family relationships. Some grandparents and parents interpret these as giving a purpose, or meaning, to the grandchild's death. Rose shared with her mother a belief that "something good comes out of it. Yes, it gives a meaning. It would be awful to think that there was no meaning behind anything. That she died just because she died" (Rose 2:11).

### ➤ *Re-viewing self.*

The challenge and changes, discussed earlier, which occur when a grandchild dies can lead to a re-viewing of oneself. This can bring new insights and perspectives about "who one is", and "how one is" as a person. This encompasses the grandparent as a whole person, rather than defined by roles and relationships within the family. Individual grandparents have insights and perspectives which are specific to the context of their own lives. Three aspects which recur are "*Sense of growth as a person*", "*Changing position to join the 'other' club of people who been bereaved*" and "*Re-visiting own mortality*".

#### *Sense of growth as a person*

This reflects a perspective that, as a consequence of the experience of having a grandchild die, "self" has gone beyond what one would have thought possible or expected. It encompasses new understandings of grief, pain, skills and resources to cope - often with a sense of new depths, strength and self awareness. Rupert talked about this as character building in the face of adversity. Benita called it the "Matthew experience", which she hoped she would always retain and share with people. It can mean grandparents having a sense of quiet pride in themselves, for not just surviving but for extending and growing. Such growth is not only a sense of internal change - it is perceived externally. First, by other family members, such as the parents of the grandchild, who are proud of the growth and second, by changes in the roles and activities that grandparents undertake. For some, it adds a new dimension of understanding to their professional work roles; for others, it means taking on new activities to support bereaved families or fund-raise on their behalf.

Joining the "other" club

Having other people perceive that they have joined the "other club" of people who have had children or grandchildren die, can change how grandparents see themselves. Having been admitted, by circumstances not choice, to this "other club", a whole range of people now identify that grandparents will understand, or share with, their experiences. Sometimes complete strangers come "out of the woodwork" to talk about what happened when their child or grandchild died. Or people, known to the grandparents for years, who have never previously talked of their loss, now feel safe to do so. In effect, it uncovers a complete subculture of families bereaved by the death of a child. And yet, many grandparents clearly identify that, whilst there is a common meaning of the shared event of the death of child or grandchild, the individuality of the person also means that all bereavements are uniquely experienced.

Re-visiting own mortality

Death is a fact of life and the death of a grandchild means that many grandparents give some thought to their own mortality. This re-visiting is not associated with any identified sense of fear. Diana felt, "Life is for living at the moment and I enjoy that, although I am quite prepared to accept that it is not always going to be like that and I will face that" (Diana & Rupert 2:19). Sometimes grandparents have a sense of achievement and fulfilment for life already lived, which can contribute to looking forward to death as a time to re-join family members, including their grandchild.

➤ *Reviewing the family*

The challenge of having a grandchild die does not dramatically alter the nature of existing relationships which grandparents have with their own child and their child's partner. However, grandparents generally feel that relationships get "closer" than they were before. So, if a relationship was previously close, it is now even closer, and if it was a polite, distant relationship then it is, perhaps, a little less distant. The idea that a crisis or challenge pulls everyone together forever more, is not evidenced here. Whatever the relationship Margaret felt that it made her value the family members who remain, "I think that you think, 'Well, goodness ,

aren't you lucky to have everyone you've got?" (Margaret & Keith 1:35). Being a member of family means knowing the strengths and weaknesses of other family members, and how they are likely to react in a particular situation. This is especially true for parents who have watched their child grow to adulthood. The challenge of having a grandchild die means that grandparents, as parents of the parents, may identify new facets, or perspectives, of their child, or child's partner, previously not appreciated. This can occur either by spending time together, with opportunities to learn about aspects which already exist, or because of new aspects which emerge as parents cope with, and respond, to the tragedy. By way of example, Alex & Benita came to appreciate the extent of Sarah's involvement in the community, after meeting the constant stream of visitors who came to Sarah & Frazer's home to farewell Matthew. The new aspects which grandparents see emerging in the parents are universally positive and focused on two characteristics; strength to cope and personal growth to contribute to the community. In describing their own feelings about the parents' ability to cope, grandparents commonly used the word "amazed". In terms of personal growth grandparents valued parents' contribution to the community in general, and to bereaved parents and to self-help groups specifically. Implicit within this appreciation is the valuing of something good arising from the death of their grandchild.

## AND NOW- MOVING TO AN OVERVIEW OF THE WHOLE

The construction above provides a rich understanding of the complexity of grandparent bereavement, it is now time to take a step back and look at how that complexity might be represented at a conceptual level and in diagrammatic form. *Figure 6.1: One Joint Construction of Grandparent Bereavement* provides a means to see the interrelated aspects of the construction at a conceptual level. It also represents the importance of family as a context to grandparent bereavement, which forms the conclusion for this chapter. It has four separate **circles** which symbolize the underpinnings of the construction of grandparent bereavement. The circles are named: "The Family"<sup>3</sup>; "Self as Individual"; "Parent First and Foremost-Grandparent Second"; and "Empty space-

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<sup>3</sup> I have used this font to differentiate the circles are encompassing the different aspects of the construction discussed in the previous part of this chapter.

Keeping place". They underpin each of the seven aspects (categories) which make up the whole construction. These aspects are represented as lines, or the spokes of a wheel, joining up, or crossing, the circles. They are named: *"When the world turns upside down"*; *"You have all those extra ones when you are a grandparent"*; *"Being with"*; *"Helping out as parents of the parents"*; *"Coping as knowing, caring and doing"*; *"Placing the grandchild in the family"*; and *"Putting loss in place"*. To understand what the diagram is re-presenting we can look at an example. *"You have all those extra ones when you are a grandparent"* is about the pain which grandparents feel, primarily for the bereaved parents and then themselves (so, it crosses the circle "Parent first and foremost - grandparent second") at the death of their grandchild (so, it crosses the circle "Empty place - Keeping place"). What the death means in terms of loss is perceived for self, for the parents and also for the family (so, it crosses the circle "Family") and the feelings as responses to this loss are different for individual grandparents (so, it crosses the circle "Self as Individual").

If we look more closely at the four circles; the representation of the circles within each other symbolizes a) that things go round and round with no obvious beginning and end, and b) the ripple effect of (Jordan et al., 1993). By exploring each circle separately the interrelated nature of this construction will become clear.

### ❖ Family

The event of, and experience of, grandparent bereavement occurs within the circle of the "Family" where members support, and are supported by each other. So, how is "family" constructed in this construction? It is perceived as resting on relationships of blood and intimacy which stretch across 3,4 or 5 living generations, and further generations if dead family members are included. The focus of much of this construction, of "When an infant grandchild dies", is on "family" being three generations, grandparents, parents and grandchild(ren), since this is the family context in which the bereavement occurs. In this context "family" is constructed in relation to the parents and includes both maternal and paternal grandparents of the dead grandchild. Family members are linked and united. Elwyn described this as, "you have your family ups and downs and you can't

always agree all the time, can you? But if there's trouble, we're always ready to help one another. That's important" (Elwyn 1:11). Where "family" is constructed from the position of the grandparents outside the context of "When an infant grandchild dies", then family includes all their children, sometimes their siblings, and parents, in addition to all the grandchildren. In this context, maternal and paternal grandparents do not, generally, include each other in their definition of "family".

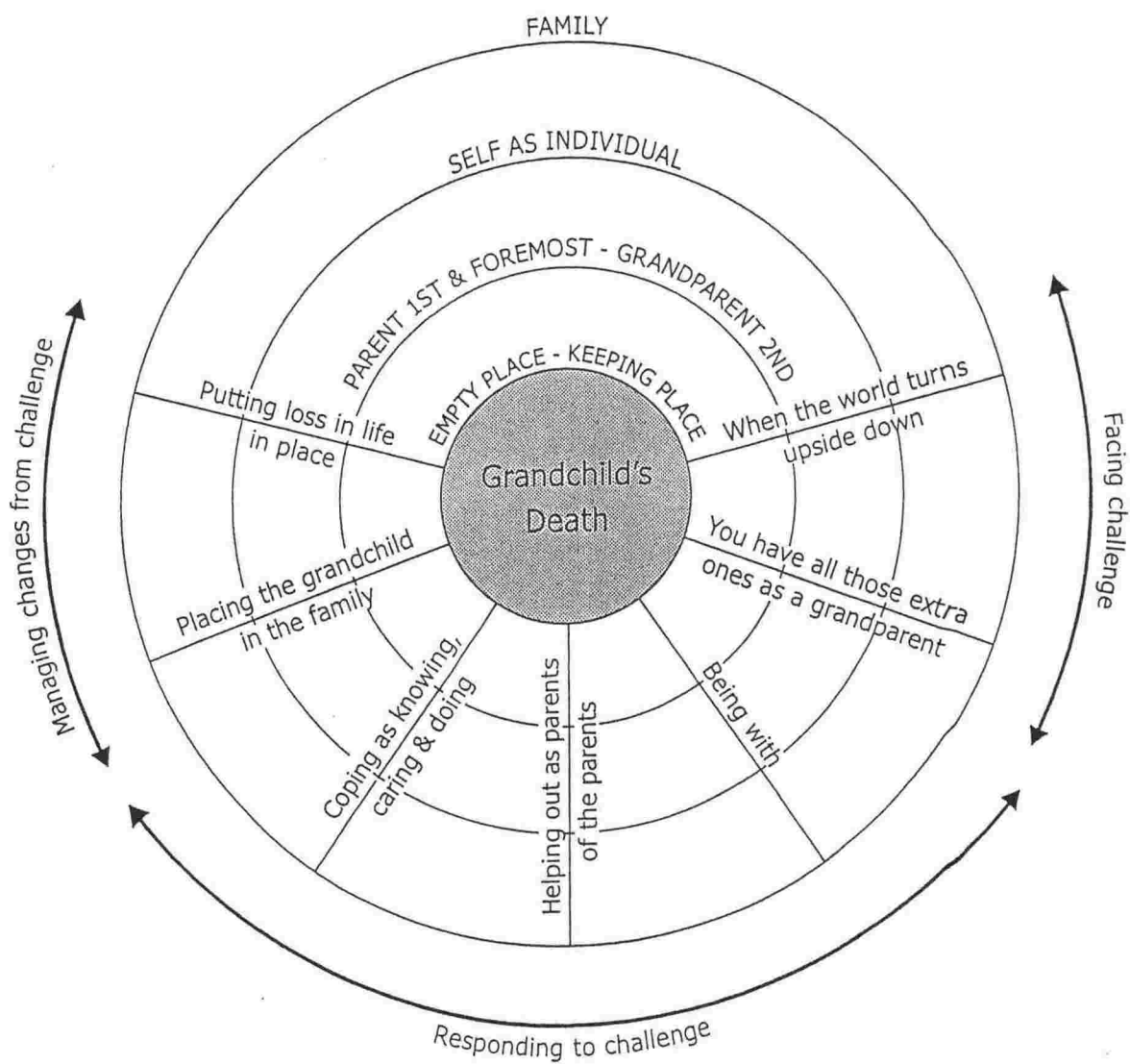


Figure 6.1  
One joint construction of grandparent bereavement

### ❖ Self as Individual

As Colston explained, being a member of a family is part, but not the whole, of "Self as an individual". The person who is a grandparent is made up of other roles, activities and beliefs. All of these aspects of self are brought by the grandparent to face, respond to and manage the changes arising from the challenge of a grandchild's death. Grandparents hold skills, knowledge, and particular beliefs about life or previous experiences of loss as resources for themselves, for the parents and for the family when a grandchild dies.

Appreciating grandparents as individuals underlines the unique and differing meanings of the same shared even of the death of a grandchild. This joint construction illustrates that there are shared meanings, but also emphasises that aspects of the experience are unique and are constructed in different ways by individuals living in different contexts and family worlds.

### ❖ Parent first and foremost - grandparent second

This circle reflects the two intertwined positions which grandparents hold in the family – they have a dual role. The circle name re-presents the sequence order in which these roles occur, and the role which is given priority when a grandchild dies, that of being a parent. It was Benita who made a link to a conference presentation<sup>4</sup>, she heard in the early 1990s, about children's death.

The comment was made by the person giving the paper that grandparents were a much left out group of people at the death of a child. And, that it was important to remember that before we were grandparents we were parents. And I thought that I think that sums up very much how we feel.  
(Alex & Benita 1:26)

So, whilst this study and construction is about grandparent bereavement which focuses on the role of being a grandparent, it is the role as "*parent of the adult parents*" which is the strongest voice heard in this construction. The phrase "Parents first and foremost" is used to indicate that, in this situation, grandparents feel for, and want to help, not just their own child, but also their child's partner. Elisabeth wrote, "Because you have known your child for so long, you grieve for her first and foremost. With us, we never saw Martin alive, so we could only grieve for this dear, little baby whose life was so short" (Elisabeth 6:3).

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<sup>4</sup> I have had no success in identifying the speaker but acknowledge their idea.



"Grandparent second" does not imply that being a grandparent is of lesser importance to being a parent. This is not the case as the pain and experiences in the individual stories show. It does reflect taking a secondary role to the primary grievors – the parents.

#### ❖ Empty space - keeping place

This circle holds within it the central event and centre of the diagram, - the grandchild's death. "*Empty space*" and "keeping place" are intertwined and are not time dependent, or sequential, because "empty space" continues forever and keeping place starts from the moment that the grandchild dies. "*Empty space*" can be a space which is both physical, like an empty cot no longer needed or slept in; and emotional, as Catherine said, "Samuel's not here- there is the gap... There is a space there. I still feel quite intensely that gap when I see photographs. When I see Rachel, Keith and their three little girls and there is one missing" (Catherine 2:12 & 18). This has remained the most apt term to express this and it has been used in the same context as the "The Empty Space Phenomenon" (McClowry, Davies, May, Kulenkamp & Martinson, 1987) which is discussed further in the next chapter. "keeping place" is a term that balances "*empty space*", both figuratively and alliteratively. When there is an "empty space" within the family, the question is "What do grandparents and other family members do?" "Keeping place" sums up the range of re-constructive activity which occurs, both physically and psychologically, as grandparents place their dead grandchild in the family and re-place their own world which may have turned upside down, momentarily or longer-term, with the shock and impact of a grandchild's death.

Moving outside the circles we reach the underpinning idea of the death of a grandchild bringing challenge and change to individual grandparents and the family represented by three separate arcs for different areas of the circle. These form the three parts to the challenge: "**Facing the challenge**"; "**Responding to the challenge**"; and "**Managing changes from the challenge**". These parts could appear as sequential, like periods of time (see Figure 6.1, p. 377) but they are interrelated. For example, whilst people describe feelings of shock, which are

part of **"Facing the challenge"**, these also become part of the memories which grandparents talk about and so they move on to become part of *"Managing changes from challenge"*. As Figure 6.1 represents **"Facing the challenge"** encompasses the world turning upside down at the unexpected death of a young grandchild, the feelings grandparents have for their own pain, for their children and for their grandchild(ren) and what it is that grandparents have lost.

**"Responding to challenge"** encompasses some of what bereaved grandparents "do" such as being with and helping out parents and their family, and also as individuals coping with the challenge. **"Managing changes from the challenge"** encompasses the changes that occur from the challenge in terms of family structure, where the grandchild "fits", and self as an individual. The image of challenge that we used in this construction was of a sailing ship, which could symbolize the family, on a calm voyage. The ship suddenly finds itself at the edge of the "known" world and sailing into uncharted waters, storms add to the experience of having to "ride it out", through a short or long journey, until calmer seas, and familiar landmarks, are sighted. The image seems appropriate for NZ, where the ancestors of the current population, whether tangata whenua or later arrivals, have arrived by boats sailing beyond the edge of the "known" world; and for the UK where some of the forebears went in those sailing ships.

## TO CONCLUDE – THE DANCE

In this construction, the strength and love of grandparents for their child's family shines through the complexity and individuality of the ways of being a bereaved grandparent. This is what I, personally, take away from both this construction and from the individual stories. The other impression of the whole construction, which remains with me, is the sense that grandparent bereavement, explored within the family, is like a complex dance. All the members of the family are involved and are dancing with each other - grandparents together with their partner, child, child's partner and other family. Each dancer has their own particular dance steps and these are altered to try and match the steps of their dance partner - which reflects the synchrony, unity and mutuality of feelings, care and support which exists in families at different times after a grandchild dies. Equally, at other times, one dancer is performing tango steps when the other is trying to do a waltz. There is a mismatch between what one is trying to do and

what is expected. This is a feature of everyday family life, not just the situation after a grandchild dies. Sometimes the difference between the dance steps matters and causes tension for individuals and family relationships. At other times the difference between the dance steps is "just how things are" within a particular family and this does not cause distress. What remains constant across individuals, and over time, is that "Family matters". It is the meanings encompassed in these two words which form the centre of the construction of "When an infant grandchild dies".

This chapter has explored the shared and differing meanings, shapes and forms of grandparent bereavement held in the joint construction. Combining this joint construction with the stories in Part 2, offers a perspective of personal experienced combined with the conceptualisation presented in *Figure 6.1: One Joint Construction of Grandparent Bereavement*. The next chapter debates the position of the stories and joint construction in relation to the extant literature to uncover similarities, differences and new ways of constructing grandparent bereavement.

## CHAPTER 7

### ISSUES AND CONTEXTS OF GRANDPARENT BEREAVEMENT

#### SETTING THE SCENE

This chapter offers my construction of the stories of grandparent bereavement in Part 2 and the joint construction in Chapter 6, positioned in relation to existing literature on bereavement, families and nursing. This story is distinct from the joint construction which was told as the voice and view of the group. In this chapter, it is my nurse-researcher voice which debates where this research fits with, challenges and extends existing ideas about grandparent bereavement. Whilst the chapter is written from my perspective, I have sought to work “with” the constructions of participants, and not to step back and write a story of a case “about” a particular aspect of bereavement (Frank, 1995, p. 158). As part of this process, the chapter has been sent to participants for comment, and it reflects their agreement with these interpretations.

I fully acknowledge that this is my selection of literature, which I believe illuminates particular aspects of the stories and joint construction. There is a wealth of other writing that could be discussed. In positioning my thinking in this chapter, two particular perspectives about bereavement have shaped the discussion. These were a re-conceptualisation of bereavement discussed in the book entitled *Continuing Bonds* edited by Dennis Klass, Phyllis Silverman and Stephen Nickman (1996) and the concept of disenfranchised grief extended by Charles Corr (1998-9) from Kenneth Doka's work (1989). I read this material after the fourth hermeneutic dialectic circle in 1998; whilst the ideas did not shape the discussions with participants they have underpinned my thinking as expressed in this chapter. To provide the time context of this chapter, it is relevant to note that I sourced literature to frame this discussion until mid-1999 when the chapter was sent to participants for comment.

I have continued to refer to "grandparent" bereavement whilst acknowledging that this research largely reflects the constructions of grandmothers - 13 of the 16 grandparents in the study. I want to emphasise that the three grandfathers in this research provided a perspective which enables me to claim this as research about **some** grandparents' constructions. I am also aware that similar, higher rates of participation by grandmothers are reported in other studies of bereaved grandparents ranging from 70-80% (DeFrain et al., 1991-92; Fry, 1997; Ponzetti & Johnson, 1991) and in sociological studies of grandparents (Kivnick, 1982; Somary & Stricker, 1998). In addition, other research on grandparenting has focused solely on grandmothers (Robertson, 1977; Timberlake, 1981, Wearing & Wearing, 1996). There are several possible reasons for more grandmothers taking part in this study. A range of research has identified that maternal grandparents, grandmothers in particular, have the greatest amount of contact with grandchildren (Cherlin & Furstenberg, 1986; Hartshorne & Manaster, 1982) and greater satisfaction in being a grandparent (Somary & Stricker, 1998). Therefore, maternal grandmothers might take part in research because they have a higher investment in the role. Of the participants in this research, 69% were maternal grandmothers, however, there are no details of grandparent lineage for comparison in other studies of bereaved grandparents. Another possibility is that more grandmothers, particularly maternal grandmothers, were involved in this research because mothers attending the self-help groups where information on the research was disseminated, passed this, first, to their own parents. Additionally, spousal bereavement of grandparents may inflate proportions of grandmothers. In this study 4 of 16 grandparents were widows. In P.S. Fry's survey (1997) 65% of participants were widowed and given that 70% of the 152 grandparents were grandmothers, this means that many were widows. This suggests there may be fewer bereaved grandfathers participating in research studies because they are no longer alive.

Having clarified these points, the following discussion is formed around three interrelated areas: grandparent bereavement constructed through relationships within the family world; grandparent bereavement as a journey – but to where?; and grandparent bereavement constructed outside the family world.

## GRANDPARENT BEREAVEMENT CONSTRUCTED THROUGH RELATIONSHIPS IN THE FAMILY WORLD

The individual stories and the joint construction illustrate that grandparents, and others, construct grandparent bereavement, in the context of the family. Grandparent bereavement is about a relationship with a particular grandchild who has died, but it is not a relationship that exists in isolation. It is defined by three relationships; between grandparent and parent, between grandparent and grandchild, and between parent and child. All three relationships frame how grandparent bereavement is constructed. Therefore, it is worth briefly considering what makes "family" before exploring the two focal relationships that a grandparent has in the family, those of grandparent-parent and grandparent-grandchild(ren).

### What is family?

Death of a family member presents a challenge to families because it affects everyone. It has been described as a "death ripple" (Jordan et al., 1993, p.425) which extends through the social network of people who normally support each other (Vachon & Stylianos, 1988). Consequently it places a challenge on family relationships (Jordan et al., 1993). "Family" has been seen as an important context for many aspects of individuals' and family life. These include: shaping constructions of reality (Reiss, 1981) where shared beliefs can operate as a family paradigm; developing roles and relationships of family members (Aldous, 1978; Duvall, 1977); linking to wider society (Bronfenbrenner, 1979); and being the focus for health care and nursing (Anderson & Tomlinson, 1992; Whyte, 1997). But what is family? David Cheal (1991) undertook a critical review in his book "Family and state of theory" and proffered the view that redefinitions of "family" occur as a result of family life changes. He then suggested that researchers who construct definitions will often be one step behind how families may be defining themselves. "Family" as a unit of research analysis can vary considerably (Cheal, 1991; Uphold & Strickland, 1989). This is evidenced in a range of research studies about infant death with reference to "family" in the title. In some of these, "family" is constructed, but not explicitly defined, as the unit of parents and children (Baumer, Wadsworth & Taylor, 1988) or the loose term "family members" is used (Kellner, 1981) with the role of the family as



accompanying mourners in the background (Lewis, 1979). The nuclear family, as a unit of functioning, and potentially for research analysis, is still widely promoted in media images (Cheal, 1991), social policy, and family nursing models (Wellard, 1997). However, participants in this research had a different and clear construction of family, which is congruent with the recent trend in family nursing for family members to decide who counts as "family" (Wright & Leahey, 1994).

Participants in this research constructed "family" as multigenerational, not as a nuclear form of parent-child relationships, nor with the unspoken assumption of this structure by referring to grandparents as "extended" family. Instead grandparents, parents and grandchildren were all part of the "family". When family was constructed on the basis of relationships through the parents, then grandparents identified their "opposite number", the parents of their child's partner, as part of the family. However, when "family" was constructed on the basis of grandparents' relationships, then it did not generally include their "opposite number", but it did include their other children and their families. This presents the perspective that "family" can be identified in different forms depending on the position and the purpose for which it is constructed. This fits with a postmodern view of family as having multiple meanings, as opposed to a fixed structure (Cheal, 1991). Accepting this perspective of grandparents as part of family, the following discussion is framed around the family relationships which form the context in which grandparent bereavement is constructed, those of; grandparent-parent, parent-child, grandparent-grandchild.

