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EUTHANASIA FOR CHILDREN?

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Any thought of child euthanasia seems quite shocking on first instinct. However, Belgium forced a flow of international discussion through its extension of euthanasia laws to suffering patients of any age. This essay looks at its possible application in New Zealand, considering the competence of minors, the need for parental consent (or not) and issues of mental suffering. A final conclusion is drawn that euthanasia, if legalised, would be appropriate only for patients 16 years and over. This essay draws analogies with the law around consenting to other medical procedures, abortion, transgender treatment and contraception. For patients under the 16 age threshold, paediatric palliative care is convincingly the safest and most comprehensive option to assist young terminally ill children and their family through the final stages of life.

Key words: euthanasia, minors, Belgium, palliative care.

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I Introduction

On 13 February 2014, Belgian lawmakers voted by a large majority, 86 to 44 (with 12 abstentions), in favour of the extension of their 2002 euthanasia law to minors.¹ This topic is a live one in New Zealand as evidenced by Maryan Street's End of Life Choice (EOLC) Bill introduced into Parliament in December 2012. It was removed from the ballot late last year out of concern for its debate in election year.² Street was concerned that "it would not get the treatment it deserves" as the Bill "needs sober, considered reflection", which is uncharacteristic of election time.³ This research essay analyses the extension of euthanasia laws to minors. A conclusion on whether euthanasia should be legalised in New Zealand is not drawn, though some arguments both in favour and against are presented. It draws upon the Belgian law as a model, analysing the various criteria that must be met in order for a competent minor to be granted a euthanasia request under that law. For the purposes of this essay, euthanasia is the act of deliberately ending the life of another person by non-violent means.⁴ End of Life Choice, the preferred term in New Zealand, advocates voluntary euthanasia, of which consent and knowledge are obtained when ending another's life.⁵⁶

While there is no express rule regarding euthanasia in New Zealand, any form of it is strictly illegal. Homicide is defined as the killing of a human being by another, directly or indirectly, by any means whatsoever.⁷ Only culpable homicide is an offence, which means that the killing involves an unlawful act.⁸ The illegality of euthanasia is also evident in the criminalisation of aiding and abetting suicide.⁹ This stance is reinforced by the New Zealand Bill of Rights, stating that "no one shall be deprived of life except on such

¹ Associated Press Brussels "Belgium passes law extending euthanasia to children of all ages" *The Guardian* (online ed, 13 February 2014).

² Isaac Davison "Labour: Euthanasia bill will return" *The New Zealand Herald* (online ed, Auckland, 16 October 2013).

³ Hamish Rutherford "Voluntary euthanasia bill withdrawn" *Stuff* (online ed, Auckland, 26 October 2013).

⁴ Ruth McManus and Rosemary Du Plessis "Death and dying – Euthanasia" (13 July 2012) *Te Ara – the Encyclopedia of New Zealand* < <http://www.teara.govt.nz/en/death-and-dying/page-6>>.

⁵ "Frequently Asked Questions" (21 July 2014) Voluntary Euthanasia Society of New Zealand Incorporated <<http://www.ves.org.nz/faq>>.

⁶ "Frequently Asked Questions" (21 July 2014) Voluntary Euthanasia Society of New Zealand Incorporated <<http://www.ves.org.nz/faq>>.

⁷ Crimes Act 1961, s 158.

⁸ Section 160(2)(a).

⁹ Section 179.

grounds as are established by law and are consistent with the principle of fundamental justice”.¹⁰

Children are a vulnerable group and thus in need of extra protections,¹¹ as evidenced by the Children, Young Persons, and Their Families Act as well as the Care of Children Act (“COCA”). Children are dependent on others because of their developmental needs.¹² Internationally, there are covenants in place to uphold rights of minors. Article 24 of the United Nations Convention on the Rights of the Child states that “every child shall have, without any discrimination as to race, colour, sex, language, religion, national or social origin, property or birth, the right to such measures of protection as are required by his status as a minor, on the part of his family, society and the State.”¹³ In New Zealand, the Age of Majority Act states a person attains full age at 20 years.¹⁴ Previously, the age was set at 21 years.¹⁵ For the purposes of this essay, therefore, a ‘minor’ or ‘young person’ refers to anyone younger than 20.¹⁶

The competence of a child to make a decision on euthanasia is the focal point of this discussion. Section 36 of the COCA would support, if such a law was introduced, the imposition of a minimum age of 16 years. At this age, young persons are entrusted with the right to obtain a driving licence, consent to medical procedures, consent to sexual intercourse and refuse treatment for mental illness.¹⁷ Though minors under the age of 16 are, in some respects, very competent and able, this age bracket brings complications of parental consent and the risk of coercion or lack of independent skills to make a choice to end life. This essay supports the imposition of better education and an appeal to the Ministry of Health to increase funding and resources to raise the standard of paediatric palliative care in New Zealand.

¹⁰ New Zealand Bill of Rights Act 1990, s 8.