### **Grandparent-parent; a relationship of parent-child**

The central focus of grandparents in this research has been on their bereavement constructed within their relationship with the parents of the grandchild, not on their direct relationship with the grandchild. This appears to reflect the strength of the parent-child relationship in adulthood, and that the grandparent's relationship with the infant grandchild is mediated through the parents, as primary carers, or the mother as nurturer during pregnancy. Marie provides an example of this when she explained that she knew Ruby through Rose; this differs from the direct relationship a grandparent might have with a grandchild who is older and less dependent on the parent as primary carer.

Whilst not part of this research, grandparents increasingly act as primary carers for their grandchildren (Ahmann & Shepherd-Vernon, 1997; Kelley, 1993) which would add another meaning to grandparent bereavement experienced in that context.

Parenthood changing over time was how Colston described her views of being a parent (see p. 353) as through that relationship she became a grandmother. This represents a developmental perspective of parenting which changes during the life cycle (Cusinato, 1994). When their children are young, the parents' role involves making decisions for, and protecting, their child. As children grow to adulthood and parenthood, the role of their parent is renegotiated to support the young parents in ways which the young parents perceive as helpful, such as babysitting (Kivnick, 1982a; Robertson, 1977). Thus from a developmental perspective, being a grandparent rests on two parent-child relationships at different life stages.

Why is the parent-child relationship so strong? Dennis Klass and Samuel Marwit (1988-89) claimed that it is different to any other form of human relationship. In a review of parental bereavement occurring at any age, Brian De Vries, Rosa Dalla Lana and Vilma Falck, (1994) concluded that this relationship has an enduring strength over the life course. It is a relationship of nurturance, of psychological meaning and of biological reproduction. Bowlby's work (1969, 1980) drew together biological, ethological and psychological perspectives within the mother (parent)-child relationship as attachment theory. As a theory it continues to be widely debated and explored in the context of perinatal care and bereavement (e.g., Kennell & Klaus, 1998; Krone & Harris, 1988). This perspective is of relevance to this research, since it offers a way of understanding the strength of relationship between parent and child established at birth, continuing through childhood and into adulthood (Weiss, 1991). The strength of this relationship is evidenced in the joint construction with the circle of "Parent first and foremost-grandparent second" (see p. 377). Constructed within this relationship bereaved grandparents emphasise the primacy of their feelings and concern for the parents, and a wish to offer support to the parents.

### ➤ Feelings and concern for the parents

In the individual stories in Part 2 the feelings and concern for the parents shines through as a major part of grandparent bereavement. The pain as a parent of the parent is also presented in the clinical literature (Donnelly & Haimes, 1993; Gyulay, 1975) and in research studies (e.g. Ponzetti & Johnson, 1991). Kowalski (1987) noted that both paternal and maternal grandparents were concerned about the mother, with feelings about the grandchild being secondary. Similarly, Ponzetti, (1992) reported, in a comparison of 36 parents and 28 grandparents from American families where 21 children had died aged 1 month to 30 years, that "parents' reactions" were focused on their child, whereas "grandparents' concerns" (p. 69) were about their child, the parent. He concluded that the role of parent appeared more salient than the grandparent role in terms of grandparents' reactions to the death of a grandchild. Eighty American SIDS grandparents reported that watching their child's pain and being unable to make it better was, "the hardest thing of all to deal with" (DeFrain et al., 1991-92, p. 178). This mirrors the reflections of many of the grandparents in this study at having to watch the parent's pain and being unable to "fix it" (e.g., Ailsa, p. 278; Catherine, p. 319; Marie, p. 270).

Feeling helpless in the face of the parents' pain is not a feature unique to grandparent bereavement. It is a familiar feeling, particularly for anyone working in a supportive role, because we are all helpless to alleviate the other person's pain (McKissock & McKissock, 1991). However, the unique aspect for grandparents is the helplessness which is grounded in their role as a parent. Rando (1986) perceived this as contributing to grandparents' "double grief" in that "They not only lose their grandchild, but they "lose" their child as well, as they cannot rescue their child from bereaved parent status" (p. 37). Whilst the grandparents in this research did not express their feelings in this manner, the joint construction does speak of the same struggles constructed in different ways within the categories "*Being with*" and "*Helping out as parents of the parents*" where the emphasis is on the parent wanting to care for their child. Fry (1997), in a study of 17 American grandparents, also identified the complexity of grandparents' reactions, particularly for grandmothers, "because of the sheer inability to separate it [their own grief] from the grief they feel for their children".

This was expressed to such an extent that, as one grandmother explained, "It is almost as if we don't mind forgetting little Josh, so it gives us more time to help Rick [son] and his wife" (p. 130). None of the grandparents in this research talked of "forgetting" their grandchild, but several offered a different way of viewing the same issue. As Margaret & Keith explained, it was appropriate to focus on Sarah & Frazer because they were here and something could be done for them, whereas Matthew's pain had ended (see p.242). This interrelatedness of grief for self and parents was constructed by Gerner, a bereaved grandparent and a counsellor, in her book *"For Bereaved Grandparents"* (1990) as a fork with two tines. Whilst the tines on a fork are equal in size and length, the bereaved grandparents in this research put the parents' pain and distress before their own.

### ➤ **Putting the parents' pain first**

A number of grandparents, like Colston (see pp. 190-191), talked about putting the pain of the parents first, choosing to support the parents and not to share too much of their own pain with the parents. There is no indication in the work of DeFrain et al. (1991-92) or Ponzetti (1992) as to whether other bereaved grandparents did this. The decision, for grandparents in this research, appeared to be based on the relationship of parent-child, albeit adult child, and not wanting to further burden that child. It was often a short-term strategy because, in the long-term there was no intention to protect them from the reality of the grandparents' feelings. However, Gerner (1990) suggested that there can be another element in the decision not to share feelings with the parents, which is about self-questioning of a legitimate claim to grieve in comparison to the parents' grief. One grandmother explained in Fry's (1997) second study, "I am afraid to talk with the children for fear that I will say the wrong thing or put my own pain before my daughter's. After all my first thoughts should be for my daughter's pain" (p. 128). This was not a conflict identified in the grandparent's stories in Part 2, but it is a perspective that can be heard in Maxine's description of her mother-in-law's apparent non-response to Matthew's death (see p. 304).

A hierarchy of pain, or grief, was part of the joint construction where many grandparents perceived their child's pain as worse than their own (see p. 339). This might be a reflection of not having the "right" to feel as much pain as the

parents. However, the stories in Part 2 reflect grandparents' sense of being one relationship removed from the grandchild in which case it might be expected that the pain and sorrow would be "different". Whether "greater" or "different", grandparents and parents were aware of the feelings and distress of each other. In contrast, the experience of Sally, a bereaved grandmother reported by Katherine Donnelly and Judith Haines (1993), is a reminder of other viewpoints which are not part of this research. She described the influence of parents' expectations on whether grandparents construct their grief as legitimate, "There is the silent kind of grief [of a parent] that says. "Your grief is not as bad as mine. You are only a grandparent" (p. 29). Parents in this research did not share this response and were concerned to claim and recognise their parents' bereavement, as opposed to denying or overlooking it. Given the pain that grandparents feel both for parents and for themselves, what is outstanding is the commitment grandparents give to support the parents and act as a family resource.

### ➤ **Support to the parents of the grandchild**

When a grandchild dies, many grandparents, as this research illustrates, offer considerable support to their child. In doing so they often receive support in return with the chance to talk about their grandchild; although the stories and the joint construction emphasise that the primary intention was to give support to their child, the adult parent, at this time. In the joint construction (see pp. 347-356), we identified two aspects of support: "*Being with*" (*sharing time, humour and feelings*); and "*Helping out but not taking over*" which included giving "*advice/information*" and "*practical help*". These closely reflect the three dimensions of social support that Frode Thuen (1997) identified in a study of Norwegian SIDS parents. The dimensions were: *instrumental*, helping with chores and childcare; *emotional*, providing a sense of comfort and love; and *informational*, providing advice or information. In the Norwegian study "family members" (not defined who was included in this term) provided the largest amount of instrumental and emotional support, in comparison to friends, neighbours, professionals and the Norwegian SIDS society. If we assume "family members" includes grandparents then there is similarity with this study regarding extensive provision of support. However, the grandparents in this research were also identified as offering

informational support, which included offering advice on organising funerals and death notices.

To gain a perspective of whether other grandparents construct support as part of their relationship as "*parent of adult parents*" it is possible to explore other research with bereaved grandparents and consider research situated in the context of "every day"<sup>1</sup> grandparenting. In the literature on grandparent bereavement, there is no discussion of support in Ponzetti and Johnson (1991), Ponzetti (1992) or DeFrain et al. (1991-92) where the research focused on the "reactions" to, and "psychological effects" of, the death of a grandchild. However, support was part of "*Changes in adjusting and coping over time*" (p. 132) for the 17 grandparents in Fry's (1997) study. Fry found that at the 6 month follow-up interview grandfathers, in particular, perceived that helping with childcare, spending time with the family and offering financial help had assisted their own coping. However, this does not reflect the same sense of "*Being with*" and "*Helping out*", **for** the parents, as opposed to **for** oneself, which appears in the joint construction. This probably reflects the differing research goals. Fry's purpose was to "*better understand the complex nature of grief and the emotional complications of bereavement in older adults*" (p. 125) which is reflected in the emphasis on grandparents as individuals, whereas this research has focused on grandparents as members of families.

There is more extensive evidence of support which grandparents give to parents when a grandchild is disabled or born prematurely. These are bereavements bringing loss of dreams and expectations. Brigit Mirfin-Veitch, Anne Bray and Marilyn Watson (1996) undertook a study of 12 parent-grandparent pairs in NZ families where a child had an intellectual or physical disability. They found extensive evidence of the support which grandparents offered to parents. The authors found that 75% of parents reported receiving considerable support from grandparents, which included childcare, housework, financial help and emotional support. In this research, the stories in Part 2 illustrate similar, extensive levels of support were offered by grandparents. Veronica Rempusheski (1990) found a similar emphasis on support for parents when she explored the experiences of

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<sup>1</sup> I have used this word to denote grandparenting in non-bereavement associated situations.



15 American grandparents (three of whom were first-time grandparents), whose grandchild was born prematurely and admitted to NICU. Within the basic social process of "*Becoming or beginning to feel like a grandparent*" there were ten categories, of which two related to the grandparents' role in relation to the parents. The first, "*Being there/being with*" which was about physically and emotionally sharing in the experience is similar to "*Being with*" in the joint construction. The second, "*Acting to protect*" was about grandparents seeking "*to provide a better environment for the highly stressed parents*" (p. 50), such as childcare for other grandchildren. This is similar to the joint construction category of "*Helping out and not taking over*" where grandparents sought to provide parents with time and choices. However, in contrast to the grandparents in Rempusheski's study, grandparents and parents in this research reflected on, and rejected, the word "protection". They perceived it to hold the connotation of shielding and returning the parent to the role of a child being "protected" by its parents. It is possible that 9 years from Rempusheski's publication, the connotations of the word "protection" have changed from when the participants in Rempusheski's study accepted this interpretation of their activities. Or the difference in views may reflect the meticulousness of participants in this research in debating and distinguishing between the parent-child relationship of childhood and that of adulthood. In the latter relationship, grandparents perceived that parents could not be protected, because most were living an experience which grandparents had not experienced; they could only offer support and care.

When comparing the support which grandparents offer bereaved parents with the support that grandparents provide as part of "everyday" grandparenting, it appears that the support is of the same type. Studies of everyday grandparenting identified that grandparents' provided childcare, emotional support and childrearing advice (e.g., Kornhaber & Woodward, 1981; Robertson, 1977; Somary & Stricker, 1998; Wearing & Wearing, 1996). These are similar areas of support to those identified in the joint construction where the context was bereavement, not everyday activities. Whilst support from grandparents is generally provided to the parents, an area which has been debated in the sociological literature is the function which such support offers the family.

*Support to the parent acts as a family resource*

Whilst grandparents offer support to the parents their support also acts as a family resource; it can represent seeking to secure the future of the parent's family, with partner, and existing or future grandchildren. Many of the grandparents in this research valued their role in passing on to the next generation the family values and relationships (Neugarten & Weinstein, 1964) which they had experienced with their parents and grandparents. Timberlake (1981) called this an "expansion of self beyond their lifetimes (p. 63). However, grandparents in this research did not perceive that their support was endeavouring to secure the physical, or genetic, survival of the family. They offered support at an operational and practical level of caring. Many of the support activities of grandparents in this research are consistent with the symbolic functions of grandparenthood. Vern Bengtson (1983), citing the work of Lillian Troll, described grandparents at a time of family stress or crisis, as "family watchdogs" (p. 22). This phrase has the connotation of guarding the wellbeing and survival of the family. The difference in this research is that, instead of claiming a guarding role, which is suggestive of having the power to do so, the joint construction positioned grandparents as support actors for the lead players, the parents. A consequence of taking on this support role meant that grandparents, at times felt helpless and powerless (see p. 355).

*Expectations versus a wish to offer support?*

There remains a series of interesting questions surrounding grandparents' provision of support. Do grandparents offer support to their child, child's partner, and child's family because they **want** to? If so, do they want to offer support because of the significance invested in their relationship with the family? Conversely, how much is the provision of support shaped by a social construction that grandparents are **expected** to do this as part of their grandparent role? Constructions of grandparenting exist which appear to expect grandparents to be a family resource. These include educational programmes, similar to parentcraft classes, to "help" grandparents support to young families (Barranti, 1985; Castiglia, 1994; Horn & Manion, 1985; Strom & Strom, 1997). However, it seems that grandparents in this research wanted to offer support to their child's family, since they talked extensively about "how" to offer support with

sensitivity to avoid taking over from the parents. Sensitivity and concern were not features identified in any of the studies discussed earlier (DeFrain et al., 1991-92; Ponzetti, 1992; Ponzetti & Johnson, 1991; Rempusheski, 1990). This may reflect the use of constructivist inquiry as methodology in this research; since the discussions which teased out the role of grandparents as "*parent of adult parents*" took place during the second and third hermeneutic dialectic circles with participants. These debates were not part of earlier conversations. When assessing the nature and extent of support to offer, the grandparents in this research appeared to consider the existing expectations of, and relationships with, the parents. This reflects the complexity of roles within the family and fits with the view of Robert & Shirley Strom (1997) who thought that the grandparental role in the family "is partly defined by the expectations of relatives" (p. 281). The tensions associated with expectations of grandparental support have been discussed in the sociological literature with reference to the concept of double-bind.

#### *The question of a double bind*

Thomas (1990) wrote in the context of everyday grandparenting, "It is proposed that grandparents may face a double bind in attempting to meet parents' expectations; parents may expect grandparents to simultaneously be supportive without interfering" (p. 169). Interestingly, the grandparents in this research seemed to be one step ahead of this dilemma. They had their own expectations of themselves as being supportive but they were very careful not to overstep the mark, wherever this mark was placed by each individual family, or to take over from the parents. The concepts of "a double bind" or "walking a tightrope" which I discussed with participants were not favoured. People, such as Keith, explained that they saw it as a question of being sensitive and placing the parents first (see p. 354) – a perspective which seems to be grounded on a clear view of roles and relations within the family. However, whilst not called a double bind as such, the joint construction did identify the complex dance where, at times, dancers' steps were mismatched as grandparents and parents had differing hopes, or expectations, such as sharing feelings (see pp. 350-351 and p.381). Another possible double bind which could arise was highlighted by Donna Gaffney

(1992), a nurse writing about the family life cycle in relation to SIDS families. She proposed that,

*The young family has a brief history together. They will have limited experience of crisis, if any at all, and are unable to predict how significant others will respond. Support systems are not fully developed and adults may depend more on their families of origin rather than their partners. (p. 680)*

This view was not confirmed in the construction. Grandparents clearly respected the parent-parent relationship which is illustrated in their stories of giving their child time with their partner and making conscious choices not to always be there (e.g., Catherine, p. 318; Colston, p. 191). In addition, some of the individual stories emphasise grandparents' wishes to support **both** parents of their grandchild, which possibly reduces the potential for biological attachments to family of origin to divide the parents. Apart from Terese's daughter's partner, who was away for some time after Bernadette's death, the constructions in this research are formed in the context of stable relations between the parents of the grandchild. This means the research has not explored the meaning of grandparent bereavement shaped by being the parent of a solo parent or a parent who is not a regular carer for the grandchild.

### ➤ **Existing and changing grandparent- parent relationships**

Whilst all the parents in this research wanted, and when they received it, highly valued grandparents' support, it cannot be assumed that support is always wanted or accepted by parents. Gyulay (1975) and Julia Hamilton (1978) noted that when the parents reject such support it could lead to grandparents having feelings of guilt and anger. Similarly, Jenny described her confusion and pain when Sue rejected her help and presence (see p. 159). Research with grandparents whose grandchildren had disabilities emphasised the importance of pre-existing relationships in the provision, or lack, of support from grandparents (Mirfin-Veitch et al. 1996, 1997; Mirfin-Veitch & Bray, 1997). The authors noted that those grandparents who were "supportive" had a pre-existing positive relationship with the parents which had no periods of conflict and had a closeness which included reciprocity of support where both grandparents and parents helped each other out at different times. Sarah and Alex & Benita made this point when they commented on their relationship, not as a unidirectional flow of support but as a two-way, mutual relationship.

Images persist in conversations and the media that "bad times" or crises pull families together. In the discussions through this research both grandparents and parents identified, that over, time relationships between each other did often become "closer". But "closer" was relative to how the relationships were before the grandchild died (see p. 374). In the comparison of 36 parents and 28 grandparents from the same families Ponzetti (1992) made the distinction between changed **feelings** and changed **interactions**. Slightly more parents (56%) than grandparents (53%) reported changes (direction unspecified) in their feelings towards each other, but only 36% of grandparents and 44% of parents believed that their interaction patterns changed (nature of the change unspecified). In line with Ponzetti's work, only a few participants, in this study, felt that the relationships changed, such as Colston's comment, that there is now little that she does not discuss with Christine (see p. 194).

However, when considering the idea of changing grandparent-parent relationships, it is important to remember that relationships are changing with the birth of a new baby (Bright, 1992) and the death of a baby layers further changes on top of the changes resulting from the birth. This was most apparent in this research when the infant who died was the first baby born in the family and the changes in relationships were interrupted. As both Jenny and Elisabeth described, they sought to recognise the existence of the new family and offer support, and time alone, for the parents to create being a family with their dead baby. At the same time, they were both struggling with the meaning of their grandsons' deaths for their identity and relationships and grandmothers. Hence, the complexity of bereavement situated within a family in which relationships and roles are changing and emerging prior to the death.

### **Grandparent-grandchild relationship**

Part of grandparents' loss and grief is centred around the grandparent-grandchild relationship. The death of a grandchild brings a loss based on the meaning the grandchild holds for the grandparent and also the loss that they perceive it causes for other family members, including other living grandchildren.

### ➤ Own loss of a grandchild – the feelings

The grandchild's death brings a range of reactions including a sense of disbelief, feelings such as sorrow and anger, and physical changes such as crying and weight loss. Whilst not described by participants in this form, it is possible to see the four categories of expressions of grief (affective, physical, cognitive and behavioural) described by Worden (1991). Whilst I have separated different aspects of grief for the purpose of discussion, I believe this is an artificial distinction and that the stories in Part 2, support the view that bereavement/grief is a blending of reactions (emotional and cognitive) to loss (Rosenblatt, 1996 citing Wikan). Feelings of shock in "When the world turns upside down" were mirrored in two themes of Fry's (1997) study; "Emotional rupturing" which included shock and disbelief, and "Shattered belief systems" which reflected feelings about the "grave untimeliness" (p. 128) and unfairness of death. In the sequence of life expected in Western society parents do not survive their children at any age (Moss, Leshner & Moss, 1986-87; Sanders, 1979-80), let alone an infant at the beginning of life which is seen as the very "antithesis of death" (Rando, 1986, p. 3). The death of a grandchild violates the expectations of two parent-child relationships which assume a grandparent will pre-decease their child, who in turn will pre-decease their child (the grandchild). Similar feelings of shock and/or disbelief, were reported in Ponzetti (1992) and DeFrain et al., (1991-92) and are generally seen as common cognitive expressions of grief (Worden, 1991; Kalish, 1987). In the joint construction shock and disbelief accompanied other affective expressions of loss which were a continuing sense of sadness and pain, sometimes anger, and rarely guilt. That the sadness and, at times, sharp pain continues is evident throughout the stories and is still part of the postscripts which people have written 4 years after the research began. The question of whether there is, or should be, an endpoint to those feelings is debated in the next section; grandparent bereavement as a journey - but to where?

Anger was, and still is, felt by some grandparents in this research in relation the question "WHY their grandchild died?". This brings with it, an existential challenge to answer. Grandparents' anger was identified by DeFrain et al. (1991-92) as a common feeling, but was not mentioned by either Ponzetti (1992) or Fry



(1997). This may reflect different meanings of bereavement, and the sense from all four studies is that it is not a central part of the bereavement.

However, there are considerable differences between the four studies in relation to feelings of guilt. Clinical literature has identified guilt as part of grandparents' grief (Gerner, 1988; Gyulay, 1975). DeFrain et al. (1991-92) found that, of 80 SIDS grandparents, 29% expressed feelings of "personal guilt" (p. 170) at being responsible for the baby's death because of identified incidents or a belief that they should have been able to prevent SIDS. As the authors point out many SIDS parents also hold a sense of guilt and responsibility, in large part because SIDS is a diagnosis based on excluding all other causes, which means that the causal mechanism is unidentified. Given the voluntary nature of grandparenting, where parents are the primary carers for the infant, it is surprising that nearly one third of the grandparents still felt personal guilt. Such guilt was not part of the joint construction in this research.

Whilst DeFrain et al. (1991-92) did not identify survivor guilt, this was the second largest factor (accounting for 18.6% of total variance) in the first part of Fry's study (1997) of factor analyses of questionnaires from 152 grandparents bereaved in the last 3 years. Included in this factor was the guilt of still living when the grandchild had died, and more subtle aspects such as feeling a burden for causing the family grief and being punished for earlier sins. In this research Ailsa, alone, described a momentary sense that it should have been herself, not Conor, who died. Nor was survivor guilt a familiar feature of the practice of Barry and Jane in health care, although Diane, a bereavement support co-ordinator, mentioned it as a possible part of the bereavement process. The difference between the two studies is possibly related to the age of the grandchild at death. In Fry's study, grandchildren who died were aged 6-32 years, of whom 75% were aged 10 years or more. In this research all grandchildren were infants who died unexpectedly from stillbirth to 9 months. It is possible that survivor guilt is more commonly experienced when grandparents have a sense of what is lost through the death of that unique grandchild, based on a direct relationship with the grandchild (Factor 3 in Fry's study). In contrast, the grandparents in this research had a relationship with the child which was primarily through the parents, or mother, of the infant.

Gerner (1990) described five types of guilt in the self-help booklet "For Bereaved Grandparents. She identified the guilt as: *survival*; *moral* (that the death is a punishment which Fry included in survival guilt); *geographic* (being far away when needed by the parents); *devastating* (when grandparents were involved in the cause of death); and *recovery* (feeling better when the parent is not)<sup>2</sup>. These types of guilt were not identified in the joint construction of this research. This may mean that people who took part in this research were willing to talk of their experiences and had used this strategy from the time the grandchild died which had helped them not to have a sense of guilt. Or, it is also possible that the participants who were 6 months to 14 years from the time when their grandchild died at the time the study started, did not remember feelings of guilt. This suggestion is debatable since many grandparents could recall very vivid memories of the time that their grandchild died. Alternatively, this observation may reflect the multiple constructions of the experience when a grandchild dies.

In considering possible reasons for the differences in reported levels of guilt feelings it seems unlikely that American society places greater expectations of responsibility on grandparents leading to more feelings of guilt. The other possibility is that grandparents may be influenced by a social construction of grief which "should" include guilt. This led me to consider whether guilt is less common than is believed. Gerner (1990) wrote in the American self-help resource that "Almost every grieving person experiences guilt and grandparents are no exception". As the grandparents and parents in this research had not read this resource material when first sharing their stories and they went on to construct grandparent bereavement without reference to guilt, it does suggest the possibility that the concept of guilt is overemphasised. In addition, guilt was not mentioned in two other studies of reactions of bereaved grandparents (Ponzetti, 1992; Ponzetti & Johnson, 1991). Ironically, social constructions of ways that bereavement and grief "should be" can cause people to feel guilty. Demi and Moore (1984), found that bereaved parents felt "grief guilt" (p. 107) when their behaviours did not meet personal or societal expectations of grieving. Whilst Corr (1998-9) proposed that constructions of the expected nature and

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<sup>2</sup> Page numbers are not supplied in the booklet by Gerner.

form of bereavement can disenfranchise individuals' ways of being bereaved by only supporting grief which conforms to expectations (see further discussion p. 419).

Another affective expression of grief, which is commonly associated with bereavement, is depression. It is one of the main outcomes studied in a range of bereavement research (Zisook, Schuchter, Sledge & Mulvihill, 1993; Vance, Boyle, Najman & Thearle, 1995). Depression was not part of how grandparent bereavement was constructed in this research. I believe this finding does not represent an unwillingness on the part of participants to identify themselves as depressed, since several grandmothers described depression as part of their experience of being widowed. Similarly, depression was not reported in three other studies of grandparent bereavement (Fry, 1997; Ponzetti, 1992; Ponzetti & Johnson, 1991), although DeFrain et al. (1991-92) noted that it was amongst grandparents' "*many emotions*" (p. 179). Nor is depression referred to in the clinical literature (Donnelly & Haimes, 1993; Gyulay, 1975). This is, perhaps, surprising when, as Kalish (1987) noted, depression is often seen as the "*most familiar mental-health problem of the old*" (p. 34), where "old" is used implicitly as aged late 50s on, which is the age group of grandparents in this research. However, the findings of Zisook et al. (1993) challenged the view of Kalish and noted that older widows/widowers adjusted better, and experienced less depression, than younger counterparts. They proposed that older people might be more adaptive because they draw on life experience. This point was also made in the joint construction of this research (see p. 357) and is congruent with a constructivist view of developing a more sophisticated personal construction of bereavement over time.

The absence of depression in the joint construction may indicate that whilst the death was devastating to grandparents, it did not, generally, challenge self-identity in the way that parental bereavement does (Rando, 1986; Kalish, 1987). The meaning of a grandchild's death for the everyday life of most grandparents is not an "in your face loss" with empty room and bed, unused clothes and an everyday routine which has empty gaps. As Ailsa explained, Conor's death was very painful but it did not change the fabric of her everyday life in the way that her husband, Harold's, death had (see p. 281). Alternatively, if I used the

extensive list of differentiated symptoms of depression proposed by Rando (1986) which includes feelings of helplessness and powerlessness as “manifestations” (p. 18) of depression, then I could construct depression as part of participants’ experiences because these feelings are part of the joint construction. However, participants did not construct their experiences in this way. This highlights the importance of considering who constructs individuals’ experiences of bereavement; the individual, the clinician, the researcher?

Other studies noted physical and behavioural expressions associated with grandparent bereavement such as crying and shaking (DeFrain et al., 1991-92), insomnia (Ponzetti, 1992) and confusion, agitation and restlessness (Fry, 1997). Some grandparents in this research had similar experiences, which included lack of appetite and weight loss. However, these aspects of their loss were not part of how most grandparents and parents saw their bereavement. Several people, like Marie, had not “known” that these changes were a common part of the experience. In contrast, everyone in the research had heard about “stages” in bereavement/grief. It suggests that the social construction of the affective aspects of bereavement is much stronger than a wider appreciation of bereavement as an experience which can include a range of changes including physical signs and symptoms. However, it is not possible to explore this idea in relation to the other research studies referred to above, because there is no indication of whether the physical and behavioural expressions of loss were identified by grandparents or by researchers.

Moving from the range of feelings associated with the death of a grandchild the next aspect to consider is the meaning of the loss. What meanings do grandparents ascribe to the death of their grandchild?

### ➤ **The meaning a grandchild holds for grandparents**

Chapter 6 explored the meaning that grandchildren’s characteristics such as gender and birth order can hold for bereaved grandparents. Ponzetti and Johnson (1991) noted that the sex and age of a grandchild were not significantly associated with grandparents’ need to talk; but this observation does not enable an assessment of the meaning that the grandchild held for the grandparents. Fry

(1997) found in factor analyses that the participants' responses to the death included regrets about not telling the grandchild how much they were loved and an appreciation of the grandchild's special qualities. This suggests that the grandparent-grandchild relationship had a meaning unique to each grandchild; a view that is reflected in some of the stories in Part 2. The variety of feelings about, and meanings of, the grandchild's death in the stories in Part 2 do not lend support to Christine Littlefield and J. Philippe Rushton's (1986) sociobiological theory of grief. Their theory views grief as a function of the DNA potential of the grandchild and predicts that: a) maternal grandmothers will grieve more than any other grandparent and; b) that feelings for the death of a healthy grandson will be greater than those for a healthy granddaughter or unhealthy grandson. The richness and diversity of the ways in which the participants in this research constructed the death of a grandchild suggests that the experience is considerably more complex than genetic linkage. In addition, Littlefield and Rushton's work may be limited by having asked parents to report on grandparents' grief instead of asking grandparents themselves.

The meaning, which the deaths represented to Jenny and Elisabeth, was that of a threat to their role as first-time grandmothers. This has not been discussed in other literature on bereaved grandparents. Jenny's self-questioning was of her own self identity. Could she call herself a grandmother? Whereas Elisabeth claimed for herself the role of grandmother as part of her identity, but her friend questioned her social status in that role. Kay Talbot (1996) explored the same challenge to self identity experienced by five mothers whose only child died. She concluded that to survive the death the women created and found opportunities to keep a connection with their child and their identity as a mother. There are parallels in the stories of Elisabeth and Jenny, who spent time thinking of Martin and Jordan and thus, maintained a connection with them. In addition, they chose to take part in this research and gained an opportunity to write about their grandchildren. This, in turn, provided acknowledgement from the world outside the family that they were grandmothers in a study of bereaved grandparents.

Another aspect of the meaning a child represents is personhood, or conversely non-personhood (see Marie, p. 272). Carolyn Krone and Chandice Harris (1988) described this concept in the context of parental bereavement following perinatal

death. In developing this perspective the authors cited the ideas of Bowlby and Rubin in relation to parent-newborn bonding. Krone and Harris proposed a process of claiming the infant into the family called "lost infant: *establishing personhood*" (p. 5). In a study of 20 families the authors identified claiming behaviours such as touching, holding, naming and attaching importance to gender and familial characteristics of the infant. The process of establishing personhood resonates with some of the stories and the joint construction. Daniel's resemblance to Lindsay, Elwyn's dead husband, meant that Daniel represented, in Elwyn's eyes, the continuation of the family. This became part of the loss when he died. Conversely, Marie's view of Ruby as a "no person" rested on the lack of opportunity to claim her through the meaningful ritual by which she had claimed her other grandchildren - that of holding her. In contrast, a similar, but different ritual, in another family context, helped Benita to claim the reality of Matthew's death by bathing him, as she had done with her two granddaughters. It suggests that each family develops patterns and precedents, which act as rituals, for incorporating new members, whether alive or dead, into the family.

Another way of claiming the grandchild into the family rests on the particular links and symbols that are held by the grandparents. In this light, mystical experiences can be seen as a process of claiming the grandchild into the grandparent's life, and may be into the family life. So what are mystical experiences?

They can include a premonition of the death, a visitation from the loved one at the time of, or following, the death, an unusual dream or nighttime visitation, the presence of the loved one sensed through sound, smell, touch or taste. (Frogge, 1996, p. 12)

In this research Benita talked of her sense of premonition before Matthew's death, which was especially strong when she saw small angels in the florist's shop and had a sudden realisation what their use might be. Similarly, Catherine described a visitation after Samuel died when she fell asleep and heard the bells of *Waltzing Matilda*, which meant to her that her grandfather was looking after Samuel. When talking about her experience, Catherine regretted it had been herself, not Rachel, who heard the bells. Rachel, too, regretted not having this experience. Both experiences speak to establishing a special relationship with the grandchild that is part of claiming the grandchild as a unique person. Whilst Catherine and Benita's families incorporated these experiences into the family stories about Samuel and Matthew, I would be cautious in thinking that a



mystical experience for one family member will always be accepted or shared with other family members, since they are very unique and personal. Having considered the possible meanings associated with the death, the next section considers the "pain" which grandparents feel in the context of their relationships with other family members.

### **Pain felt for other family members**

In this research several grandparents described their pain **for** the grandchild's loss of a future. It was entangled with, but also separate from, **own** sadness and pain **for** the parents at not seeing the grandchild grow into the future (see Alex' eulogy p. 256). This combination makes up the grief, which Gyulay (1975) described as "threefold" (p. 1478). Unrecognised in the triple grief is the pain some grandparents feel for other, living, grandchildren's confusion and the perception of what they have lost through their sibling's death, which Colston described (see p. 190 & 193). Some of the stories in Part 2 illustrate that the relationships which grandparents hold with other living family members, such as partners, own parents, other children (siblings of the parents) are an important context to their bereavement. Betty described her concerns at breaking the news of Gracie's death to her son and daughter-in-law, who was pregnant at the time. Colston wrote of having to support her mother in addition to other family members. These are reminders of the multidimensionality of bereavement constructed as an experience through both relationships and social context

Moving from the ways in which bereavement is constructed within the family the next section considers how grandparent bereavement might be constructed as a journey with, or without, an endpoint.

## **GRANDPARENT BEREAVEMENT CONSTRUCTED AS A JOURNEY**

Several grandparents described their grandchild's death using the imagery of a journey. It is an image used extensively by C.S. Lewis (1956) in a "Grief Observed", Writing about his feelings after his wife's death, he wondered where his journey of grief would lead and commented that, en route, he had seen the

same landscapes several times. This section considers four questions in relation to how the joint construction "fits" with other conceptualisations of bereavement in the context of a journey. How do grandparents cope on the journey? Why do conversations, often as stories, seem to help on this journey? Is the journey a crisis or transition? Can the journey be seen as having an endpoint?

### **How do grandparents cope on the journey?**

In the joint construction we used "coping" to encompass the strategies which grandparents used to respond to, and manage, the challenge created by a grandchild's death. "Coping" can also be constructed to include making sense of what happened, which was part of *"Putting loss in life in place"* in the joint construction. By first reviewing strategies for coping, including possible gender differences, this leads into coping as ways of constructing meaning.

The joint construction discussed grandparents coping in relation to doing, caring and knowing (see pp.356-361). Fry (1997) found that grandfathers coped by offering practical help to the family and by keeping busy at their work, whereas grandmothers sought to share their feelings. Ponzetti and Johnson (1991) and Ponzetti (1992) also noted the latter point. A similar perspective of gender differences, both in relation to the expression of feelings and coping strategies, is presented in studies of parental bereavement. Researchers have reported that fathers perceived their role was to support the mother (Puddifoot & Johnson, 1997), not to express their own intense emotions (Kimble, 1991), and to actively cope by organising the affairs related to the death (Dyregov & Matthiesen, 1987; Littlewood, Cramer, Hoekstra & Humphrey, 1991). There are similar findings in studies of grandparent bereavement emphasising grandfathers as being "strong and silent" (DeFrain et al. 1991-92, p. 176). Gyulay (1975) believed that grandfathers, more than anyone else in the family of a dying child, were isolated, because of "their role expectation and triple-layered grief" (p. 1478). I believe the perspectives in this research only partially confirm ideas of a gender differentiated division of labour (Riches & Dawson, 1996a) and such ideas can obscure the role of individual differences in shaping constructions of bereavement. In this research the differences between grandmothers and grandfathers' reactions and activities were located in different contexts and

experiences, such as Alex' pastoral experiences which meant he was comfortable talking about feelings. In addition, each grandfather had different opportunities that shaped how they coped. Rupert and Keith, who worked their own farms, had few opportunities to meet people to talk about their experiences, but they did have plenty of time to be quiet and to think. Similarly, the stories in Part 2 illustrate that grandfathers and grandmothers helped to organise affairs related to the death and to be strong for the parents. These are coping styles associated with a father's role in parental bereavement (see earlier discussion), but also with the role of being a "*parent of the adult parents*" (see p. 353).

Irrespective of differences in coping styles, the grandparents and parents in this research identified that grandparent couples supported each other emotionally by sharing **in** the experience, even if not all the grandfathers readily shared their feelings **about** the experience. This point fits with the comment of DeFrain et al. (1991-92) that couples generally seem well aware of each other's coping styles and work with these, as opposed to creating conflict from the difference. In the joint construction another aspect of coping was "*coping as caring*". This included both giving and receiving support. I have discussed grandparents giving support earlier, but now consider ideas of support **for** grandparents.

### ➤ **Support for grandparents**

In this research grandparents received support from their partner, if alive, and this was regardless of whether the partner was the grandchild's grandparent or step-grandparent. Other sources of support included family, friends, church and local community. This finding is similar to the 80 grandparents in the study of DeFrain et al. (1991-92), of whom 20% attended a SIDS support group meeting, which is a slightly higher proportion than the 2 out of the 16 grandparents in this study. In the joint construction we identified geographic accessibility and perceived relevance to self as reasons for many grandparents' non-attendance at such groups. Four of the six parents in this research attended, and helped to run, such groups and many studies report parents attending such groups (Longman, 1995; Riches & Dawson, 1996a; Talbot, 1996; Thuen, 1997). Given that grandparents perceive groups as valuable for parents, but not as useful for themselves, why might this be?

The answer may lie in the uniqueness of the parent-child relationship (Klass & Marwit, 1988-89) which presents unique struggles with which to come to terms (Rando, 1986). Western societal views of death are often not supportive of the bereaved in general, and of parents of infants who have died, in particular (see further discussion p. 419). In such a social climate self-help groups offer a place to belong as part of a "culture" of bereaved parents (Riches & Dawson, 1996a) where it is possible to talk about and acknowledge their child (Farnsworth & Allen, 1996). In contrast to parents, most grandparents do not appear to face the same struggles related to role and identity and may, therefore, have less of a need to belong to the self-help group culture.

The provision of support encompasses more than just self-help groups. It can include talking with other bereaved grandparents and with health/bereavement professionals face-to-face, or even joining a bereavement chat group on the Internet. Written information from booklets and via the Internet constitutes forms of support at an informational level. Very few grandparents in this research identified any form of extrafamilial support as valuable, or necessary, to bereaved grandparents, and there are no comments for comparison in other studies of grandparent bereavement. However, all the grandparents, in this research, valued the opportunity to talk about their experiences in the series of conversations during the research, which in itself offered a form of support and acknowledgement. This appeared particularly important in situations, like Jenny's, where there was "bereavement overload" (Moss & Moss, 1997, p. 4) with multiple, sequential losses close together. Conversations offer ways of making sense and meaning- the cognitive aspect of bereavement, which I have discussed, in the next section.

### **Making sense and meaning**

The cognitive aspect of coping and living with the death of a child has been studied in the context of parental bereavement (Braun & Berg, 1994; Riches & Dawson, 1996b; Talbot, 1996). Fry (1997) identified in the factor analyses that the recovery process included "working out 'personal meaning for life'" (p. 127) which, for some grandparents (unspecified number), included deepening religious and spiritual beliefs. Similarly 90% of 80 grandparents felt that religious

beliefs were helpful (DeFrain et al 1991-92) or provided comfort for 42% of 45 grandparents (Ponzetti & Johnson, 1991). The joint construction explored "*Coping as knowing*", often in the short-term in relation to particular worldviews, such as religious, spiritual or "homespun" beliefs (see p.358) which contributed in the longer term to "*Living with the grandchild's death*" (see p.372). In this research, religious faith offered some, but not all, grandparents, a means to construct a view of the grandchild's death. As Alex said in his eulogy to Matthew, such a view does not answer the question WHY? but accepts at an ontological level that Christian reality is grounded on the love of God and life after death. Other research has not clearly confirmed the role which religion can have in assisting people to cope with adult death (Cartwright, 1991). Religious beliefs in combination with a death have been associated with personal growth and persisting depressive symptoms in bereaved parents (Videka-Sherman, 1982), and also positively assisting SIDS parents to find meaning (McIntosh, Silver & Wortman, 1993).

What this study offers is the perspective that, with or without overarching religious beliefs, grandparents constructed a view of their grandchild's death which fitted their individual beliefs and was acceptable to them to live with. Beliefs might include the perspective that "these things happen in life", and that "things which cannot be changed have to be accepted". This observation is congruent with the work of Mildred Braun and Dale Berg (1994) who undertook a grounded theory study with 10 mothers who had experienced the unexpected loss of a child. They identified that if the death did not fit within the mothers' "prior meaning structure" (p. 114), in the form of the worldview held before the death, then there was a period of disorientation until adjustments were made to the prior meaning structure to account for the death and to give a "sense of meaning and purpose in life" (p. 124). As a substantive theory it has the potential to account for the different ways in which individuals make sense of death and why this varies in duration. The authors were careful to point out that, even with a prior meaning structure which acknowledges that children can die, the pain is still intense, what is lessened is a "crisis of meaninglessness" (p. 122). Such a perspective fits with stories in this research, which reflect the different ways that grandparents' worked with the question "Why did my grandchild die?" So, what

are the processes that seem to help in making sense of the death and adjusting worldviews to accommodate the death? Research with bereaved mothers, and some fathers, indicates that conversations with self and others help in this process (Farnsworth & Allen, 1996; Riches and Dawson, 1996a, 1998; Talbot, 1996). Is this true for grandparents?

### **Conversations and stories on the journey**

Talking is the thread which goes through the joint construction, whether talking with oneself on the tractor, with a partner, with the parents, or with me during the research. Why might talking be so important as a way of coping and making sense of what has happened? Riches and Dawson (1996b) proposed that, for parents, a child's death creates a "fault-line in reality" (p. 2). Talking is one response to that "fault-line" since it can contribute to creating a mental narrative of events and feelings, which go to make up self as a reflexive construct (Riches & Dawson, 1996b, citing Giddens). This idea resonates with the view of stories told in conversations as "a way of re-drawing maps and finding new destinations" (Frank, 1995, p. 53). In the context of which the maps are of our lives, and the stories link the past - to the present - to the future, as a cohesive sense of self through time. I believe the stories in Part 2, reflect this process where participants shared part of their self-narrative, about "When a grandchild died".

During this research there were a number of participants who redrew the maps of their lives in response to the "grandchild's death. I believe that others had reviewed their maps prior to the research and told a cohesive self-narrative in their story and conversations. For these participants, the "new destinations" (Frank, 1995, p. 53) were defined in relation to new activities and understandings which were discussed in the joint construction in the category "*Re-viewing self*" (see p.373). Amongst those who re-constructed their self-narrative during the research, was Jenny. Through her letters Jenny shared and explored who she was (see pp. 159-160), and she struggled with where Jordan's death could be fitted into her view of life and family. I believe she re-constructed her self-narrative to include his death within her belief that life is uncertain and her identity as a person and as a grandmother (see p. 160 & p.439). In this respect, a number of grandparents, like Jenny, commented that taking part in the



research was therapeutic because it provided an audience with whom to share their ideas which then came to form part of their changing self-narrative. I also believe that, unlike some other audiences, such as the friends Elisabeth and Terese described, our conversations in the research were open to how individuals wanted to construct their experiences into their views of their lives, without assumptions that bereavement should fit any particular model.

If conversations can be useful as a place to tell a story and explore what the death means to self, then with whom do bereaved people talk? Margaret Stroebe, Mary Gergen, Kenneth Gergen and Wolfgang Stroebe (1992) cited the work of Rosenblatt and Meyer when they proposed the use of dialogue with the deceased person to enable dealing with unfinished business. When an infant dies it may be difficult to hold a series of conversations with them, because their personality can only be guessed at in order to anticipate the direction that their replies might take. What may be useful are conversations with other people who have known the deceased. Tony Walter (1996) noted from his experience of his friend, Corina's, death, such dialogues are not for social support for each individual's grief but are "an intrinsically social process in which we negotiated and re-negotiated who Corina was, how she died and what she meant to us" (p. 12). This is the sense that comes through many of the stories in Part 2; the conversations between different family members were about who the grandchild was, what they were like and what they might have been. This view of conversations as a way to reconstruct a view of the deceased, means that bereaved people want to talk to people who **knew** the deceased, not strangers (Walter, 1996). By way of example, it was imperative to Pip and Donald, to provide opportunities for grandparents and friends to "know" Gracie, so that they would remember and talk about her afterwards (see p. 215).

Having explored conversation and stories as part of the process of making sense of the grandchild's death, the next section reviews whether the journey of grandparent bereavement can be constructed as a crisis or a transition.

### **Crisis or transition on the journey?**

"Crisis" has been used to describe the effect of infant death on the family (Gaffney, 1992; Quirk, 1979) and effects of bereavement in general (Vachon & Stylianos, 1988; Raphael, 1984). However, participants in this research did not construct their bereavement as a crisis. They did not perceive an imbalance between the "problem" (the death) and the "resources" available to respond to the problem, which are the defining features in Gerald Caplan's (1964) crisis model. Instead they constructed the death as a "challenge" which started them on a journey. This perspective does not preclude other grandparents, who did not take part in the research, constructing their bereavement as a crisis, but for this group of participants, it was not part of their constructions.

So, if not crisis, what about transition? Again it was not a concept or word used by participants, whereas challenge and change are part of many people's everyday vocabulary. The concept of transition has been used in nursing literature (e.g., Chick & Meleis, 1986; Schumacher & Meleis 1994), sociological literature (Golan, 1981; van Gennep, 1960) and as a model for bereavement (Parkes, 1972). Naomi Golan (1981) described it as "a period of moving from one state to another with an interval of uncertainty and change in between" (p. 12). Golan's description of "uncertainty and change" works well with the ideas of challenge and change in the joint construction and her view of moving between "states" is congruent with the earlier discussion regarding the re-construction of self-narrative to integrate the grandchild's death into a life story. In the context of family nursing, Laura Clarke-Steffen (1993) offered a model of family transition based on research with families who had a child recently diagnosed with childhood cancer of good prognosis. She described the transition as moving from a "fracturing of reality", as life was before the child was ill, to a period of "limbo" around the time of diagnosis, and then eventually reaching a "new normal" (p. 288) for the family including role reorganisation, evaluation of priorities and new worldview. The "fracturing of reality" appears to reflect the same meaning as both Riches and Dawson (1996b) "fault-line in reality" (p. 2) and "*When the world turns upside down*" in the joint construction (see p. 335). The concept of a "new normal" appears similar to participants' constructions which emphasised moving from the upside down world to a life which carries on and "becomes the norm"

as Ailsa said (see, p. 282). However, within this "norm" things will never be the same again because there has been a permanent change and space created by the grandchild's death.