¹¹ Human Rights Commission *Human Rights in New Zealand Today - Chapter 4: The rights of children and young people* (August 2004) at 1.

¹² At 1.

¹³ United Nations Convention on the Rights of a Child, art 24.

¹⁴ Age of Majority Act 1970, s 4.

¹⁵ Law Reform Commission *The Law Relating to the Age of Majority, the Age for Marriage and Some Connected Subjects* (1977) at 15.

¹⁶ This differs from the Belgian age of majority which is set at 18.

¹⁷ The Kiwi Families Team “Legal Age Guidelines” Kiwi Families
<<http://www.kiwifamilies.co.nz/articles/legal-age-guidelines/>>.

A large part of this essay employs responses from a number of professionals and others with differing views on child euthanasia (Appendix 1). Approval was granted by the Pipitea Ethics Committee of VUW to conduct these interviews, which were either in person, by phone or over email. The reason for this approach was to obtain personal opinions on a hugely contentious and sensitive subject. Unsurprisingly, Professor Van der Werf Ten Bosch from Belgium fully supported child euthanasia laws while Maryan Street supports the idea of euthanasia but not for children. All three palliative care doctors strongly opposed the idea. The interviews showed that the issues of greatest unease in New Zealand are a child's competence, parental consent and the imposition of a minimum age.

II The Belgian Framework

A Loi modifiant la loi du 28 mai 2002 relative à l'euthanasie, en vue d'étendre l'euthanasie aux mineurs (Appendix 2)

The Belgian law, assented to by King Phillippe without resistance,¹⁸ allows for the inclusion of patients under the age of 18 to be euthanased if several conditions are met. It requires that:¹⁹

- 1 The minor has a terminal illness
- 2 with unbearable physical suffering
- 3 that cannot be relieved.
- 4 The minor must, when making the request, be in a “capacity of discernment” (meaning ‘competence’)²⁰
- 5 as attested by a psychiatrist or psychologist.
- 6 The application must:
 - i. be in writing; and
 - ii. emanate from the minor; and
 - iii. be made repeatedly.
- 7 Written parental consent must be given.

¹⁸ The Voice of Russia “Belgian King Philippe signs controversial child euthanasia into law” (Moscow, 3 March 2014, 15:48).

¹⁹ (12 December 2013) 5-130 Belgium Senate.

²⁰ *Projet de loi modifiant la loi du 28 mai 2002 relative à l'euthanasie en vue de l'étendre aux mineurs* (Appendix 2).

- 8 A doctor must assess the patient's request to end life in each case and must be aware of the patient's medical folder.
- 9 Counselling is offered to families.

Belgium's decision to pass the amendment was formulated on the same fundamentals as the 2002 Act legalising adult euthanasia.²¹ That original Act set euthanasia at 18 (Belgian age of majority) but also included emancipated minors (a young person who gets married).²² The key difference in its application to all minors is that it explicitly prohibits psychiatric disorders and introduces the important qualification of 'capacity to discern' to assess the competence of a child.

*III The process*²³

Jutte Van der Werf Ten Bosch, a child oncologist at Brussels University Hospital, explained the process by which euthanasia would be administered to a child. There comes a time where the family is advised that no further medical treatments or procedures are available to the young patient. Doctors will explain the child's prospects and what comfort can be offered, of which euthanasia is included. It may be that the family have already discussed such matters or, alternatively, the child has advised a family member, guardian or close friend of the wish not to endure the last part. If the parents are capable of listening to their child, they will advise the doctor of their child's request. If not, no further action can be taken to pursue euthanasia; it is mandatory that the parents agree to the procedure. Where parents do consent, the psychological team will step in and organise several meetings with the child and the family. A second doctor will give an opinion, and approval is sought from the special Euthanasia committee, which makes a decision on each individual euthanasia request. Provided that the child is found to be sufficiently competent and the parents have formally agreed, a plan is then formulated. Subsequently, the legal work is prepared and the drugs are administered. Van der Werf Ten Bosch adds that, if a doctor refuses to perform euthanasia based on their own ethics, they should refer the patient to a colleague who can help them.

²¹ Bernard Dan, Christine Fonteyne and Stephan Clement de Cleyt "Self-requested euthanasia for children in Belgium" (2014) *Lancet* 671 at 672.

²² Belgian Civil Code, art 388.

²³ Interview with Jutte Van der Werf Ten Bosch.