Klass (1996) described grief in the form of a transition as, "the processes by which the bereaved move from the equilibria in their inner and social worlds before a death to a new equilibria after the death" (p. 200). Is this how the stories and the joint construction sit? In the sense that the time of shock, disbelief and challenge fades, then there is a new world, or there are new equilibria, to be found. However, the perspectives of transition offered by Klass and Clarke-Steffen (1993) both appear to view it as a process between life **before** and life **after** the critical event. In contrast, "*Placing the grandchild in the family*", as part of the joint construction (see pp.362-370), views bereavement as having the potential to be life **with** the grandchild's death. Life **after** appears to rest on the premise that transition as grief and bereavement ends. This follows the ideas proposed in the work of Bowlby (1961), Lindemann (1944) and Worden (1983) as the withdrawing of emotional energy in order to be able to re-invest it in future relationships; a view of death which was not supported in the joint construction where emotional energy continued to be invested in a relationship with the dead grandchild. The debates about "life after" and "life with" leads to the consideration of whether there is an endpoint to bereavement, or whether it is a permanent journey, or even multiple journeys with multiple endpoints?

### **Is there an endpoint to the journey?**

One of the debates we had during this research was at what "point" did people see themselves in relation to the bereavement caused by their grandchild's death? Were they "over it"? Or had they "resolved" or "accepted" their bereavement? These are familiar phrases in relation to grief, which reflect images of bereavement as an illness or a finite time period. When our conversations started, 5 months to 14 years after their grandchildren died, participants still had vivid memories of, still missed and still thought about the grandchild who had died. Grandparent bereavement was constructed as retaining this connection to their grandchild. This was not seen as "odd" or "unhealthy" or as an "ended relationship". The grandchildren were still part of the

family. In this sense being a bereaved grandparent is a permanent, although not central, part of self-identity.

This construction does not entirely fit with the view of "healthy" bereavement outcomes, such as "resolution of the loss, satisfactory adjustment, and a reintegration into life with new and satisfying attachments valued in their own right" (Raphael, 1984, p. 61). I could ask, from a constructivist perspective, whose criteria are used to decide "satisfactory" and "healthy"? Nor does *"Placing the grandchild in the family"* (see pp. 361-369) entirely fit into a view of chronic grief - characterised by repeated reviewing of memories and continued distress such as crying (Raphael, 1984). Current ideas of grief are largely predicated on the "dominant model" (p. 14) of grief/bereavement (Silverman & Klass, 1996) which has been widely accepted and used by health and bereavement professionals during this century. Explained from varying theoretical perspectives, the model of healthy grief has been constructed with an endpoint where the bereaved person lets go, or disengages, or detaches from the person who died and moves on in life with the ability to engage in new situations, attachments and relationships (e.g., Bowlby, 1961; Lindemann, 1944; Parkes, 1972; Parkes & Weiss, 1983; Raphael, 1984; Worden 1983). As I debated in Chapter 2, much of the research underpinning these ideas has used particular clinical samples, which could be called biased. In addition, some models and theories have been proposed and have continued in existence despite contradictory evidence (see review in Silverman & Klass, 1996). So, how else might remembering and still hurting for their grandchild, up to 17 years after the death, be constructed?

Silverman and Klass (1996) proposed a new understanding of bereavement and grief. "We are suggesting a process of adaptation and change in the postdeath relationship and the construction and reconstruction of new connections.... We cannot look at bereavement as a psychological state that ends and from which one recovers" (p. 18). This perspective fits with the joint construction where *"Placing the grandchild in the family"* represents the place of the grandchild being maintained within the family. Similarly, *"Putting loss in life in place"* offers a differing view of bereavement which does not necessarily construct it as having

an endpoint. The idea of reconstructing new connections resonates with ideas of self-narrative and with the discussions in this research about meaningful dates and milestones where new connections with the grandchild are established as the family grows older, so the grandchild grows too (see p. 369)

The possibility of multiple ways of grieving, and of constructing bereavement, is congruent with the ideas I have reviewed earlier. In addition, McClowry et al. (1987) described multiple ways of grieving in a study of 49 families, in which parents and siblings took part 7-9 years after death of a child with cancer. The authors identified three patterns of grieving in response to the initial empty space of the death; “*getting over it*”, when people no longer described intense grief or memories; “*filling the emptiness*”, when people kept busy with new activities or work in voluntary organisations; and “*keeping the connection*” (pp. 365-7), when the existence of memories sustained the place of the child in the family. The idea of “*keeping the connection*” contradicted existing views of bereavement where such a perspective would be pathological. Whereas the authors noted that family members had a sense of “*balance*” and the family members “*expressed satisfaction with their present lives, [and] they continue to reserve a small part of themselves for the loss of a special relationship which they view as irreplaceable*” (p. 368). Similarly, Mary Kachoyeanos and Florence Selder (1993) reported that bereaved parents needed to be able to “*hold on to the memory of the child*” (p. 48), which was reported by Larry Peppers and Ronald Knapp (1980) as “*shadow grief*” (p. 47). After looking at the stories in Part 2 in relation to ways of grieving, I believe that participants keep the connection with the grandchild in different ways and to a differing extent. This raises an interesting question. Did people self-select to join this research because they keep the connection and it is, therefore, meaningful to talk about their experience? Therefore, did people who have gotten over a grandchild’s death, or keep very busy after such a death, choose not to take part in this study? This research does clearly show that a number of families actively maintain the place of, and links with, their dead grandchild. This may reflect shared beliefs in the family paradigm about caring for, and looking after, members of the family even when they are dead. It is not possible to compare this idea with the study of

McClowry et al. (1987) since it is not stated whether multiple members of the same family shared the same, or different, grieving patterns.

### ➤ **Some aspects of continuing bonds to consider**

The idea of keeping connections, or continuing bonds, is not new. It was part of the romanticist view in the nineteenth century (Rosenblatt, 1996; Stroebe et al. 1992), which prized, and even idealised, broken hearts and continuing bonds after death; consider the stories of Queen Victoria in lifelong mourning. It is beyond the scope of this thesis to explore, in-depth, the debates surrounding these views and the subsequent changes in social attitudes to death. In brief, these changes have included increasing medicalisation which sequesters death away from every-day life, and the valuing of individuation and autonomy as opposed to having a reliance and dependence on relationships with others (Mellor & Shilling, 1993).

Several aspects of the concept of continuing bonds are relevant to grandparent bereavement. First, McClowry et al. (1987) observed that the quality of the relationship, seen as being special or irreplaceable, was related to whether the death was experienced as a continuing “empty space”. This can illuminate the reason grandparents, in this research, held dual age images of their grandchildren (see p.369). These images were part of “*Placing the grandchild in the family*” and were not part of grandparents’ experiences in relation to people who had died at an older age, and who did not have this “specialness”. Second, there is a distinction to consider between “feeling the emptiness” and undertaking activities to avoid feeling the “empty space” (McClowry et al, 1987, pp. 365-7). As some of the stories in Part 2 describe, some grandparents kept busy whilst still keeping the connection with the grandchild as a continuing sense of loss. A point which McClowry et al. noted; keeping busy is not always synonymous with avoiding the space.

Do other bereaved people keep the connection and maintain continuing bonds in the same ways as in the joint construction? Other studies have explored this in relation to parental bereavement (Brice, 1991; Kachoyeanos & Selder, 1993; Klass, 1996; Riches & Dawson, 1996a, 1996b, 1998; Rubin, 1996); to children



who are bereaved (Buchsbaum, 1996; Silverman & Nickman, 1996); and for spousal bereavement (Conant, 1996). In particular, photographs and memorabilia appear to have a number of functions for bereaved parents by providing “an important prop both as an object of personal internal conversation *with the deceased* and as a vehicle for conversations between surviving relatives and others *about the deceased*” (Riches & Dawson, 1998, p. 124). Given the age of the grandchildren in this research, the conversations seem to be with oneself and others, not with the dead grandchild. In this respect, looking at photographs can contribute, not to detachment, but to establishing a place in the family and a connection with the grandchild. In the context of conversations, photographs and symbols are valuable since they can introduce the dead grandchild to people who have not met the child previously. An example of this is provided in Part 2 where many of the stories include photographs and symbols to introduce the reader to the grandchild/child. However, it is worth noting that photographs can have different meanings for the family as a whole and for individual members (Davies, 1987). Sarah highlighted this in relation to the photographs of Matthew. Margaret, her mother, liked the photograph of Matthew when he was dead, as opposed to photographs taken when he was alive, with various tubes and machinery attached to him. It took Sarah and Benita longer to accept that this was the “best” photograph to represent him. The opportunities which photographs offer for dialogues to keep the connection with the grandchild, throws light on why Terese regretted that photographs had not been taken of Bernadette.

Whilst the concept of continuing bonds or connections offers a very valuable perspective to explore the joint construction and the individual stories, this does not mean that I would exclude the value of some of the ideas within the dominant model of bereavement. This point is revisited in the conclusion, since a postmodern view of bereavement enables bereavement journeys to be travelled in different ways, to different and changing destinations. Much of the existing discussion in this chapter has focused on the world of the family. It is important to remember that grandparents spend much of their lives, and time, outside the physical and emotional context of the family world. The next section explores grandparent bereavement constructed in this other world outside the family.

## GRANDPARENT BEREAVEMENT CONSTRUCTED IN THE WORLD OUTSIDE THE FAMILY

This section considers how grandparent bereavement may be constructed by others outside the family which, in turn, shapes and forms the constructions of bereavement held by individuals and their family. This discussion of the world outside the family reflects dominant views of Western society and I fully acknowledge this does not debate the different constructions of bereavement held by members of other cultures determined by ethnicity (Eisenbruch, 1984) or other characteristics. Equally, I am aware that I could emphasise constructions held by particular groups in society, which may not be held by individual members of those groups. As this is a study with 23 NZ participants, of whom 3 self-identify as part Maori, it could be considered relevant to explore Maori constructions of death within this chapter. However, the beliefs underpinning tangihanga were not part of the three participants' experiences, although funeral arrangements and the blessing of the house for Samuel, were organised by Rachel and her family, to acknowledge his Maori ancestry. Instead of focusing on beliefs of particular social or cultural groups, I have sought to look at the wide social context that may impact on bereaved grandparents; in particular whether death is taboo and the concept of disenfranchised grief.

### Death as taboo – or not?

The social context of the communities and society within which grandparents in this research live, appears to offer complex and, at times, mixed messages regarding bereavement. First, we receive reminders from the media that death is taboo, where "taboo" is used in the context of something which is forbidden or denied (Walter, 1993). Philippe Aries (1974) drew on the notion of taboo by citing the work of Geoffrey Gorer in "The Pornography of Death". Aries incorporated this concept into his historical review of "Western attitudes towards DEATH: from the middle ages to the present" when writing about society's denial of death. In extending this idea, Stinson et al. (1992) proposed that parents live in a society where perinatal death is taboo. Certainly maternity practices in the middle decades of this century operated as if death was taboo by using strategies such as the "rugby pass" (Lewis, 1979, p. 305), where stillborn babies were whisked out the door giving their parents no chance to see or hold them.

Health professionals undertook such manoeuvres in the belief that this would minimise attachment and thus aid grieving mothers. The stories of women in *"Still life: stories of hidden loss and forbidden grief"* (Tonkin, 1998) bear witness that this practice did not help. This is corroborated by the stories of women who talked of such experiences to Alex, Benita and Betty.

In the 1990s when the grandchildren of this research died, is death still taboo? What is the evidence to support such a view? First, many of the writings from researchers and clinicians, which I have cited in this chapter, are from the 1980s onwards. So, death does not seem to be taboo in the professional literature. Second, there has been a profusion of self help books on death, dying and deathing (Eisenbruch, 1984). Amongst the self-help material for bereaved parents, some include reference to grandparents (Deveson-Lord, 1987; Horchler & Morris, 1994; Murphy, 1990; Nicol, 1997). And there are a few resources written specifically for bereaved grandparents (Gerner, 1990; Kolf, 1995; Leininger & Ilse, 1985). In addition, there is an explosion of resources about infant death accessible from the Internet via particular organisations, such as SANDS, Western Australia home page<sup>3</sup>, or accessed through searching a web site dedicated to bereavement, such as Growth House<sup>3</sup>. So, death is not taboo in the self-help context. Third, in the wider social context there is extensive coverage of death in media reports (Walter, 1993). These reports are on a global level, such as the massacres in Kosovo in 1998, on a personal level with coverage of deaths such as Diana, Princess of Wales; and on a population level with statistics of people dying from a particular disease. So, death does not appear to be taboo in the media context where we live. Fourth, the fact that participants stepped forward join this research and other such studies (Cook, 1995) indicates bereaved people are willing to talk in detail about death and that it is not taboo within their own lives. Overall, a picture emerges that death does not appear to be taboo and that this is not part of the context of grandparent bereavement.

Another construction of death is that it is "distanced", which means that it is talked about indirectly (Mellor & Shilling, 1993) as opposed to openly. This

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<sup>3</sup> Details of location in reference list.

perspective does fit with the comments of the joint construction where death was known, but was believed to happen to "other people". Moving death out of everyday life, through practices that place death into hospitals, hospices, funeral services, can create a view of death as "uncomfortable". This discomfort can be felt by the people surrounding bereaved grandparents and reflect on how they view the grandparents' bereavement. The discomfort may mean grandparents may be denied the opportunity to talk about their grief (see Terese, p. 201). The discomfort of other people was raised and discussed in the joint construction in relation to the question "How many grandchildren do you have?" Such discomfort on the part of the inquirer was accepted or avoided, rather than challenged, by grandparents.

Maurice Eisenbruch (1984) described the mixed messages that others can offer the bereaved "The community may pay lip service in allowing the bereaved to express sadness for as long as necessary, yet actually be ambivalent about tolerating the bereaved who does so" (p. 324). This sums up the paradox associated with the idea of discomfort; theoretically society may believe that bereavement should be acknowledged but in practice the distress of bereaved people is hard to face. One way out of this is to give a message that "Yes, it's really sad, but things should be getting back to normal". This is what Jenny felt when she wrote that she felt that people no longer wanted to listen to her. The idea of "normal" returns us to ideas about bereavement, which emphasise arriving at an endpoint. The consequence of holding a view that people should be "getting back to normal" is that their grief is disenfranchised.

### **Disenfranchised grief**

Disenfranchised grief was defined by Doka (1989) as "the grief that persons experience when they incur a loss that is not, or cannot be, openly acknowledged, publicly mourned, or socially supported" (p. 4). It has a number of potential meanings in relation to grandparent bereavement. First, as Corr

explanation is that a constructed hierarchy of grief continues, despite earlier work by Alice Lovell (1983) which challenged this assumption. The hierarchy suggests that the older the infant, the greater the loss and grief intensity. As all the grandchildren in this study died aged less than one year, grandparents' grief could be viewed as of little importance if the hierarchy view is adopted.

Elisabeth's friend who wished, after Jordan's death, that Elisabeth might become a grandmother in the future, possibly represents this view of a hierarchy, where stillbirth does not count. It is still a prevalent view. It is reflected in the fact that it has only been in the late 1990's, that NZ local councils and self-help groups have worked to acknowledge the existence of dead children by providing memorial gardens specifically for infants and children.

Second, grandparents' grief is potentially disenfranchised because grandparents are older people. This can be a combination of expectations that older people have life experience and, therefore, should be able to cope because older people "often internalise societal expectations that their grief is less important than the grief of others" (Moss & Moss, 1997, p. 11). This was not a perspective supported in the joint construction.

Third, disenfranchisement of grandparents' and others' grief can occur when there are expectations that grief, or being bereaved, will follow particular patterns. The result of this is that social support is not offered in situations outside the expected pattern. This was part of the subtle social context for some participants. Ailsa described her frustration with the community view that things get exponentially better after a death (see pp. 281-282). Instead, she encouraged her family to still ask how people were a year or more after a death (see p. 168) because other people no longer asked. Rose was glad to have a chance to challenge the hierarchies of grief, which she perceived existed in the community (see p. 161). Interestingly, in the joint construction, grandparents did not disenfranchise their own, or the parents' grief by ascribing to views of bereavement which precluded keeping a connection with the grandchild. This was despite being aware of ideas about stages and endpoints of grief. This may, again, reflect that the participants in this research had a particular construction of their bereavement which supported continuing bonds and therefore, sought the opportunity to talk about these as part of the research.

However, the final area of disenfranchisement brings us back to where we started in the research, that grandparents are "*Forgotten grievers*" (Gyulay, 1975, p. 1478). Nearly 25 years after Gyulay wrote her article, it appears that many grandparents are still forgotten by people outside the family. With lack of acknowledgement of their bereavement their grief can be disenfranchised. For example, grandparents talked of people asking them how the parents were (see Benita, p. 244), which supports the view that there is little recognition of grandparents' own feelings. Similarly, Barry, Jane and Diana identified that there is little acknowledgement of grandparents in their practice. This does not reflect an undervaluing of their bereavement, but represents the limited opportunities to meet grandparents when services for child health and funerals are primarily centred on the nuclear family model. In addition, the role which grandparents construct their bereavement around, as "*parent of the adult parents*", casts them in the support role which does not position them to be recognised in the world outside the family. An example of this may be seen in the public birth and death notices. Prior to starting this research, I collected birth and death notices from the Otago Daily Times for a 6 month period (August 1<sup>st</sup> 1995 to January 31<sup>st</sup> 1996). The notices are widely read in the community where people are closely interlinked and keep an eye on the "hatching and despatching". During that time there were 24 death notices for infants, of which 4 were written by grandparents and 12 mentioned grandparents amongst other family members. This evidence supported the perspective presented in the joint construction, that the parents publish the birth and death notices, some of which mention the grandparents. However, many grandparents do not live in the same geographical area as the parents which means that unless they place a death notice in their local paper there is no opportunity for grandparents to publicly acknowledge, and receive acknowledgement from their community of, their bereavement.

Jenny's impassioned comment was a plea to be acknowledged. She wrote,

[I want] to be acknowledged by "society and the media" to be suffering a great loss. Not just be accepted as the 'tower of strength' for everyone else and as the 'bottomless pit of experience' to be drawn on at will. But to be in need of a hug or a friendly ear, or just someone to sit and walk with in companionable silence. (Jenny 4:1)

By acknowledgement she meant recognition of grandparent bereavement, not huge outpourings of sympathy. In this research parents, grandparents and



health/bereavement professionals recognised that grandparents were unacknowledged. For some this research was an opportunity to have their voice heard by others (see pp.166-169). Similarly, DeFrain et al. (1991-92) found that grandparents "*wanted people to think of them too, because their hurt is very real after such a great loss*" (p. 180). Paradoxically, whilst wanting acknowledgement, some grandparents do not claim their status as bereaved grandparents, when the opportunity arises, because of the discomfort it would cause the inquirer. So the circle goes on; with grandparents concerned for and supporting parents, receiving support and recognition from the parents, but not widely recognised as bereaved in their own right. The final question is whether grandparent bereavement is disenfranchised because it is not socially supported, or because it is just not recognised – an act of commission as opposed to omission. Corr (1998-9) believed that it was overlooked and that once recognised it would be publicly acknowledged. Given the interest and concern shown by people, who ask me about this research, I would support his view. Such a perspective leaves open for the future the possibilities of claiming acknowledgement for bereaved grandparents amongst the wider community and amongst health/bereavement professionals.

## **CONCLUSION – TO RECAP**

During this research several participants wondered if we were going to produce a model of bereavement from the study. Perhaps the continuing search to find universal models is, as Jean Benoliel (1985) wrote, because loss is paradoxically both a unique and a common part of human life. However, I believe that the diversity of constructions within the research, and the debates within this chapter, provide support for a view which celebrates the variety of constructions of grandparent bereavement, and does not support a universal model. I noted, in earlier chapters, that the intent, and philosophical assumptions of the research, precluded a position that was going to generalise the findings of the research far and wide. Instead, I do believe that it is appropriate to support the statement which Brian De Vries (1997) wrote about kinship bereavement occurring in later

life. He concluded,

First, four broad generalisations about bereavement are offered: 1) Bereavement is a complex experience, 2) influenced by the context within which the loss takes place as well as 3) the nature of the lost relationship and role the deceased played, 4) with an endpoint which is variable and unclear. (p. 141)

It is an appraisal of bereavement which is reinforced and refined by this research; the refinement being point (4) where the notion of "endpoint" could be replaced by "*Putting loss in life in place*" from the joint construction.

The re-construction in this chapter is, in effect, a smorgasbord of research and ideas, of which parts illuminate or fit with this research. Instead of selecting one model of bereavement, I hope that I have illustrated that a number of perspectives are relevant to this construction of grandparent bereavement. Rejecting the idea of one "right" theory or reality of bereavement opens the door to considering how a number of constructions of reality are equally "valid" and equally "helpful" in exploring the complexity of how individuals construct their experiences as bereaved grandparents. For example, ideas around attachment and bonding appear to fit with grandparents establishing personhood and claiming their grandchild but equally, these attachments do not have to be relinquished in order to invest in another relationship such as the birth of another grandchild. It is possible to have a continuing connection. Similarly, the idea of transition offers ways to explore whether there is a finite time period between life **before** and life **after** the grandchild, and if so, how do we then account for the constructed reality of living **with** the death?

Given the constructivist inquiry approach of this research, I have placed emphasis on the cognitive aspects of bereavement. In the context of exploring ways in which grandparents make sense of the death it appears that stories and conversations, which have been a key part of the research process, are equally valuable as part of the bereavement process.

As I noted through this chapter, this research offers a construction that explores only some of the ways bereaved grandparents construct their experience. There are many grandparents' whose perspectives are not included, such as grandparents identifying with a range of cultural perspectives, grandparents as

carers for their grandchildren, and grandparents whose children are solo parents. However, amongst the diversity of the stories in Part 2, there are also areas of shared understanding that enabled the development of the joint construction. This means that, in supporting diversity in bereavement, I am not envisioning as many totally different constructions of reality as there are people. Instead, I believe that this chapter offers support for a postmodern view of multiple meanings of bereavement with multiple ways to be bereaved (Stroebe et al., 1992). To return to the metaphor proposed by participants, this means journeys using different forms of transport to reach different, and changing, destinations. Different forms of transport represent different ways to be bereaved which might include using reflexive conversation to contribute to a continuing self narrative (Walter, 1996) or not to talk about the bereavement at all. The journey destination might be to continue the connection with the deceased or it might be to reach a sense of "over it" detachment. Ailsa implied this when she said "Some people get over it very quickly and others take a long time [implying different journeys] but time will eventually give you a new life or make things seem more normal [which suggests different goals or endpoints]" (p.268). Following through the idea of a journey to differing and changing destinations offers the possibility that different ways and meanings of bereavement may suit at different times in the same person's life. By way of example, Elwyn had been happy with a perspective of bereavement as a transition where she "got over" Lindsay's death and carried on running the farm and raising her family. It was with Daniel's death that she reflected on how she felt about, and where she wanted, Lindsay and Daniel within her life. She then worked on constructing a continuing relationship with both of them. Whilst not explored in detail in the research, this is a possibility that is congruent with ideas of reconstructing connections with multiple meanings and multiple ways of being bereaved.

Finally, having located this research within the extant literature and explored the understandings it offers to re-view this literature, the next chapter explores the possible meanings these ideas might have for individuals, families, practitioners, communities and researchers.

## CHAPTER 8

### THE END AND THE BEGINNING

#### PRE-AMBLE

This chapter is an ending for two previously encountered stories in this thesis; namely the constructions of grandparent bereavement, presented in Parts 2 and 3; and of my journey through this research, discussed in Part 1. There are multiple ways of finishing stories or drawing to a conclusion. This is the ending I propose for what has been constructed as nursing thesis for a doctoral award. If this text was constructed for another purpose the end would be different. There may be other endings that you, as a reader of the text, think of depending on what has spoken to you in earlier chapters. In Chapter 1, I claimed a place for this research in relation to new perspectives of grandparent bereavement and of constructivist inquiry for research with a nursing focus. I am going to return to these two areas before reaching the farewells from participants in their postscripts.

In positioning this conclusion I want to return to the idea of storying as the thread running through this thesis. I am proposing this chapter, and the whole thesis, are considered in relation to Frank's (1995) writing on narrative ethics, which I referred to on page 329. He explored the idea of thinking **with** stories, whether one's own or other people's, to shape one's future becoming. Frank's argument was that "Professionals understand stories as something to carry a message away from – as in, "What did you learn from ..." in contrast to "what a listener becomes in the course of listening to the story" (p. 159). So, I am suggesting we consider what has spoken to us in these stories so far, since the real conclusion of this research is about what stays **with** us, as part of our future becoming. With this in mind I have written this chapter as a short discussion of the things which speak to me as future possibilities for myself, for people, for practice and for research.

## A RE-VIEW OF GRANDPARENT BEREAVEMENT

I use the term "grandparent bereavement" without qualifying it to situations where infants die unexpectedly, aged less than one year, because this has remained the constant perspective of this research. After the discussion in Chapter 7, I believe that the similarity of issues around multiple griefs for grandparents whose grandchildren died (Fry, 1997; Ponzetti, 1992; Ponzetti & Johnson, 1991) means that there is a place to have a general discussion around grandparent bereavement. I accept that such a discussion rests on believing in the diversity of meanings of bereavement to individual people, constructed in a much wider context than solely the age and cause of death of the grandchild.

This research has used a process, and created a place, for 16 grandparents to develop and claim a voice for their experiences after their grandchildren had died, supported by the voices of 6 parents and 3 health/bereavement professionals. For me, this is the most powerful and poignant part of both the thesis and the research. The stories speak to the struggles, the insights and the different ways in which individuals constructed their experiences and yet, within the diversity, the experience is centred around their family relationships - in particular, as the parents of the parents. It is summed up in the thesis title in the phrase "*Family matters*" where both meanings of the word "matters" are part of the research construction.

So, what do I believe this research offers to the existing knowledge about grandparent bereavement? The question can be answered in relation to what it offers to participants, to existing and future bereaved grandparents and families, to us as people, to practitioners (nursing and other), and to future research directions. In considering what this research can offer, I am acknowledging that the participants and I have already started to share these ideas and stories widely so that the voices of participants are heard by different audiences, from self-help groups and conferences, to practice and academic journals. The emphasis is on what the voices and stories "might offer" for people to hear and think about. The recipients of the stories can then decide for themselves if they stay with the stories and voices, and if these have any relevance to their lives or practice. In this respect, my partnership with the participants extends beyond this

thesis, since one of my first beliefs was research to offer knowledge that is of use in people's lives (see p. 11); to achieve this the research texts have to move beyond this thesis to other audiences.

### **What might the research offer to participants and other grandparents and families when a grandchild dies?**

First, I believe, as the stories in Part 2 illustrate, many participants in this research support my construction that they have claimed a voice. However, they do not describe it in this way. Instead, they described the research as a chance to make a difference, to ask people to think about grandparent bereavement, to remember and talk about their grandchild or child, and to create a memorial or a purpose to the pain. In this sense the research has a place in their lives and part of their gift is a legacy to their families in marking the life and death of their grandchild or child (see pp.166-169). The research with the participants' stories is also a legacy for existing and future families, whether as something which is already being talked about in self-help group meetings, or as a published book of stories, which is accessible to the public in a way which an academic thesis is not. None of the participants would claim that their story provides **the** way to be a bereaved grandparent because, as discussed in Chapters 2, 6 and 7, there are multiple ways to be a grandparent (Giarrusso et al., 1996) which intersect with multiple ways to be bereaved (Stroebe et al., 1992; Walter, 1996) with the resultant potential for multiple ways to be a bereaved grandparent. What the stories can offer are different ways to view "When a grandchild dies" and, as some participants found when they read each others' stories, the different perspectives presented in the stories offer the potential to re-view and re-construct one's own experience in the light of these experiences.

### **What might the research offer to us – as people?**

I believe the voices in the research can speak to us as people, individuals and members of the community – outside any practice or academic hat that we might wear. The voices could make us stop and think. This might mean appreciating the potential extent of grandparent bereavement in sheer numbers of grandparents and the potential intensity of pain(s) or grief(s) which can accompany the challenge of a grandchild's death. Have we realised this?



I thought I had an appreciation of grandparent bereavement from my clinical practice, which was why I started out in this research. The stories have offered me the chance to hear of grandparent bereavement in ways that I had not appreciated before, and to scratch the surface of the complexities arising from an infant grandchild's death. Having heard the voices in the research there are multiple ways we might be with bereaved grandparents and families. In particular, the issues of acknowledgement and listening have been the threads running through the constructions in this research and might be areas to consider when meeting bereaved grandparents. Moving from the possible implications for individuals, what might the research offer to the roles held in clinical practice?

### **What might the research offer to practice?**

In using the word "practice" I am particularly interested in nursing practice. This includes paediatric nurses, Plunket nurses and public health nurses in NZ, and their counterparts in the UK, such as health visitors; all of whom are involved with families where infants die. However, I am also conscious that this has relevance to the practice of doctors working with bereaved families, midwives caring for families (which was where I first became most involved in families' bereavement) and other professionals such as counsellors and grief co-ordinators with funeral directors.

This research does not claim to provide any definitive answers for situations where, as practitioners, we encounter bereaved grandparents. I believe the stories and joint construction offer us, if we wish to work with them, ways to look at how grandparent bereavement can be for some grandparents. In particular this thesis highlights some issues of which to be aware in our practice, such as the importance of grandparents' roles and relationships as "*parent of the adult parents*" which can bring both pain and the need to "*be with*" the parents. In addition, some grandparents take a very important and active part in creating and maintaining a space for their grandchild, which remembers and acknowledges his/her life and death as a member of the family.

By being "aware" I mean being alert to the intergenerational perspective of infant death and not solely viewing the "family" as defined by the parent-child relationship of the nuclear family. Holding an intergenerational perspective would mean recognising the support that many grandparents offer, and the pain that they feel, when a grandchild dies. In terms of feelings, we could recognise that there are multiple griefs, or pains, which grandparents experience in the context of the web of relationships that they hold in the family. Those feelings may be very powerful and devastating; in part because, as a parent, the grandparent has to watch the pain of their child knowing that there is nothing that can "fix it". Whilst age and life experience may bring knowledge and skills, it does not remove the pain and loss which, as Elisabeth described, meant that Martin's death was "the hardest problem I ever coped with" (see p. 209). From the constructions in this research, recognising, and acknowledging grandparents' pain and grief might just mean thinking to ask the grandparents the simple question "How are you?". Or, in situations where we only meet the parents of the child it might be acknowledging to them, without detracting from the acknowledgment of their grief, that we appreciate their parents are bereaved, too. In this acknowledgement we might offer an opportunity for some grandparents to claim their bereavement beyond their role as supporters.

I believe we could acknowledge the role that some grandparents take in supporting the parents and their family - support offered in a range of ways at the time a grandchild dies and over the following months and years as the family manages the changes arising from the death. In valuing and acknowledging their role I am not suggesting that we presume grandparents automatically provide extensive support to the parents. To do so would be congruent with current health policy, which is shifting increasing responsibility onto individuals as carers for other family members. Such an assumption, however, would disadvantage some grandparents who might feel guilty at being "expected" to offer support when, for a variety of reasons, they are unable to do so. This parallels the discussion in Chapter 7 of disenfranchised grief where expectations constrain the ways in which individuals can "be". Whilst emphasising the support which grandparents offer their families, I believe this research offers a reminder that such support is not a unidirectional flow of energy and effort. In many families

support is given, and received, by family members within the context of the mutuality of their relationships.

One of my original research questions was "*What recognition or support might grandparents want from the community or health workers?*" (see p.51) and at the end of the research there is an answer. During the conversations in the research, we have explored at length the differing ways in which grandparents see support from agencies, families, and other people and how these can change over time. After completing the research, I can find no "take home message" that grandparents want regular follow-up or grandparent support groups. This does not fit with my beginning etic view which was grounded on a belief in the benefits for grandparents accessing a group or befriending service. Neither individuals' stories nor the joint construction identified a clear wish for professional services to be provided for bereaved grandparents; although grandparents did value acknowledgement of their bereavement from health/bereavement professionals. I fully recognise that this research reflects the views of a motivated, self-selected group of people and I do not make claim, from this research, that all bereaved grandparents are happy without the assistance of professional support services.

That extrafamilial support from professional agencies was not part of the joint construction is, perhaps, just as well - given existing funding arrangements for the provision of NZ health services<sup>1</sup>. Currently, there is no identifiable place where grandparent bereavement might fit into the Health Funding Authority (1999) business plans for child health or the elderly under the funding agreement with the Minister of Health for the period 1999-2000. The only potentially relevant funding lies in the mental health business plan contract where the emphasis is on "crisis" and in no respect did grandparents construct their experience as a crisis congruent with the contract assumptions of crisis as severe impairment of functioning. This review of the current funding agreement does identify a point to consider, when health care practice is fiscally oriented to health outcomes, goals and budgets, there seems to be no place within this construction of health care to include grandparent bereavement. In which case one must ask, will grandparents continue to be "*Forgotten Grievors*"?

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<sup>1</sup> I have commented on the NZ context, since the study was located here, as the place from which I undertook the study.

Even **if** there was funding dedicated to bereaved families **and** more grandparents wanted some support from health/bereavement professionals, then what intervention would be offered and what is the evidence to support it? If we momentarily leave aside what form an intervention might take, depending on our construction of bereavement and grief, there has actually been remarkably little research on the efficacy, or otherwise, of professional interventions. Parkes (1980) reviewed the limited evidence at that time and concluded that professional and self-help support appeared to be "helpful". Whilst Richard Lilford, Peter Stratton, Susan Godsil and Anjali Prasad (1994) found no evidence of a beneficial effect of counselling on the mental health of bereaved parents. Lack of control groups, differing outcome measures and unclear definitions of intervention make it difficult to make comparisons. Most notably, Middleton and Raphael (1987) wrote with acerbity, "Assuming that research, to date, has been done for reasons that included providing a means by which bereaved people at risk could be identified, assessed and treated, it is surprising that there are so few clearly accepted guidelines that go much further than what could be normally considered common sense" (p. 330). Leaving aside the debate about "at risk" and "treated", the common sense approach still prevails 10 years on, both in practice and with family members supporting each other, as this research demonstrates. A survey of sudden unexpected infant death in the UK, which included GPs and health visitors, noted that many felt too inadequately prepared, supported and supervised to be able to offer families (implicit definition as parents and siblings of the infants) support (Dent, Condon, Blair & Fleming, 1996). If education for professional practice, combined with common sense, means that practitioners feel inadequate, where does that leave grandparents, who are generally the main supporters for the parents?

So, returning to the common sense approach, does this research offer us, as practitioners, any insights on how we might "be" with bereaved grandparents? I believe the process, as a series of conversations within a relationship of partnership and respect, offers some insights for practice. But, you might say, that is what nurses, midwives, doctors and grief co-ordinators do anyway: they listen. Yes, they do listen. The difference from my perspective, having practised in that way for a number of years, is that whilst listening, we generally have a paradigm which determines how we view our role, in assisting the bereaved. So,

we might practice specifically to Worden's (1991) tasks of grief, or in a more eclectic view we might practice with a view that "time heals" or that "continuing bonds need to be maintained". What I am proposing from this research process is that we recognise the diversity of constructions about bereavement and the possibilities this has for our role with each family – in which I am assuming grandparents might be part. So, instead of using one construction of practice with grandparents, or families, we could consider offering choices. The choices we could offer would be about the directions they might take in their grief, so that they are aware that there are different journeys, not just one construction of bereavement.

Why do I believe this was part of the process of the research? I think of the conversations that I had with people like Elwyn. She joined the research with a construction of what Lindsay's death meant to her. During our conversations she reviewed her ideas to reconstruct a different relationship with Lindsay in the context of Daniel's death. Similarly, Ailsa holds a view that life goes on and becomes the norm, at the same time as continuing to miss, and have an empty space for, Conor. These are different, but not necessarily conflicting, ideas which she holds in her construction of her bereavement.

These ideas resonate with a view of "*culturally embedded practice*" (Stroebe, et al., 1992, p. 1211); where practitioners might work with bereaved grandparents and their families, within the "*rich texture of possibilities*" (p. 1211) of the meanings and ways in which individuals are, and want to be, bereaved and to grieve. Such a perspective would be congruent with the work of Braun and Berg (1994), Riches and Dawson (1996a) and Walters (1996) which highlight the importance of being able to talk and make sense of what has happened. Nancy Moules (1998) emphasised that to acknowledge differing views of grief means that, "*clinical practice with the bereaved must be open to the legitimacy of others*" (p. 50). This perspective has attendant implications for practice, such as not defining bereaved people according to discourses which label them as, "stuck in their grief", or as being "in denial". In this light, practice with bereaved people and families could be constructed as working with the issues and beliefs that people hold within their own context, which would then shape the form and direction of the ways in which they were bereaved. This view fits with ideas

proposed in the context of working **with** families (Hartrick, 1998; Hartrick, Lindsey and Hills, 1994; Wright, Watson and Bell, 1996). Such a view contrasts with practice being planned around the "needs" of a client; needs which are defined by the practitioner who is standing in another context holding a different worldview to that of the client.

Returning to the process of conversations, active listening and storying, I want to consider what the process offered for participants in this research and how this relates to clinical practice. One construction of the process in this research is that through telling their story some participants gained acknowledgement of their bereavement, as well as the opportunity for "testimony" where "repetition" in the telling and retelling of the story, "is the medium of becoming" (Frank, 1995, p. 159). Such a process can be viewed as exploring and constructing the story of the experience as part of the continuing self narrative (Riches & Dawson, 1996a; Walter, 1996 citing Giddens) which positions the death in relation to who grandparents are now and into the future. For some participants, the conversations did not extend to explore future "becomings" but concentrated on the remembering and the re-ordering of events and ideas so that their story was, so to speak, straight at this point in time, and it could be repeated again and again. Such a construction of the process fits with the earlier work discussed on storying and meaning-making (Brody, 1987; Frank, 1995; White & Epston, 1990). This research offers a place for nurses, and other practitioners, to claim listening to stories as a central part of their practice, instead of defining, and negating, this activity as "I've **just** listened to him/her talk". In this sense practice would be shaped less by "working with" people, and more by "being with" people – in the way that bereaved grandparents sought to be with the bereaved parents. Stories and conversations offer ways to enter, and be with, bereaved people. Whilst this suggestion does not offer a checklist of what to do with bereaved people, such a way of being in practice does enable the "rich texture of possibilities" (Stroebe et al., 1992, p. 1211).

In closing this section I am acutely conscious that these thoughts may well remain "might be's" and "possibilities". Not because these ideas do not speak to our practice, but because the system in which we practice will continue to make the nuclear family our first, and often only, point of contact. Whilst family/whanau



is a key part of the NZ Child Health Strategy (1998), such a policy document does not guarantee resources to extend the provision of care for family/whanau of children to include other members, such as bereaved grandparents.

### **What might the research offer to possible research directions?**

With regard to future research directions, I believe there is a place for different research approaches to suit different goals. It could be “valuable” to explore key aspects of the joint construction with a larger group of participants who had grandchildren die at different ages, and who might complete a self-report questionnaire. This might identify whether the construction reflects key aspects of diverse experiences. Such research could consider dual-age images, not reported as such in other literature, and could explore further the low occurrence of guilt in this research, when compared with other studies. Similarly, it could be “valuable” to extend this research using constructivist inquiry to explore how grandparents who are primary carers for grandchildren, or whose children are solo parents, perceive their bereavement – how would these constructions relate to the joint construction in Chapter 6? In addition, how does the joint construction fit with an intergenerational construction of bereavement after a child dies, where parents, grandparents, grandchildren, and other family members construct their own **and** other family member’s experiences? This would give further insight into the ways in which roles and relationships shape the bereavement, which would develop the existing joint construction to become more informed and sophisticated.

The question I ask myself is, for whom and why would such research be “valuable”? During this research I have worked with ideas about bereavement and grief which appreciate individual difference, whilst acknowledging similarities. I have moved to a postmodern perspective of bereavement with multiple meanings and ways of being bereaved, in which case, is there any point in undertaking future research? Holding a postmodern position means that the possibility of finding a universal model, or meta-narrative, does not exist. On the other hand such research could extend understandings and contribute to the ever evolving development of constructions of bereavement, in the way that the studies in “*Continuing Bonds*” (Klass et al., 1996) have done. Would such

research be valuable to families, to nurses and other health and bereavement professionals? Such research might increase awareness of the complexity of grandparent bereavement; it might also be a reminder of the implications of culturally safe practice that respects other worldviews in relation to bereavement. What such research is not going to provide is a checklist, or a set of principles to apply to clinical practice with bereaved families. So, leaving some of the possibilities this research offers in relation to "When a grandchild dies", what about the research in relation to methodology?

## **A RE-VIEW OF CONSTRUCTIVIST INQUIRY IN THIS RESEARCH**

I believe this research can offer a view of the strength of this research approach, a comment on the limitations of constructivist inquiry, a contribution to the debates around ethical issues in family focused bereavement research and the issues surrounding rigor.

### **The strengths and possibilities of adapted constructivist inquiry**

A large part of this thesis has been a series of stories about a lengthy and complex research journey using constructivist inquiry informed by a range of other writings and perspectives. I stated, in Chapter 3, that I supported Appleton and King's (1997) view that constructivist inquiry has potential to be used in a range of nursing and health research. I still support that view as I end this thesis. I believe Chapter 4 offered a story of the potential strength of hermeneutic dialectic circles as **process** to work in a relativist position with multiple constructions - a process within, and then across, groups which enabled us to share, discuss and debate in a series of stories and conversations. In particular, the recycling around the circles was valuable when the research was about a personal and painful experience. It enabled us to uncover aspects of individual, and then joint, construction(s) which were not initially visible to either myself or the participants, such as the complexity of being a parent of an adult parent and what this means. The strength, which I believe the circles offered across groups, was the dialogue between individuals, metaphorically sitting in their different groups, with different perspectives. Given that both nursing and health issues are

situated in the context of working with many other groups - clients, colleagues, families, the community, management . . . the list continues - such a process offers a way to consider dialogue across a range of individuals to potentially integrate differing constructions in a bigger picture. The integration of storying and conversation as relationship with constructivist inquiry, as I discussed in Chapters 3 and 4, can offer possible ways in which similar, and extended, approaches might be used in a wide range of nursing and health research. In particular, during the research I valued Frank's (1995) perspective of working **with** stories and the ideas of partnership in positioning the research relationship. It has meant I accepted, and worked with, participants' constructions, which has suited how I have envisaged their "gift" and is congruent with a relativist ontology where all constructions are equally meaningful. However, I am aware that such a position precludes assessing, writing **about**, or disentangling power structures (Hammersley, 1992) particularly within the relationships between multiple family members. In this sense, I do believe constructivist inquiry, in the adapted form used in this research, is like any other research approach; it is suited to particular areas of inquiry, and not to others.

### **A contribution to the debates around ethical issues in family focused bereavement research**

There is a move towards, and call for more, research with multiple family members (Handel, 1996), as researchers and clinicians grapple with the importance of context in which people live their lives. In the field of bereavement research there has been a range of work with multiple family members including both partners or an intergenerational perspective (e.g., Daly, 1992b; Clarke-Steffen, 1993; Rosenblatt, 1995). I discussed in Chapter 5 some of the issues which arise in research which combines bereavement and family research. Both are "seen" as personal and painful areas with attendant ethical issues and "risks" for participants. These have been reviewed in the context of bereavement research (e.g., Cook, 1995; Parkes, 1995) and in family research (e.g., Gilgun et al., 1993; LaRossa & Wolf, 1985). However, identifying, discussing and reading about potential ethical issues that may occur cannot entirely predict the range of situational ethics which emerge during the research relationship interactions. This research, and thesis, offer some further ways of "seeing" these issues and

"risks". Whilst the ethical considerations of constructivist inquiry was a large thrust of Guba and Lincoln's writing in 1989, it was my nursing practice which guided the positioning of the research relationship as a respectful partnership. This led to the decisions of how I believed the research "should be" in relation to Other and, in particular, constructing participation as a "gift" relationship, in line with the work of Limerick et al. (1996). Some of the debates in Chapter 5 offered contributions to the dialogue about thanatological research in the family; the value of multiple members' perspective when families share their constructions of reality and how to work with these "safely" when uncovering the complexity of relationships and roles within the family. Similarly, the original challenge of colleagues questioning the possible "risks" to participants was explored and itself challenged by the constructions, which participants developed, of taking part in the research. This thesis joins with the work of Hutchinson et al. (1994) to stand at an open doorway looking at ways in which we, as researchers, might construct research processes which have maximum potential for both participants and researcher.

### **Thoughts on quality and crises**

In Chapters 3 and 4 I shared some of the tensions I felt about the concepts of rigor and quality within the research and this thesis. I explored the congruence of using a series of criteria in a study using a relativist ontology and the consequences of placing a heavy reliance on member checking which is, itself, an interaction that can be constructed in different ways by the researcher and participants. Standing at the end of this research, and this thesis what comment would I make about the quality of the research and text? Most importantly, I believe in the quality of the joint construction and stories based on the circling process (described in Chapter 4). I believe that using a series of conversations enabled the development of the most sophisticated and powerful (in terms of explanation) joint construction that the 26 participants and I could develop at the time of mid-1999. In the context of the quality of this thesis I suggested, in Chapter 3, a position of compromise where the crises of representation and legitimization were the issues to consider, rather than a series of criteria that I could evidence as being "met" through a range of strategies. In relation to these "crises", I leave it with audiences who hear about, and read about, this work to

consider the position that Other has held in the research and in this text. In terms of claiming the authority of this text, I have written this thesis, and the conclusion in particular, by claiming the possibilities, not the absolutes, which it can offer. My own personal reference point for this work was the comment from Denzin and Lincoln (1994) which questioned whether, "not only the researcher's interests, but also the interest of those studied" (p. 578) have been served? I believe that, whilst my interest is the completion of a doctorate, this has not superseded the interests of the participants who have willingly supported this journey.

## FAREWELL

So, to an end. This chapter has re-viewed the possibilities of this research as an exploration of grandparent bereavement and the use of an adapted form of constructivist inquiry. If I summed up in one sentence, what this research means to me, it is that "*Family matters*" in the multiple ways of being a grandparent, of being bereaved, and of responding to the challenge of "When an infant grandchild dies". And what of my future dreams? Having reached the end, which in the beginning was quite unknown to me, I now see the research and this thesis in a different way. It is part of my future as a person, as a nurse and as a researcher. The essence of this is captured by TS Eliot (1952, p.145), who wrote,

We shall not cease from exploration

And the end of all our exploring

Will be to arrive where we started

And know the place for the first time.

## AND FINALLY - POSTSCRIPTS FROM PARTICIPANTS

People who wanted to let you know what has been happening for them since the introduction chapter was written have written their news for you below.

**Jenny** writes, "Since Harry's birth I've had time to evaluate my feelings. For Sue and Chas, having the day-to-day trauma of another pregnancy quite naturally brought thoughts, or fears about, Jordan into their minds. Once Harry arrived they seem to be coping very well, although understandably they are a little over protective. Tony and I are overjoyed at now having two beautiful grandsons to love and watch grow up. I feel very great love for Lee, our adopted grandson, this has been a great shock. I really thought having a "natural" born grandson would still be a bit more special but it's not - it's just different. All I can say is that when Jordan died we had so much love ready to give that we took Lee to our hearts and he's received this great outpouring of emotions. We so love our little grandsons and feel blessed to be part of their lives, as Jordan will always be part of our lives. Being included in this study has been a learning curve about our loss, other people's loss and the slow journey towards a normal life where we all feel comfortable with our experiences and memories of Jordan's birth/death arrival and he was and will forever be our very precious grandson."

**Colston** writes, "Recently we remembered Christopher's 7<sup>th</sup> birthday. I have problems thinking of him as a possible 7-year-old rather than the baby we see in the photographs. Christine was very emotional on the day, which unfortunately was a few days before her first son's 12<sup>th</sup> birthday. She had to gather herself to help him and be happy with his friends on that day. I was surprised at the depth of emotion we still felt on that day. The year 2000 will bring semi-retirement from my pastoral responsibilities, leaving more time for family, enjoyment, relaxation and much needed rest. I'm not sure how I am going to cope with less involvement, time will tell!"



**Terese** writes, "I am very fortunate, and really lucky, to have all my family and grandchildren living in the same area. And see them often, with the younger ones staying with me occasionally. Bernadette would be 17 now. I often wonder what she would be like and if our lives would be any different."

**Diana & Rupert.** Diana writes, "Since Gracie's death I have experienced another two totally different types of grief. I now know that what one holds on to is the positive, not the process of coping during the time of grief. Gracie will always be the beautiful baby girl who, when I held her, appeared perfect - that will never change."

**Alex & Benita** write, "The 7 years that have passed since Matthew's birth and death have given us time to ponder on a number of things.

Time is what we wish to comment on. We use the expression, "Time is a great healer". People say this is a cliché, but more often as a kind cover as they struggle to find a way to express something that few words can express. For us time is one of the greatest gifts we have. There is always time for the important things, and the building up or repairing of disrupted relationships demands a large portion of this time. In this time God has said to us, "I understand your grief and there is no compensation. But if you are looking for richness of relationships and all the loving in the world, here it is in the person of a kind loving son, a daughter-in-law who gives great joy, and three unique, beautiful grand daughters full of life, loving and laughter."

**Sarah & Frazer.** Sarah writes, "It has been 7 years since the death of Matthew and the memories are still very vivid. Sometimes the pain creeps back in. He is, and always will be, a special part of our family. Jessica (6) has never met him, yet she is quick to tell anyone who will listen about her brother. Rochelle and Rose still relate experiences of him in their school work like Rochelle's poem below."

**The Sleeping Baby – by Rochelle- sister of Matthew<sup>2</sup>**

The room is silent, silent and dark  
 Four pairs of eyes stare anxiously  
 As the sleeping baby gasps for breath  
 Then begins to breathe normally again

The sleeping baby lies soundly in his  
 Loving Grandfather's arms  
 He stirs but doesn't wake  
 This baby is surrounded with love  
 The love of his Parents and  
 The love of his Grandparents

This baby is also in pain and suffering  
 He is dying and no one can help  
 Not the doctors or anyone  
 The only help he can get is love  
 Love is all anyone can give him

Suddenly the baby starts gasping again  
 But this time he doesn't begin to breathe  
 Normally again  
 It stops .....everything is quiet  
 All that can be heard is the sobbing  
 And the question in every one's mind  
 Why us? Why did it have to happen to us?

**Rose** says, "Since Ruby's death I have grown closer to John, and in myself I feel stronger and that I have a lot more insight into other people's feelings. Whilst we would never want Ruby to have died, we do feel that given that it happened, a lot of good has come out of it. This includes being actively involved in the Dunedin Baby Bereavement group and during the last 2 years I have been completing papers towards a degree in social work, and I look forward to working with families in the future.

In the last year my mother, Marie, has become increasingly unwell with both bad arthritis and Alzheimer's. she spent some time having respite care when my father could no longer care for her at home and she now needs full time hospital level

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<sup>2</sup> With special thanks to Rochelle for her permission to include this poem.

care. At the time she became unwell she used to read and re-read, endlessly, her story of Ruby, which is in Part Two. In many ways we worried that she only read her story and nothing else, but it seems to have been her way of making sure that she remembered Ruby. Now when she cannot remember recent events, the **only** exception is her memories about Ruby. This to me is an expression of her strength and commitment to holding on to Ruby because she knows how important Ruby is to me."

**Ailsa**, writes, "It is now nearly 10 years since my husband died and 5 years since Conor was with us for such a short time. I seem always to have linked these two milestones together. I have also come to realise that, if you allow it, time will eventually allow you peace of mind, or perhaps it is just acceptance of what life has thrown my way. I feel comfortable in this room of my house<sup>3</sup> which has now become the norm. I do find that I worry a lot about my older grandchildren, who are now in their mid and late teens, when they are driving or travelling away. I don't know if this is the result of losing one grandchild and the fear of anything happening to another or as Marcus, my eldest grandchild, said, "Nana, you would be like that anyway". Jonathon continues to give me much joy and tempers the loss of Conor somewhat, and I am so thankful for the abundant love of all my family."

**Elwyn** writes, "I am now retired and with a backlog of porcelain dolls, made over the years, to dress, sewing for other people, golf, secretary of the Probus club, my garden and family interests. My days are busy and fulfilled. As we grow older, those special little people, who were in our lives for such a short time, will forever hold a special place in our hearts."

**Beth** writes, " When Daniel died in 1993 our world was full of pain and unanswered questions. Now 6 years on our pain has changed to softer memories and they have become a natural part of our family life."

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<sup>3</sup> The image which Ailsa used in relation to bereavement p.282.

**Maxine** writes, "In 1999 many things changed for me. My fourth child, was born 5 weeks prematurely. Steve and I wanted to call him after my half-brother who died of cot death. When asked, my mother and step-father were really pleased for him to be named in memory of their son. This has contributed to the fact that the family now talks openly about their feelings, and it is no longer everyone mollycoddling each other and protecting each other by not talking about things [like the death of Matthew]. I now talk openly with my mother-in-law, we each ask the other questions, and I no longer feel that I have to support my mother. Instead we are all here for each other. My mother loves every chance to babysit for Shaun [our new baby] and so do Steve's parents. Talking and sharing has become very direct and open which makes everything more "fun". "

**Rachel** says, "I still think of Samuel, and enjoy having the chance to talk with other people about him, he is a very important part of our lives. I have been studying full-time in the last 3 years and during that time I have had tremendous support from my family and we are all looking forward to my graduation in December 1999. I look forward to my future practice as a midwife supporting and caring for families."

**Catherine** writes, "In November 1998, Paul and I were married. Six of the grandchildren walked down the aisle with us. What a joyful occasion! My children, grandchildren, family and friends danced at our wedding and had a "bit of a do" in our garden the day after the wedding. Enjoyed by all - young and old. There were family absent. My youngest son, David, who was overseas, three lovely grandchildren who live in the North Island, my dear parents who are deceased and of our course our little boy, Samuel. Life goes on.

PS Today is the anniversary of Samuel's death."

**Diane** wrote, "I retired from my position as grief support co-ordinator in December 1997. I feel privileged to have had the opportunity to do this work and to see the strength of the human spirit as the journey was made through grief to healing and wholeness again after the loss of a loved one."

# **Appendices & References**

# Appendix 1

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Dunedin  
New Zealand

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AUTHOR/EDITOR:	GUBA
VOLUME/ISSUE #	
TITLE OF SELECTION:	THE HERMENEUTIC DIALECTIC CIRCLE
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\_\_\_\_\_  
Signature of Requester

Date 24/12/98

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Ms. Alison J. Stewart

Dunedin  
New Zealand

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BOOK/JOURNAL TITLE:	FOURTH GENERATION EVALUATION (C)
AUTHOR/EDITOR:	GUBA
VOLUME/ISSUE #	
TITLE OF SELECTION:	THE METHODOLOGY OF CONSTRUCTIVIST INQUIRY
TYPE OF EXCERPT:	figure PAGE(S):
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- Permission is granted for non-electronic print format only. Use of selections in electronic media such as, but not limited to the Internet, Intranet, or CD-ROM is prohibited. However, permission is granted for transcription via non-standard size audio tape for use with the blind or visually impaired.
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Alison J. Stewart  
Signature of Requester

\_\_\_\_\_  
Signature of Requester

Date 04-12-98

\_\_\_\_\_  
Date:

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**Appendix 2**  
**Excerpts from audit trail review**

Table A2.1: Audit Trail Categories, File Types and Evidence – using the format of Halpern cited in Appendix A of Naturalistic Inquiry (Lincoln & Guba, 1985, pp.382-4).  
Updated at the time of writing the thesis.

□ File Type	□ Evidence	□ Location
<b>RAW DATA</b>		
<b>a) from participants in hermeneutic dialectic circles</b>		
Tapes or letters	Description by participants, discussion and debate of constructions, experiences	<ul style="list-style-type: none"><li>• Examples- Chapter 4</li><li>• Original material in each participants' box file</li></ul>
Comment on booklet resources for bereaved grandparents		
Photographs/symbols	Copies obtained with permission	<ul style="list-style-type: none"><li>• In stories in Part 2</li><li>• Copies in box files</li></ul>
<b>b) from me, as the researcher, in the hermeneutic dialectic circles</b>		
Field notes	Ongoing combined log/journal with description, reflections after interviews, letters, and other events such as relevant documentaries/films	<ul style="list-style-type: none"><li>• Recorded in 3 volumes over 4 years</li><li>• Analyses journal separate</li></ul>
<b>c) Unobtrusive measures</b>		
Public documents	<ul style="list-style-type: none"><li>• Birth/death notices</li><li>• News paper articles</li><li>• Published material e.g. self-help groups</li><li>• Documentaries and films in area of infant death/family issues</li><li>• Published professional literature relating to methodology, bereavement (general, infant, nursing, grandparents, family)</li><li>• Unpublished professional literature e.g. doctorates</li><li>• Ongoing literature/ internet searches</li></ul>	<ul style="list-style-type: none"><li>• Box file of notices</li><li>• Resource box files with videos, article clippings</li></ul>
		Filed in separate legal document boxes according to topic: methodology general, methodology specific, grandparents & family; bereavement general; bereavement infant
<b>Cont'd overleaf</b>		

Private records	Unpublished material e.g. poems and personal stories of members of self help groups	Resource box files
Physical traces	Gravestones of grandchildren of participants in photographs	Participants' individual box files
	Gravestones of children in general, as background material on where children are remembered publicly	Photograph file- decision not to include this material and to publish separately
<b>DATA REDUCTION ANALYSIS</b>		
Reflections on field-notes	Summary of points to consider/explore in next discussions	Written in journal after each interview/letter.
Summaries of transcripts (of tapes and letters) and other raw data	Coding in margins of transcripts of: units of analysis, categories and issues to explore	Participants' individual box files
	Analyses journal with section of comments about other raw data e.g. gravestones, death notices	Analyses journal
	Summary of relevant literature	ENDNOTE database
Units of information used in analyses	Unit cards sorted to categories.	All unit cards for each participant in envelope in individual box files- with a record plan for each participant e.g. Appendix 7
Theoretical notes	Working "hypotheses", developing ideas (memos), revisioning categories, "rules" for units in categories	Analyses journal noting timepoint for these materials
Mind maps	Ideas of relationships between categories and subcategories	Analyses journal and large poster sheets
Developing individual stories	Drafts of stories as constructed from conversations with each participants. Become a voice for each person	Drafts in participants' individual box files
<b>DATA RECONSTRUCTION AND SYNTHESIS</b>		
Categorical structure (definitions, relationships)	Overviews of group constructions March 1997, November 1997	Copies sent to all participants, material in Appendices ??
Findings and conclusions	Final joint construction checked in 4 <sup>th</sup> circle and July 1999	Accepted joint construction presented in Chapter 6

Final report	Individual stories grouped in families with chosen names and symbols of importance	Part 2 of thesis- the stories of all the participants
	Presentations of material – PhD schools, conferences	Filing cabinet files of all presentations
	And future publications ....	
<b>PROCESS NOTES</b>		
Methodological notes: procedures, decisions, strategies, rationales	Notes, comments and insights I wrote down at the time I had them	In research journals (vols 1-3, not differentiated into field notes and methodology)
	Debriefing with supervisors, documented	
	Confirming changes with ethics committees for approval	See approval letters in earlier appendices
	Monthly review of progress & decisions	Copies sent to supervisors and recorded in c:/PhDjournal folder
Trustworthiness notes: credibility, transferability, dependability, confirmability	Discussed PhD school	See Table A9.2 below
	Ongoing notes & comments	Research journals
Audit trail notes: substance & structure  NB: Cross referencing materials and decision relies on dating e.g. date on Transcript 1 of Participant 1 can be located through index in research journal 3 to find correct page for associated field notes	Dates attached to all documents, entries, raw data;	Materials located in box files for participants, death notices, resource materials
	Chronological research journals (vols 1-3)	Stored in filing cabinet
	Summary of whole research in chronological sequence grouped under date, action, thinking, blends lines of data collection/analyses and thinking. Recorded until April 1997, presented at PhD school.	Part of PhD school presentation folders
<b>INTENTIONS/ DISPOSITION</b>		
Research proposal – goals intended, methodology, relevant literature	Research proposal document	C:/PhDproposal folder and file in filing cabinet
Personal notes: reflexive notes, motivations	Reflexive accounts, debates about choices and decisions	Research journals, examples through this thesis
Expectations (predictions, intentions)	Record my own views, etc construction(s) Review these every few months and reflect on changes	Research journals
<b>Cont'd overleaf</b>		

<b>"INSTRUMENT" DEVELOPMENT</b>		
Initial questions for interviews/letters	Emphasis on story, "Tell me when...."	Details in transcripts
Ongoing discussion within the circles	Issues to develop from previous conversations	Ideas recorded in analyses journal
Consent forms	Develop according to issues arising & submit for ethics committee approval	<ul style="list-style-type: none"> <li>• Copies signed by participants in individual box files.</li> <li>• Master version in c:PhDforms folder</li> </ul>
<b>*COMMUNICATION WITH PARTICIPANTS</b>		
Ongoing contact	Newsletters	C:/PhDadmin folder
	Phone calls	Record in contact log back of research journal 3

\* not part of Halpern's original ideas in Appendix A (Lincoln & Guba, 1985)

## Table A2.2:

### Trustworthiness and other criteria.

(Discussed PhD school April 1997, not updated since).

<i>Issues in relation to rigor</i>	<i>Evidence/thoughts about</i>
<b>Credibility</b>	
<ul style="list-style-type: none"> <li>• Prolonged engagement</li> </ul>	<ul style="list-style-type: none"> <li>• Take time to get trust and explore constructions- ongoing contacts for discussion and debate</li> </ul>
<ul style="list-style-type: none"> <li>• Persistent observation</li> </ul>	<ul style="list-style-type: none"> <li>• Issues and focus in study emerging as going round circles, not entirely as I imagined when writing the proposal</li> </ul>
<ul style="list-style-type: none"> <li>• Peer debriefing</li> </ul>	<ul style="list-style-type: none"> <li>• Explore ideas, values and decisions with supervisors – issue to consider when methodology not one that "peers" have used</li> </ul>
<b>Cont'd overleaf</b>	

<ul style="list-style-type: none"> <li>Negative case analysis – refining to account for all known cases</li> </ul>	<ul style="list-style-type: none"> <li>Seek to include and account for differing views and constructions e.g. grandparent participants' differing views about coping and a parent (Maxine) reports giving not receiving support which differs from other parents' perspectives - how to include these differences in analyses?</li> </ul>
<ul style="list-style-type: none"> <li>Progressive subjectivity</li> </ul>	<ul style="list-style-type: none"> <li>Ongoing describing and recording my existing beliefs, values and constructions in journals. Discuss these with supervisors to explore whether these shape how I view the data to place by construction over and above those of participants</li> </ul>
<ul style="list-style-type: none"> <li>Member checking</li> </ul>	<ul style="list-style-type: none"> <li>Occurs during hermeneutic-dialectic circles e.g. reflective summarising in interviews/letters. "So, you mean ..." &amp; "What do you think...?"</li> <li>Part of the process of story construction</li> <li>BUT things to think of how member checking managed, since I wonder if some participants confirm per se, or are unsure about taking an active critical role in debate.</li> </ul>

Transferability	
<p>"the burden of proof for claimed generalizability is on the <i>inquirer</i>, while the burden of proof for claimed transferability is on the <i>receiver</i>" (Guba &amp; Lincoln, 1985, p.241)</p>	<ul style="list-style-type: none"> <li>Stories contribute to provide thick description</li> <li>If a joint construction develops then need to consider how to write this to reflect the experience</li> </ul>

Dependability	
<p>How consistent or stable are the data over time? Excludes, "methodological changes and shifts in constructions are expected products of an emergent design" (Guba &amp; Lincoln, 1989, p242)</p> <ul style="list-style-type: none"> <li></li> </ul>	<ul style="list-style-type: none"> <li>Maintain audit trail of materials and changes in thinking, since dependability about process of study.</li> <li>BUT I wonder if the changing ideas of participants over time show how time dependent member checking is, in that confirmed ideas at one point, and then change and confirm at a later time point</li> </ul>

Cont'd overleaf
-----------------



Confirmability	
<ul style="list-style-type: none"><li>• “concerned with assuring data, interpretations and outcomes of inquiries are rooted in contexts and persons apart from the evaluator are not simply figments of the evaluator’s imagination” (Guba &amp; Lincoln, 1989, p.243)</li></ul>	<ul style="list-style-type: none"><li>• The steps in the process can be tracked to original material (e.g. Table A9.1)</li><li>• Need to consider how I write the report so that the reader can track construction(s) back to contexts of participants</li><li>• Giving participants copies of all the changing materials from transcripts, to overview of group constructions (March 1997) should enable them to track the development of the analyses</li></ul>
Fairness	
<ul style="list-style-type: none"><li>• Sourcing, checking and presentation of different constructions which are treated equally, with not one construction privileged above another</li></ul>	<ul style="list-style-type: none"><li>• Including constructions of different “stakeholders” , so not solely grandparents, but those also involved with the family they are part of i.e. parents and health/bereavement professionals</li><li>• Hermeneutic-dialectic circling process enables checking and revising and not overemphasising one, even my, construction</li><li>• Will need to consider this in final stage, Guba and Lincoln propose open negotiation of unresolved “claims, concerns, issues” – will there be any/many? Does not seem so at present</li><li>• Fairness is also about how I write the text and represent other (Fine, 1994)</li><li>• Fairness is also about needing to disentangle the ethical issues of participants per se, and particular participants in families- will need to include in writing up</li></ul>
Cont’d overleaf	

<b>Ontological authenticity</b>	
<p>"extent to which individual respondents' own emic constructions are improved, matured, expanded and elaborated" (Guba &amp; Lincoln, 1989, p.248)</p>	<ul style="list-style-type: none"> <li>• Participants see the world in different ways, e.g. Elwyn and Jenny who talk/write about how the research process has altered their interpretation and construction of their experience</li> <li>• BUT should I be expecting constructions to "improve, mature, expand" implies that participants expected to change, and they might be comfy with existing construction, not need/want to change. This idea was not part of the original discussions with participants about taking part i.e. an expectation that they change</li> </ul>
<b>Educative authenticity</b>	
<ul style="list-style-type: none"> <li>• Extent to which individuals appreciate constructions of those outside own stakeholding group</li> </ul>	<ul style="list-style-type: none"> <li>• Need to consider if this occurs as increasingly cross participant circle groups with ideas</li> <li>• BUT is this the premise that participants entered the study with, which was to tell their story and engage in discussion with ideas from other people</li> </ul>
<b>Catalytic authenticity</b>	
<p>"[...] the extent to which action is stimulated and facilitated by the evaluation processes [...] acting being prompted on the part of the participants." (Guba &amp; Lincoln, 1989, p.249)</p>	<ul style="list-style-type: none"> <li>• Need to consider as study concludes- has there been changes in action</li> <li>• But do I expect this to happen? The context of Guba &amp; Lincoln's comment is evaluation research, which is different to health research, it suggests a positioning towards critical social theory. Did participants enter the research expecting this?</li> <li>• Issue of book of stories which participants want</li> <li>• Beth talked of going to see bereaved people and others state they have increased understanding- e.g. Benita- the "Matthew experience"</li> </ul>
<b>Cont'd overleaf</b>	

### Tactical authenticity

Extent to which individuals are empowered to act, by the research

- Guba and Lincoln propose that:
  - a) demonstrate that have testimonies from all groups approached (i.e. all stakeholders have a chance to have a say)- in this research have had participants from the three groups that I approached
  - b) that seek an evaluation from participants about the process and ask if participatory- to date comments from participants say YES,
  - c) I am not convinced that participants are more skilled in the use of power and negotiation which were the other aspects that Guba and Lincoln suggested in this criteria grouping, after all people did not take part with the expectation of this outcome

### Appendix 3

## Letters of approval for study from SRHA Ethics Committees 1995/1996



**DUNEDIN**  
Head Office  
229 Moray Place  
P.O. Box 5849, Dunedin  
Telephone 0-3 477 4222  
Facsimile 0-3 474 0080

### ETHICS COMMITTEE OTAGO

29 January 1996

Alison Stewart  
Senior Lecturer  
Department of Nursing and Midwifery  
Otago Polytechnic  
Private Bag 1921  
DUNEDIN

Dear Alison

#### Grandparent Bereavement

Investigators: Alison Stewart (Supervisor: Professor Jill White)  
Protocol Number: 95/12/134

Thank you for your letter of 17 January 1996 and the amended information sheet. I confirm that this study is approved in full.

Approvals granted to protocols are for 12 months. If, after 12 months the study is not completed, it will be necessary to forward to the Committee a brief report on progress made to date and a request for an extension. Please quote the above protocol number in all correspondence relating to this study.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Please advise the Committee on the completion of the study or if, for any reason, you decide not to complete it. On completion of the study a brief report should be forwarded to the Committee.

Yours sincerely

Carol Algie  
Ethics Committee Administrator



**DUNEDIN**  
Head Office  
229 Moray Place  
P.O. Box 5849, Dunedin  
Telephone 0-3 477 4222  
Facsimile 0-3 474 0080

## ETHICS COMMITTEE OTAGO

12 March 1996

Alison Stewart  
Senior Lecturer  
Department of Nursing and Midwifery  
Otago Polytechnic  
Private Bag 1921  
**DUNEDIN**

Dear Alison

### Grandparent Bereavement

**Investigators:** Alison Stewart (Supervisor: Professor Jill White)  
**Protocol Number:** 95/12/134

Thank you for your letter of 3 March 1996 in which you seek approval to extend the above study to contact several funeral organisations within Dunedin. This request is approved, on condition that no personal identifiable information about grandparents is to be collected when interviewing either Funeral Directors or Grief Workers.

Approvals granted to protocols are for 12 months. If, after 12 months the study is not completed, it will be necessary to forward to the Committee a brief report on progress made to date and a request for an extension. Please quote the above protocol number in all correspondence relating to this study.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Please advise the Committee on the completion of the study or if, for any reason, you decide not to complete it. On completion of the study a brief report should be forwarded to the Committee.

Yours sincerely

**Carol Algie**  
Ethics Committee Administrator



**CHRISTCHURCH**  
4th Floor  
144 Kilmore Street  
P.O. Box 3877, Christchurch  
Telephone 0-3 372 1000  
Facsimile 0-3 372 1015

## CANTERBURY ETHICS COMMITTEE

8 July 1996

Alison Stewart  
Nursing & Midwifery Department  
Otago Polytechnic  
Private Bag 1910  
DUNEDIN

Dear Alison

**Ref: Grandparent Bereavement Study**  
**Investigator: Alison Stewart**  
**Protocol Number: 96/039/CPD**

I am pleased to inform you that, using the delegated authority granted her by the Committee, the Chair has given ethical approval for this study to proceed. The sub-committee which examined the protocol has asked that the Information and Consent Forms be localised for Christchurch and typographical errors corrected.

Approvals granted to protocols are for 12 months. If, after 12 months the study is not completed, it will be necessary to forward to the Committee a request for an extension. Please quote the above protocol number in all correspondence relating to this study.

It is also a requirement of the Committee that researchers submit a report upon completion of their studies. I look forward to receiving your report in due course.

I would also like to apologise for the error contained in my fax to you of 9th June. Comment number 2 should have read 'With only 2 health workers being involved...'.  
.

Yours sincerely

Gail Ross  
Ethics Administrator

CC: Carol Algie, Otago Ethics Officer



## Appendix 4

### Information letters and consent forms used on entry to research for NZ participants

**NB:** Appended version for grandparents in Otago was adapted to suit parents, health/bereavement professionals and geographical location of Canterbury. The original version had a wider line spacing of text, with information letter and consent form as separate items.

#### 1. Information letter to participants

### *Grandparent Bereavement*

#### **Information for grandparents who might be interested in the study.**

Thank you for taking the time to read about this research study. My name is Alison and to help you decide if you might be interested in taking part in the study, I have written down some questions and answers below. If you have any further questions then please contact me at the address and phone number below.

- **What is the study about?**

It is about grandparents who have had a young grandchild die unexpectedly. What does this bereavement mean and what effect does this have for grandparents as individuals and as family members? What are the things which help or hinder grandparents living through this experience? The study is interested in the stories of anyone who wants to join in, it does not seek to represent the experience of all grandparents in New Zealand, in particular it is likely to be a study of predominantly non-Maori grandparents.

- **What are the aims of the study?**

- \* To acknowledge the individual and shared bereavement of grandparents.
  - \* To raise awareness amongst the community, family and health workers of the issues raised by being a bereaved grandparent and the effects this has on individuals and families.
  - \* To identify any expressed needs by grandparents for resources or support and to begin planning strategies to address these needs.
- To do this I am seeking to talk with (interview) 10 grandparents, 2 parents and 2 health workers to look at different perspectives of grandparents' experience of having a grandchild die.

- **How do grandparents hear about the study?**

Either by word of mouth, with family and friends collecting one of these sheets at the local group such as SIDS Family NZ or The Compassionate Friends group. Or by reading an advert in the local paper and asking for more information, in which case I post out this information sheet.

- **Where is the study being done?**

In Otago and Canterbury, since I can easily travel to meet people in these areas which cover a large proportion of the South Island.

- **Who is the researcher and why is the study being done?**

My name is Alison Stewart. I am British, married to a New Zealander and have been living in Dunedin since 1992, where I have been teaching at Otago Polytechnic. The study is part of my PhD thesis and it comes from my clinical experience and teaching as a nurse and midwife in New Zealand and the UK. In the UK I worked as a nurse/midwife for 3 years, offering support to families who had a young child die suddenly (whether as cot death, an illness or an accident) and researching possible causes of cot death. Originally my job focused on parents and siblings of the baby and then on health workers involved with the families. Then I became aware of a number of grandparents who wanted to talk, or had questions and issues that we had not discussed or offered any support for. Eventually, we moved from visiting grandparents to establishing a support group for those who wanted it and supporting a network of grandparent befrienders. In NZ I have continued to support families, most recently in the Baby Bereavement Group in Dunedin.

- **Who has approved the research?**

Research on health issues has to be approved in order to protect participants. This research has been approved by the Southern Regional Health Authority Ethics Committees in Otago and Canterbury. It has also been approved by the ethics committees of the place I work in (Otago Polytechnic) and the place where I study (Victoria University of Wellington).

- **If you took part in the research what would it involve?**

Joining the study is voluntary and your decision to do so in no way affects any health care which you receive now or in the future. It would mean first talking on the phone or in person, for me to answer any questions that you might have and then to sign a form consenting to be part of the research. Then we would arrange a time and place convenient for you to share with me your story of what it has been like for you since your grandchild died. This is formally called an interview- but it is really a chance for us to talk. This will probably take about 1-1.5 hours. If you agree I will audiotape the interview and you can choose to stop the tape-recorder at any point.

At the end of talking you would decide if you might be willing to talk again and if so we would arrange a time to suit you. I am aware that some people will only want to talk once and others may be willing to meet and talk two, or a maximum of three times with me. I would hope to talk further at these times about your story and to ask your ideas about the findings which are developing from talking with different people.

If you decided in hindsight after an interview, that you did not want some comment or point that you had said to be part of the study, then you can ring me up at any point and we can remove it from the study. Similarly, if you decide that you do not want to stay in the study, you can phone or write to me at any point and state that you wish to withdraw. I plan that the research will be started in 1996 and finished by early 1997, during which time we might meet 3 times for interviews if you agreed.

- **Who can take part in the study?**

- \* Anyone who is a grandparent living in Canterbury or Otago, and who has had a young grandchild die unexpectedly for whatever reason, whether cot death, stillbirth, illness, accident or other reasons. By young I mean a grandchild who was still dependent on the family as a young child (less than 12 years), infant or baby; not a teenager who was becoming more independent.
- \* As the study is about how grandparents live with their bereavement I am seeking grandparents whose grandchild died one or more years ago - whether 13 months, 2 years or 40 years ago.
- \* As I do not wish the study to cause emotional distress I would urge anyone thinking about taking part to just stop and think:
  - *Are you willing to talk about your grandchild and feelings?*
  - *Does it feel OK to imagine doing this?*

- **Are there any risks or benefits in being part of the study?**

The immediate benefits are a chance to talk and share your story of what has happened to you and your family. For many people this can be a good experience and remember that you choose what you talk about and what you choose not to share with me, since I am not a family member. Talking can have a downside for some people raising a range of strong feelings and memories. If any unresolved questions or issues arise for you as a result of joining the study, then I will help to find any necessary help that you might want - it might mean you talking with your GP. If you decided that a counsellor was needed then I could help with paying some of these costs.

The longer term benefits in telling your story are in developing an awareness amongst health workers and the community, about grandparents' bereavement and identifying things which might help grandparents in the future. If you have any costs in being part of the study such as travel or phone calls, then I can repay these. In addition to say thank you for sharing your experience, all the people in the study will be given a token of \$50 for books or for the supermarket. Everyone in the study will receive a copy of the research either in the long or short form. Funds for these costs come from my research grant.

If you have any concerns about the study then please feel free to contact my research supervisor: Professor Jill White, Department of Nursing and Midwifery, Victoria University, [contact details provided]

- **What happens to the information that you talk about?**

The things that we talk about will be typed up as notes, so if the interview is audiotaped then the whole of it will be typed up. Your name and those of your family, will be replaced with pseudonyms (you choose these pretend names if you wish) so that the interview remains confidential. I will then read and re-read your comments and those of other people, looking for the same and different issues and themes- which will become the findings of the study.

If you agree I will give to you a draft copy of the findings to see if you think that they fit your experience.

The only people who will read my notes and parts of the interviews will be myself, my two research supervisors and three other women in my study group who are doing PhDs on family issues. At no point will anyone ever link you to your interview as your name will not be on the typed interview or tape.

At the end of the study the tapes will be returned to you if you wish, if not tapes and typed material will be kept in locked storage for a minimum of 5 years, before being destroyed, with only myself having access to them. Some of the study may be published in professional journals or newspapers and where this happens I will send you a copy of the article if you are interested.

• **What do you do if you are interested in being in the study?**

Then please contact me at the address below.

• **What do you do if you are not interested in being part of this research?**

Then thank you for taking the time to read this and please dispose of this sheet. You will not hear from me again.

Alison Stewart, [contact details for home and work given]  
 Supervisor- Professor Jill White [contact details given]

**2. Consent Form for participants**

***Study of grandparent bereavement***

I have had the opportunity both to read the information sheet for people volunteering to join this study about grandparent bereavement and to discuss the study with Alison with my questions answered to my satisfaction. I understand that taking part in the study is voluntary and I know what is involved in the study and I feel comfortable to take part.

- I know that I will be invited to take part in one or more interviews which will last about 1-1.5 hours and which will be tape-recorded unless I wish the tape-recorder to be turned off.
- I know that I can choose not to answer any question that Alison asks and that if I say something, which in hindsight I wish that I had not said then I can ask Alison to remove it from the typed copy of the interview.
- I know that I can withdraw from the study at any point and that it in no way affects my present or future health care. If I choose to withdraw, then I can decide whether I want to withdraw all or any of the information in interviews which may have already taken place.
- I understand that my participation in this study is confidential and that no material which could identify me will be used in reports from this study.
- I know that information from the interviews will have no identifying names attached to it once typed up and will only be seen by people involved with Alison's research (PhD supervisors and colleagues).

- I know that the research will be written up as Alison's PhD and that parts of it may be published in professional journals and that if I consent there may be direct quotes from what I have said (which cannot be identified to me).
- I know that I will receive a copy of the thesis (or summary findings if I prefer) or publications if I want these.
- I know that if my story is going to be used in any way other than this study, such as a booklet of stories, then Alison will return to ask me to consent to this.

**Options to tick if you are happy with them**

- ☐ I agree to having a first interview.
- ☐ I agree to having a second interview (decided after the first interview).
- ☐ I agree to having a third interview (decided after the second interview).
- ☐ I agree that parts of the typed up interviews can be shown to Alison's supervisors and PhD colleagues.
- ☐ I would like to see and comment on typed copies of interviews.
- ☐ I would like to see and discuss the final draft report.
- ☐ I am happy for quotes, which cannot be identified to me, to be used in the text.

**I would like a copy of:**

- ☐ summary of final findings;
- ☐ publications based on thesis;
- ☐ copy of whole thesis.

I, .....(full name) hereby consent to take part in this study.

Date \_\_\_\_\_ Signature \_\_\_\_\_

Researcher name: Alison Jane Stewart

Signature \_\_\_\_\_

If at any time you have any concerns or questions then please contact me or my supervisor at the addresses below.

Alison Stewart [contact details for work and home given][

Supervisor: Professor Jill White, Department of Nursing and Midwifery, Victoria University [contact details given]

## Appendix 5

### Materials relating to the participation of the 3 grandmothers from the UK



**DUNEDIN**  
Head Office  
229 Moray Place  
P.O. Box 5849, Dunedin  
Telephone 0-3 477 4222  
Facsimile 0-3 474 0080

### ETHICS COMMITTEE OTAGO

1 May 1996

Alison Stewart  
Senior Lecturer  
Department of Nursing and Midwifery  
Otago Polytechnic  
Private Bag 1921  
**DUNEDIN**

Dear Alison

**Grandparent Bereavement**

**Investigators:** Alison Stewart (Supervisor: Professor Jill White)  
**Protocol Number:** 95/12/134

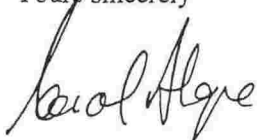
Thank you for your letter of 16 April 1996 in which you enclosed the letter from SANDS in London. I confirm there are no ethical objections to your including the grandparents in the UK in your study.

Approvals granted to protocols are for 12 months. If, after 12 months the study is not completed, it will be necessary to forward to the Committee a brief report on progress made to date and a request for an extension. Please quote the above protocol number in all correspondence relating to this study.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Please advise the Committee on the completion of the study or if, for any reason, you decide not to complete it. On completion of the study a brief report should be forwarded to the Committee.

Yours sincerely



**Carol Algie**  
Ethics Committee Administrator  
G:\ETHICS\1995\DECLT.DOC



## **1. Information letter sent to the 3 UK grandmothers**

**NB Original version had wider line spacing**

Dear [name]

How are you? How has summer been? How is the family? You may remember writing to me a while ago in response to a piece in the SANDS newsletter on information wanted. I have finally heard from the Southern Regional Ethics Committee (Otago) and from SANDS (UK) to say that they are happy for your letter and story to be included in the research I am doing.

Would you still be willing? I thought I would write a few things about what you would be taking part in (if you wished to) and where I am up to at the moment. I have also enclosed a copy of your letters so that you can see that you had written - in case it seems a long time ago.

### **Background**

As you know from the SANDS newsletter and from my reply to your letter, I am keen to listen or read the experiences of grandparents who have had a grandchild die. Whilst this is the research I chose for my PhD thesis, my hope is that by sharing these stories in articles to health professionals and possibly as a booklet of stories it will help people consider and support bereaved grandparents. As you may have read in the information sheet which I share with grandparents here and I posted to you last time, I have had the privilege in my nursing and midwifery role in the last 10 years to be with families who have had a child die. One of the things which came out of that was developing grandparent befriending and grandparent groups.

An important part of this research now, is to value you as the "experts" who know what it is like to experience the loss of your grandchild. Therefore we work as partners in writing your experiences and coming to some conclusions. This means that when I talk to grandparents here or read your letters, I come up with some ideas of central issues that are common and different for individual grandparents and then I ask you whether my ideas seem to make sense to you - whether it "fits" for you. This is different to more "traditional" research where a researcher collects the information and then goes away to come to some conclusion. Instead my aim is that you and I will come to the conclusions together.

### **What would it involve for you?**

I would like you to read the enclosed consent form and see if you feel happy with the idea of "formally" being part of this research. As you can see there are various options of what you might choose to take part with.

- You might decide that you do not want your letters to go any further and not be used in the study- if so just let me know.
- You might decide that you are just happy for me to include your letters to date in the study and do not want to write or hear from me further. If that is the case, then just let me know and write it on the consent form.

- Or you might be happy to look at a page of questions (also enclosed) and jot down your thoughts about them and then post them to me.
- In either instance do send the consent form back and let me know what you would like. As you can see the consent form emphasises that information will not be identified to you in the thesis or any articles and that I will check with you before using any quotes from you.
- If you choose at any time to say that you would like to withdraw from the study then let me know and we will arrange to stop any involvement with the work.

I am conscious that in New Zealand I travel to see grandparents and would therefore be keen to reimburse costs of postage if you wish to write to me in the future. I also ask grandparents here whether I can acknowledge their expertise by giving them a book token for approximately 20 UK pounds which they can give to family, use themselves or give to a local group like SANDS. I would also be keen to do this with you if you chose to take part. This is in no way an incentive to take part- merely a thank you for sharing a very personal and painful part of your life with me.

The grandparents here in New Zealand who have talked about their experiences have commented on how "good" "healing" or "special" it was to talk at length about their grandchild. However, I am also conscious that in thinking about your grandchild this study can lead you to reflections and feelings which are painful, which means you may need to be aware of talking, using support from places like your family or SANDS group.

### **Where am I up to so far?**

Well I have spoken with nine grandparents at present. Nearly all have met with me for a second time and we have sat and talked with the tape recorder running for anything from 30 minutes to 2 hours!. I will have seen everyone again for the second time by the end of July. I have also interviewed five parents about their experiences of grandparent (i.e. their parents) bereavement and also included the experiences of two health workers who have cared for families with grandparents. I am hoping to travel further and go to speak to a further two grandparents in August and then it will be a time of deep thought and wrinkling my forehead to start to pull out issues which are unique and common for grandparents. The plan at present is to have this all finished printed and handed in as a thesis by the end of 1997 and then to develop parts of it for articles to share the experiences and ideas with as wide a group of health workers, self help groups etc. The Director of SANDS in the UK is keen to have a copy of findings which will help spread through the UK.

### **Is there anything else?**

Is there anything else I can tell you? If there is then please write and let me know and remember I will re-imburse postage to you.

With best wishes

Alison Stewart [contact details]

## **2. Consent form for participants in the UK**

### ***Grandparent Bereavement Study***

I have had the opportunity both to read the information sheet for people volunteering to join this study and to ask any questions- which have been answered to my satisfaction. I understand that taking part in the study is voluntary and I know what is involved in the study and feel comfortable to take part.

- I know that I will be invited to write my story and to answer any questions which Alison asks in a letter.
- I know that I can choose not to answer any question that Alison asks and that if I write something, which in hindsight I wish that I had not written then I can ask Alison not to use it in the study.
- I know that I can withdraw from the study at any point and that it in no way affects my present or future health care. If I choose to withdraw, then I can decide whether I want to withdraw all or any of the information in any letters that have been written.
- I understand that my participation in this study is confidential and that no material which could identify me will be used in reports from this study.
- I know that information from any letters will have not identifying names attached to it once typed up and will only be seen by people involved in Alison's research (PhD supervisors and colleagues).
- I know that the research will be written up as Alison's PhD and that parts of it may be published in professional journals and that if I consent there may be direct quotes from what I have said which cannot be identified to me.
- I know that I will receive a copy of the thesis (or summary findings if I prefer) or publications if I want these.
- I know that if my story is going to be used in any way other than this study, such as a booklet of stories, then Alison will return to ask me to consent to this.

*(cont'd overleaf)*



## Appendix 6

### Excerpts from overviews of analyses for grandparents' and parents' circles

NB Minor editing of layout to facilitate meaning and reduce length.  
Overviews were sent with a newsletter which is not included.

#### Excerpt from Overview of Grandparents' Interviews March 1997

**Notes:** I ask would all of you to read through this and to think what applies to you and what you agree with and what you disagree with. *For example, you might go through and tick and cross the different descriptions and statements I have put below*, then we can discuss them the next time we meet. Remembering that the study has you as experts, me as the secretary/writer and it is aiming for you and I to come to a "construction" of some of the issues in grandparent bereavement.

I have written this in a somewhat impersonal style "Several grandparents thought that..." rather than "You found" or "many of you found that..." because "you" is very personal and the points below are a synthesis of sixteen grandparents' experiences and do not reflect all the things that you may personally feel. I hope that this is acceptable. In the write-up it will have stories, people and quotes and will not sound this dry.

I have also written the word "child" quite often. For example, "concerned about feelings of child" meaning the child of the grandparent and the parent of the grandchild. I have used "child" in a broad sense (as it has been used in the interviews) since at times it is referring to a daughter or son and at other times it refers to a son or daughter-in-law. I hope that this feels comfortable. At a later point we will separate out any particular issues for own child or child-in-law.

#### **Unexpected event - uncharted waters**

Many grandparents commented that the event of their grandchild's death was unexpected or unanticipated. Several people have talked about how they believed it happened to "other people" but not to themselves. One grandmother felt that part of the shock was that she had not thought about it seriously before. For several grandmothers the death of their grandchild brought home the fears that they had had as a young mother about having one of their own children die.

Several people commented that one of the outcomes of becoming part of this "Other" group of people (who had had a grandchild die) has been an increased understanding /awareness of other's pain in this situation. Also that other people then share their experiences of having a child die with you. As several grandparents noted, "you cannot know what it is like unless it happens to you".

For a number of grandparents the unexpected event was compounded by being in a situation where they had no previous experience. So, they, and their children, did not know what to expect such as delays in postmortem or choices that could be made about the funeral. Not having previous experience brought

with it surprise at the cost of funerals/ headstones and that the body of their grandchild looked so different after death - the spirit was gone.

Listening to the interviews I have the impression that because the fact of having a grandchild die is totally unexpected with no previous experience of it, the "unknownness" of the situation can create a form of tension. In the unknown situation there are constant decisions - What to do? What to say? How to get it "right"? An analogy would be like actors told to put on a production of a play without having been given lines, training or practise. When I talked this over with my supervisor we wondered whether this came in part with the fact that grandparents are always one step ahead of their child in terms of common life events i.e. they have had children, raised them and are now grandparents as their children are now having children and raising them. Yet when a grandchild dies the child (parent of the grandchild) is precipitated into an experience which grandparents (generally) have not had. What do you think?

#### **Role as grandparent during time grandchild died**

All grandparents talked about seeing, holding, touching or bathing/dressing their grandchild - all of which actions seem to have been very important/ comforting/ healing. Several grandparents talked spontaneously about "double grief/ pain" for their child and their grandchild. Other grandparents confirmed this was what they felt when I asked.

One grandparent indicated that the grief arising from the death of a grandchild was like a circle within the family - grandparents grieve for child and grandchild and other grandchildren and the parents of the grandchild grieve for the grandparents - it illustrates a mutual care and grieving.

Some of the feelings identified by grandparents have included sickness, shock, disbelief, devastation at the time of the news, anger at the systems requiring post-mortems, sadness and the constancy of the pain for their child who is suffering. For a couple of people there was a strong feeling of injustice "Why did it have to happen?"

Several people commented that their experience of grief has not been a linear process of set stages but a range of feelings which come and go. For a number of grandparents there was "difficulty" grieving for a baby that they had not "known" - who had died at birth. For two grandparents, who were some geographical distance from the grandchild who died, this created problems - it was "hard" not being able to be there all the time.

#### **Role as parent when grandchild died**

A strong theme throughout the stories is the sense that grandparents are thinking and acting as parents for a large amount of time when a grandchild dies. As a parent role the primary focus is on the child (parent of the grandchild). One grandmother noted this from a conference speaker that she had heard talk about "parent first and grandparent second".



Feelings and concern for child include:

- seeing and sharing their pain
- appreciating the stresses on the child
- concern that they have enough support from family and friends

The area of feelings seems linked to what is either an instinctive choice or a careful decision by many grandparents not to share their own feelings/ pain in any manner that might increase the pain or distress of their child. This has been talked about as putting self second and concentrating on the child. Actions to help the child include: telling the child that the grandchild is dead - rather than have a stranger do it; practical arrangements such as catering, funeral arrangements, childcare of other grandchildren; and financial assistance. Within the area of action a number of grandparents have talked about trying to "judge it right" - helping out but not "taking over" from the child.

Support for the child includes:

- listening
- hugging and cuddling
- "being with" whether short visits or a longer stay.

In the area of support several grandparents said that it was hard to leave their child (whether at the end of a day or after the funeral or in the following days and weeks) but they felt their child needed time to get on with life and re-establish a routine.

There are a number of grandparents who clearly supported parents in their choices, such as funeral arrangements, even though the parents' choices were not what the grandparents would have done themselves. Several commented that they were surprised or taken aback by the parent's decisions but would still support them in doing it.

With the wish to help the parents of the grandchild some grandparents talked about a sense of helplessness stemming from knowing that they could not make it better for their child nor protect them from the pain. A strong sense of responsibility to the child, grandchild and other grandchildren, comes through all the stories.

<p><b>Other areas included in overview, but not included in this excerpt were:</b></p>
--

- Views on Grandparenting
- Memories / Anniversaries
- Meaning of death/spiritual aspects/faith
- Support
- What the death of the grandchild represents
- Contrasting with other deaths
- Things which some grandparents perceived as affecting bereavement
- Outcomes from grandchild's death
- Comments about being in the research study

**Excerpt from Overview of Parents' Views of Grandparent Bereavement**  
**March 1997**

**[This started with the same scene setting notes as I wrote at the beginning of the grandparents' overview (see p. 461 )**

**Grandparents' role when their grandchild died**

Many parents talked about grandparents being with/ staying with, helping them (as parents) to get through this time. Physical actions/reactions such as hugging and crying seem to be an important part of being with the parents/family and sharing in this. Sharing with grandparents was an important thing- whether sharing hugs, humour or tears. In talking there was a clear sense of parents valuing the support the grandparents gave them and sometimes valuing grandparents' experience such as in organising funerals. On the one hand several parents said that they could not have got through without grandparents and in a later reflection they said that they suppose they would have got through if they had not been there but having grandparents' support made the situation "easier" - which highlights the impact grandparents can have.

Grandparents took on a variety of responsibilities which included looking after other grandchildren, providing financial support, affirming parents' decisions. One grandmother chose to tell parents that their grandchild was dead rather than have anyone else do it. She also went on to take action on behalf of the whole family and to complain about the coronial system with delays in arranging a postmortem. As some parents talked there seemed to be the same fine line that grandparents talked about - getting the balance of helping but not taking over from parents.

Within these stories, what comes across strongly to me, is that whilst grandparents are grandparents of their grandchild who died, their main role at this time seems to be as parents of the parents and that many adopt a strong parenting role.

**Ambivalence about Grandparents' Expectations**

Several parents felt that grandparents would feel (even if they did not say so) that the parents had failed as parents. Although this was a feeling and parents recognised that they did not have evidence to support this feeling. Others felt that they had not grieved or made the choices about the grandchild's funeral that the grandparents would have done. With this was a recognition that grandparents generally supported these choices even though it was not what they would have done themselves.

Attending a support group with grandparents brought mixed feelings in that parents felt they could not cry and let go in a place where the grandparents were- they had to be strong for the grandparents, which links back to the comments of concern and protecting grandparents.

### **Reflections about bereaved grandparents**

Several parents pointed out that the experience of having a grandchild die is out of sequence and is not expected by grandparents. Generally grandparents expect to die before their grandchild. Equally, several parents said that grandparents had no previous experience of this. This raises the question of whether (like being out of sequence) this is not generally expected to happen. I mean that for most events which occur in families, grandparents are always one step ahead in experience - they have already raised children and at the point they are grandparents their children are raising children.

Several parents appreciated the double loss/pain that grandparents experience - both for the grandchild and for the parents' pain. For several parents it meant seeing their parent (the grandparent) cry- which they had never seen before. Again, this might be linked to concern for grandparents- the surprise (and possible shock) at seeing one's parent (the grandparent) vulnerable and upset. We have talked in some form or another about a hierarchy of grief which is in the published literature- the idea that age or degree of relationship might affect the amount of grief (if it could be quantified). There were differing thoughts on this. One parent felt that the intensity of feelings for the loss of the grandchild was for the grandmother similar to the mother. The issue for everyone seemed to be the individual nature of grief.

Several parents reflected that they could see the grandparent parenting them (the parent) and they knew that the grandparent wanted to take their pain away - but could not. With this for at least one parent was a recognition and appreciation that grandparents did not off-load their own distress and grief onto parents who could not cope with it at that time.

The amount of pain and distress that grandparents were seen to feel was a surprise to some parents accompanied by the reflection that they knew the grandparents were grieving but were surprised at the intensity or length of it. This seems to be part of the whole situation which is unknown and unexpected - nearly every-one (whether parents or grandparents) seems to have commented at some point about not knowing what to expect, being unsure or surprised by something. The idea that the whole experience of having a child/grandchild die is out of sequence. Parents perceived a variety of coping styles used by grandparents ranging from sharing, avoidance, denial to not really knowing how the grandparents felt inside.

### **Other aspects included in the overview included:**

- Outcomes arising from the death of the grandchild
- Spiritual aspects of the grandchild's death
- Ideal role of grandparents
- Outcomes of the research

## Appendix 7

### November 1997 overview of analysis for grandparents' circle group- sent to all participants.

**NB Minor editing of layout to facilitate meaning and reduce length.**

**Overview was sent with accompanying newsletter (not included).**

### *November 1997 – Overview - Explanation of the analysis attached*

I have enclosed the analysis as it stands in brief form. The full version is from the interviews with NZ grandparents and all the letters from the 3 UK grandmothers, chopped up into pieces which are attached to card index cards and then sorted into groups which are similar or different. From this subcategories such as "memories" or "support" (lack of and availability) have been formed. I have then sorted the categories into larger groupings with an "umbrella" heading such as parenting adult parents which then has subcategories of wishes for, feelings for, actions for one's child when one's grandchild has died.

Inevitably, given the individual nature of the experience of a grandchild dying there will be bits which apply to oneself and bits that don't. The fleshed out version of the analysis will highlight this- "some grandparents have found... but others have not"

As you can see I have tried to give working titles to the categories - I have played around with these and any suggestions as to whether they "fit" or not would be very appreciated. I have found it a little like it be in advertising trying to think up a "snappy" phrase which catches the essence of the category and has a visual or story like meaning which we all relate to (such as "when the world turns upside down) rather than the fuller explanation (Grandparents facing challenge). I am still not sure about this so any input would be much appreciated. The analysis divides up into five main categories- which is how I anticipate it will be written up with quotes from each grandmother illustrating different parts of it. At present I think there will be some abbreviated stories in these chapters and then see all the stories being in an appendix to the thesis- and these will be the stories which we have talked about putting in a booklet/book which can be widely available to families and the community.

You may be wondering about the use of "**challenge**". I initially was struck by the similarity in parts to Caplan's crisis theory which argues that when a crisis, such as death, hits a person and a family the resources which people have to deal with it are outweighed by the crisis. There is then a time of trying out new strategies of coping with the aim of getting back into a form of equilibrium (which existed prior to the crisis). Like a see-saw in a children's playground when both ends are at the same height and level with each other then the person/family is in equilibrium and when a crisis occurs then the "resources to cope" at one end of the see-saw swing down and hit the ground whilst the "crisis" and stress it creates at the other end swing up towards the sky and hence there is

disequilibrium. However, when I read all your transcripts the strong feeling I had was that you and your families were not in crisis - rather you were responding the possibility that a crisis might arise for your children, but you were carefully using strategies to help and support them. This suggested to me that you were responding to a huge challenge to yourself, your child and your family and you were trying to respond to and even manage the challenge to achieve the best possible outcome for your child and family. As part of this I was also aware of the changes which arose after a grandchild dies- changes in relationships, how one views the world, health, pride in one's child... so I called the title of this latest analysis of grandparent bereavement "Challenge and Change".

What do you think?? Given that you have a very brief outline if you have any comments or suggestions I would be very grateful for them.

### **Analysis of information from grandparents- a construction at October 1997**

#### **"When the world turns upside down"**

##### **Grandparents faced with the challenge of a grandchild's death**

###### ■ *As a grandparent*

- philosophy of grandparenting
- memories of own grandparents
- effect of own grandparents on self as a grandparent

###### ■ *What is the challenge ?*

- opposite of what is expected (i.e. birth is a happy time)
- unexpected/sudden nature of the death
- unprepared for this by previous experiences
- unique nature of having a child die
- this happens to "other" people, never imagine it would happen to self

#### **"Loss of a dream /future"**

##### **Grandparents feeling the challenge**

###### ■ *Own grief*

- feelings
- guilt
- why ?
- effectors (things which are perceived as affecting grief)

###### ■ *Identifying the loss*

the death of a grandchild means ..... loss of the future/dream/future

###### ■ *Double pain*

the pain of own child is part of own grief and this is part of being parent first and grandparent second

#### **"Grandparents as parents - parenting adult parents"**

##### **Grandparents responding to the challenge**

- *As a parent - parenting philosophy of participants*

■ *Hurting and hugging*

- wish to make better for child - leading to helplessness sometimes that unable to make it better
- range of feelings in relation to child but predominantly 'pain' (includes perceiving no difference between child and son/daughter in law)
- practical measures of helping include: doing/ being; assessing extent of involvement (not taking over); affirming parents' choices (even if not own choice)

■ *The new experience of parenting* which arises from the challenge

**"Riding it out"**

**Challenge and change as a family**

■ *As a family philosophy of family and what that means*

■ *Part of the Circle of the family*

- being part of the challenge ( a privilege to be part of sharing)
- mutuality of grieving and supporting
- changes in family relationships and views (pride and surprise at strength of child)

■ *Resources and support to family as a whole and grandparents individually lack or presence, of support (various sources – people, written material)*

**"As time moves on"**

**Accommodating and managing challenge as grandparents**

■ *Making concrete the grandchild's death*

- why memories are important
- what memories/ mementos/symbols grandparents have with the focus on parents having the first right to these (e.g. photos)
- acknowledging how many grandchildren one has (how this is managed)
- defining the grandchild's position in the family (e.g. when a new grandchild is born)

■ *Putting the loss in place*

- revisiting other losses (contrast, how one relates to the other)
- changes in health and lifestyle arising from grandchild's death
- living with regrets about things not done/not known

■ *Meaning and growth*

- meaning of grandchild's death- often in context of faith
- growth perceived as arising for self from grandchild's death which can include offering support to others

■ *Reflections*

- what the issues are for bereaved grandparents as perceived by participants with the focus leading back to being a parent



## Appendix 8

### Materials related to use of pseudonyms or real names in stories



**Southern Regional Health**

*Ko te mana Hauora, Ko te mana Takato*

**CANTERBURY ETHICS COMMITTEE**

a division of the Transitional Health Authority

12 March 1998

CHRISTCHURCH  
4th Floor, 144 Kilmore Street  
P.O. Box 3877  
Christchurch  
New Zealand  
Telephone 0-3-372 1000  
Facsimile 0-3-372 1015

Alison Stewart  
Nursing & Midwifery Department  
Otago Polytechnic  
Private Bag 1910  
DUNEDIN

Dear Alison

Ref: Grandparent Bereavement Study  
Investigator: Alison Stewart  
Protocol Number: 96/039/CPD

Thank you for advising the Committee that some participants wish to retain their own names in their stories and have written to confirm this.

The Committee has noted that your final thesis and published articles using the stories will have a combination of real names and pseudonyms.

Yours sincerely

Sally Cook  
Ethics Committee Administrator



**Southern Regional Health**

*Ko te mana Hauora, Ko te mana Takata*

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## ETHICS COMMITTEE OTAGO

29 April 1998

Alison Stewart  
Nursing and Midwifery Department  
Otago Polytechnic  
Private Bag  
DUNEDIN

Dear Alison

Grandparent Bereavement

Investigators: Alison Stewart (Supervisor: Professor Jill White)

Protocol Number: 95/12/134

Thank you for your letter of 26 April 1998 and the amended consent form. The process which you intend to follow as outlined in your letter is acceptable.

With regard to your letter to the participants I would suggest you delete the final paragraph 'What happens then?', as it is incomplete and the points raised appear to have been covered earlier in the letter.

With kind regards.

Yours sincerely

Carol Algie  
Ethics Committee Administrator

## **Information letter to all participants regarding the use of names in stories**

NB Original version had wider line spacing

[contact details]

Dear

How are you? Thank you for appreciating the delay in sending you stories from the interviews that we have had together. Finally around New Year my mother, father-in-law and I started to improve and all feel as though we need a holiday now! Anyway I can now type with eight fingers and have started work again on the study.

### **The stories - where they will go**

Enclosed is a draft copy of what I would call a story, constructed from the things which we talked about in the interviews. The purpose of the stories is to be part of the thesis. My plan is that all will be included, some within the main text, quotes from all of them in the main text, and all complete stories in the appendices.

We have also discussed making stories public through seeking to publish them - the stories could be used for this but we would need to agree this with a different consent form when a publisher is found (I have had interest from one in NZ). I would also like to circulate the stories to all of you ONCE Pseudonyms are in place in the stories. This is because many of you are interested in other participants and might like to read about them. For most of you - you opted to have a copy of the thesis and realistically you will not get that until it is finished and examined- which will be a while (providing I avoid further accidents!). It may also be that you would want to add or alter your story slightly having read other stories- if so then that is fine and I have suggested a cut-off date of XXX 1998 for these changes.

### **How the story evolved**

The story is written in your words (as you spoke them in the interviews), the editing which I have done is:

- to remove things like "you know"
- clarify words often by putting in names - instead of "So she picked her up and hugged her" I would change it to "So Mary picked up Jane and hugged her".
- add a brief linking explanation between sentences - where I have done this I have noted it in italics and asked whether it is acceptable to you
- used subheadings to divide the story into sections
- grouped information into sections from the different interviews - for example you might have talked about something in Interview One and then added to and expanded what you said about it in the subsequent interviews.

As the story is written in your words it is in a friendly and colloquial style which I think flows well for the most part.

### **You choose what goes in the story**

The IMPORTANT thing to remember this is my interpretation of important points which you talked about. If when you read it you do not like the way it reads, the information is giving an impression which you do not like- then **it is your story to edit**, remove things or add things which you think are important.

### Choosing names

The other thing which is important to do at this point is to decide on names for the story as it will appear in the thesis/ publications for other people to read. Most of you have not had strong views on names. My current system has been to use the letter of the alphabet after the letter with which your name begins - so Alison would be a name beginning with "B" like Barbara. When I counted up there are now just over 80 names in all the stories and for the key names such as yourselves and your grandchild/ children's names I have avoided including that name in another story. Mainly because I felt that it might be uncomfortable to read one's name in another person's story. As many of you have discussed naming and acknowledging are very important parts of our lives, so trying to get names "Right" is important for the stories.

I have enclosed lists with **possible names for your family** based on the system of the next letter of the alphabet for the names. Now given that there are over 80 names needed AND I have tried to avoid too much duplication between stories AND I am avoiding the 80 names of the real people in the families I resorted to a Name Book with lists of names. So, if it seems that some of the names are rather "unusual" !! it is because there are quite a lot of people with real names beginning with the same letters like "R" or "C" and I have had to go wide in the search for options. So, in the POSSIBLE list I have given you there are options - now if you do not like them then that is absolutely fine and we will use any name you suggest from any letter of the alphabet (unless everyone decided on the same name when I might have to ask you to re-think the choice).

However, you may decide that you do not want PSEUDONYMS and want to use your **real names** and that is alright, I have checked this with the ethics committees who approved the research.

### Consent form

When you first joined the study all of you signed a consent form agreeing to be interviewed and deciding if you were happy for quotes to be used and whether you wanted a copy of the thesis etc. As the story ( a sort of huge quote) is a very large part of you, and potentially of the thesis I wanted to have the opportunity for you to formally consent for the story and parts of it to be used in the research. So I have enclosed a consent form where you can choose if you are happy for the story to go in the thesis, parts of it be used in the thesis as illustrative quotes and circulate the stories to each other in the meantime. To use your story further in publications for nursing/medical journals I will contact you again once the thesis is finished.

### Have I explained it clearly?

Now, I shall hope that this is all as clear as water (not mud) and if not then please let me know-

Best wishes – Alison Stewart [contact details work and home]

### So I would be grateful if you would use the reply envelope to:

- return the story with any editing you want
- decide on the names you would be happy to have used in the story
- enclose the consent form with whichever parts you want signed

<b>Consent form for the use of my story in the study of Grandparent Bereavement</b>
---

I have read the letter, which Alison wrote, accompanying the story which uses my words from the interviews which I have had with Alison.

I have had the opportunity to:

- edit the story
- ensure that pseudonyms are chosen for public use of the story
- ask any questions about the story and how it will be used in the research.

**Tick one or other of the following**

- ☐ I wish to use pseudonyms in my story
- ☐ I wish to use real names in my story

**Tick whichever of the following you are happy with**

- ☐ I am happy for my edited story to be included in the thesis in the complete form of the story
- ☐ I am happy for quotes from my edited story to be included in the thesis
- ☐ I am happy for the edited story to be circulated to other participants who might like to read it, during the time that the thesis is being finished
- ☐ I know that I have the opportunity, if I wish, to further edit or alter my story (after reading other participants' stories)
- ☐ I know that Alison will contact me for further consent to use my story (or parts of it) in publications arising from the thesis

Signed \_\_\_\_\_

Date \_\_\_\_\_

**A copy of the consent form will be returned to you.**

## Appendix 9

Excerpt from coding record of units of analysis from Participant 13's texts, coded in August 1997, was part of the process of reaching the November 1997 coding framework, presented in Appendix 7

NB Notation on the record indicates:

(2) denotes 2 units in this subcategory

1(6) denotes a unit in this category which is located on page 6 of interview 1

23/18/97 Participant 13 n=57 units

When the world turns upside down"	Riding it out	Accommodating
• unanticipated	• parent first- gear second	• Resources
opposite to what is expected	thoughts for child loss before own	support ① 1(21)
unexpected ② 1(7) 1(3)	feel for/appreciate their pain ② 1(9) 1(22)	information
unbelievable ① 1(1)	double pain	coping strategies ③ 2(15) 2(14) 2(16)
premonition	helpless to help their pain	previous experience
unprepared by previous experience	own pain eased by knowing support there	
• impact	• being a parent of the parents	• making the loss concrete
unique nature of child dying	active parenting e.g. protect	mementoes ③ 1(19) 2(10) 3(3)
feel like "only grandparents"	parenting as adults - new dimension No! 3(4)	symbols
"it happens to other people"	new insights into child's character	anniversaries
never thought it would happen to self ①	being with ① 2(2)	memories ① 3(3)
↳ 3(1)		acknowledging the number of gchild ① 3(2)
	• helping but not taking over	remembering and talking about
	help out ① 2(12)	
	with boundaries	Why concrete is important
1(6) 1(21) 1(4) 2(2) ④ ←	concern for other grandchildren	just to do it
1(6) 1(5) 1(2) ③ ←	not challenging parents' decision	for the parents
	• being a grandparent second	to compensate for non person
	feelings of loss ② 1(10) 2(25)	
	identify what the loss is for self ① 2(20)	• Putting loss in place
	important links to grandchild	spiritual links to other family ② 2(26) 2(11)
	changes in health ① 2(15)	revisit other losses ① 1(2) 2(22)
	• the circle of the family	out of sequence ① 2(24)



	space to cry for other losses	live with regrets (1) 3(3)
	mutuality or not (1) 1(8)	redefine grandchild position in family
2 1(5) 3(7)	changes in family relationships not!	
1 1(5)	changes in lives of family members	• meaning and growth
	changes in lifestyle or health (mainly grand)	meaning of the death (5) 2(20) 1(8) 3(2)
		change own position in relation to:-
		belong with the other group 2(9)
		increase awareness of help others (1) 2(21)
		thoughts of own mortality
		personal growth (1) 2(12)
		religion (1) 2(10)

feelings

reflection

- Philosophy of grandparenting 5 3(1), 3(1), 1(23), 1(16) 1(12)
- Philosophy of parenting 2 2(10) 2(16)
- Philosophy of family 1 1(10)

■ reflections on grief

- issues for bereaved grandparents as perceived by participants with the focus leading back to being a parent
- nature of grief

- hierarchy ideas 2 (8)
- feelings come and go
- survivor guilt

## Appendix 10

### Materials relating to publication of stories in book form

#### *Health Funding Authority*

CANTERBURY ETHICS COMMITTEE

7 January 1999

Alison Stewart

South Office  
4th Floor, 144 Kilmore Street  
PO Box 3877  
CHRISTCHURCH  
New Zealand  
Telephone 03 372 1000  
Facsimile 03 372 1015

DUNEDIN

Dear Alison

Ref: Grandparent Bereavement Study

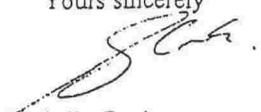
Investigator: Alison Stewart

Protocol Number: 96/039/CPD

Thank you for the information sheet and consent form for participants wanting their stories to be published as a book. The information sheet and consent form have been given ethical approval.

Thank you for keeping the Committee informed and best wishes for a successful publication.

Yours sincerely

  
Sally Cook

Ethics Committee Administrator

cc Otago Ethics Committee

**Health Funding Authority**

South Office  
 229 Moray Place  
 PO Box 5849  
 DUNEDIN  
 New Zealand  
 Telephone 03 477 4222  
 Facsimile 03 474 0080

**ETHICS COMMITTEE OTAGO**

15 April 1999

Alison Stewart

DUNEDIN

Dear Alison

**Grandparent Bereavement Study**

Investigators: Alison Stewart (Supervisor: Professor Jill White)

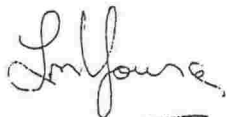
Protocol Number: 95/12/134

I acknowledge receipt of your note dated 12 April 1999 requesting a reply to your letter of 16 December 1999. Our profuse apologies for not responding before now. Your letter was inadvertently filed away unanswered.

I am pleased to advise that approval has been given for the information sheet and consent form for participants wanting their stories to be published as a book.

Once again, sincere apologies for delay and hope all goes well.

Yours sincerely



Lynda Young  
 Acting Ethics Committee Administrator



North

*Heiwa Honoa A Kahi O Te Kahi*



Midland



Central

*Te Hanga Honoa*



South

*Ka te muna Honoa, Ka te muna Te Kahi*

**Letter to all participants with consent form –**

**NB original version had wider linespacing**

Dear Everyone

Earlier in this research study on grandparent bereavement, a number of people

widely accessible. So, if you wanted your story in the book BUT had reservations about being identified through names or places mentioned in the story, we would need to change names and details.

### **What about names and details?**

One of the options on the consent form, if you decide to include your story in this project, is to indicate that you are happy with, or wish to change, real names or pseudonyms as they currently are in the thesis. If you have the real names of other family members in the story, who are not in the study, it would be worth re-checking with them (as you did for the thesis) to see if they are happy for their names to be published in a book.

### **Whose book is it?**

Given that the whole study has tried to work in what is called the co-operative research model, I believe that this is **our** book. I would suggest that whilst I would be the primary author we would want to explore with the publisher of having a way of acknowledging everyone who has stories in the book as co-authors. It might be that it has "and co-authors" on the book cover and then has full details at the beginning section of the book.

### **What about royalties?**

Unfortunately, we are not going to be rich on the basis of this book! Most royalty agreements for small market demand projects like this one offer 5-10% of the sales profit to the author(s). My suggestion for you on the consent form, is that we plan for any royalties exceeding the costs of producing the final version (which will be printing and posting draft copies to all of you), to be donated to a charity of your choice(s). It might be a charity like SANDS or SIDSFI.

### **What about decision and choices if the book is to be published?**

There will be decisions and options if the book is accepted, possibly like discussion on the book cover, who might write a preface etc. I would plan to write to all of you at any of these decision points, so that we continue to consult with each other as we have done through the research study.

If you do have any other questions or comments then please telephone me or write to me. I attach the consent form and look forward to hearing from you.

With best wishes

Alison Stewart [contact details]

**Consent for my story from the Grandparent Bereavement Research Study to be included in a published book of participants' stories.**

I have had the opportunity to read the letter that Alison sent about approaching publishers to produce a book of the stories from the research study. I have had the opportunity to ask questions and I am aware that my decision to allow my story to be included/not included is entirely separate from my consent to participate in the research study.

Please tick the following statements with which you are happy.

☐ I do **NOT consent** for my story to be included in a published book of stories from this research

Please now return the form- the following questions do not apply

☐ I **consent** and am happy for my story to be included in a published book of stories from this research

☐ I wish to keep the **SAME** names and identifying details in the story as in my story in the thesis

☐ I wish to **CHANGE** the names and identifying details in the story to be different from those in my story in the thesis

☐ I am happy to be consulted about decisions and to see the final draft of the book

I wish for any royalties which exceed costs of producing the final version given the publisher to go to ..... (Charity)

Signed \_\_\_\_\_

Date \_\_\_\_\_ 1999

---

Please return the form to:  
Alison Stewart [contact details]



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