IV An analysis of each criterion

A Minimum age

Belgium sets no minimum age for minors under this new law. The Senate strongly supported the proposition that mental age is more important than actual age. Senators argued that the system would otherwise be too inflexible to allow for the broad range of capabilities that children can have. “A child is not like any other; a case is not like any other and medicine individualises every situation and every patient”.²⁴ The downside to such flexibility is that it gives power to health professionals and psychiatrists to evaluate the child. It risks ad hoc analysis and thus could result in arbitrary decisions based on one or two doctors’ opinions. It vests huge discretion on the life of a child in those experts. Nevertheless, Belgium maintains “a strong desire to encompass freedom and solidarity for [suffering] minors”.²⁵ An age limit would increase the risk that some patients’ wishes cannot be respected.²⁶ Belgium maintains that an application may be denied if a patient is insufficiently informed of the medical diagnosis and prognosis and is simply “confused, panicked or impulsive”.²⁷ The alleviation of pain can be accomplished by alternate means.²⁸

B Unbearable suffering

It was unanimous amongst all interviewees that unbearable suffering must be evaluated by the child’s own assessment. The test is purely subjective. This is consistent with Street’s EOLC Bill, which states that a qualifying person may receive medical assistance to end their life if that person suffers from an irreversible “medical condition that, *in the person’s view*, renders his or her life unbearable”.²⁹ It insists on the notion that what one person believes to be unbearable may differ from the next.

²⁴ (12 December 2013) 5-130 Belgium Senate.

²⁵ (12 December 2013) 5-130 Belgium Senate.

²⁶ Interview with Jutte Van der Werf Ten Bosch.

²⁷ (12 December 2013) 5-130 Belgium Senate.

²⁸ See part XII *Paediatric palliative care*.

²⁹ End of Life Choice Bill 2012, cl 6(1)(b)(ii).

In order to test whether a subjective approach is preferable, the alternative objective assessment is considered. An objective test would, firstly, define unbearable suffering and, secondly, set a reasonable standard of pain. A research study by Gootjes, Zuurmond and Perez involving palliative care professionals and non-professionals attempted to discover a definition but concluded that “the only thing we know about the definition of unbearable suffering is that we do not know what it is yet”.³⁰ In terms of a standard, the suffering could be compared to how a reasonable person may feel in those circumstances. Incorporating an objective element may change cl 6(1)(b)(ii) in the EOLC Bill to: “a qualifying person may receive medical assistance to end life if that person suffers from an irreversible medical condition that results in unreasonable suffering and renders his or her life unbearable”. 90% of euthanasia cases relate to patients with terminal cancer, which is also true for young people.³¹ Therefore, hypothetically, for a child with cancer, a reasonable person would be another child with the same cognitive capabilities and same type of terminal cancer. However, cancer varies by degree and by symptoms, with some diagnoses unable to be properly ascertained. A general mould of a child’s suffering for all terminally ill children is inappropriate.

It can thus be concluded that unbearable suffering must be subjective and personal to that particular ill child. It is likely that doctors can assess unbearableness by constant pleas for pain relief, distressed facial expressions and a child asserting their dying wishes often. They may also rely on previous experiences with other patients with a similar condition.³² A doctor must listen to the patient without being judgmental because “unbearable suffering is not an unequivocal concept”.³³

C Physical suffering that cannot be relieved

This element indicates that suffering is limited to physical ailments where all medical procedures or treatments are exhausted. The situation must be “hopeless”.³⁴ Yet health

³⁰Jaap Gootjes, Wouter Zuurmond and Roberto Perez “Unbearable Suffering: Defining a concept with undefined parameters” *European Oncology Nursing Society Newsletter* (online ed, Britain, Autumn 2010) at 30.

³¹ Netherlands Ministry of Foreign Affairs *A guide to the Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act* (PlantijnCasparie, Schiedam 2010) at 19.

³² Interview with Jean Cartmell.

³³ Gootjes, Zuurmond and Perez, above n 30, at 30.

³⁴ Loi du 28 mai 2002 relative à l’euthanasie, s 3(1).

professionals submit that there is no need for physical pain and claim that almost all such suffering can be relieved through good palliative care. The World Health Organisation defines palliative care as “an approach that improves the quality of life of patients and their families associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems (physical, psychosocial and spiritual).”³⁵ Dr. Ross Drake, paediatrician at Starship Hospital, advises that there are very few circumstances where a child’s symptoms cannot be controlled.³⁶ Even in those few circumstances, palliative sedation is “considered when all other symptom-relieving measures have failed and the patient is clearly distressed.”³⁷ It “lowers a patient’s consciousness in a titrated, proportional way” to relieve those intolerable symptoms.³⁸ Though there is an increased risk of hastening death, the important factor differentiating palliative care from euthanasia is *intention*.³⁹ The former intends to relieve suffering by medication, from which death *may* result.⁴⁰ On the other hand, euthanasia unequivocally intends to end a person’s life.⁴¹ Dr. Sinead Donnelly, a consultant in palliative medicine at Wellington Hospital, suggests that more funding should instead be available for research on how to provide better pain relief for children.⁴² Hospice, a provider of palliative care services, strongly opposes a change in the law to legalise assisted dying in any form.⁴³

By a stark contrast, Dr. Jan Bernheim, Palliative Care Specialist in Belgium, claims that “within Belgium we found few professional stances contending that palliative care and legalisation of euthanasia are antagonistic, no slippery slope effects, and no evidence for the concern of the European Association for Palliative Care that the drive to legalise

³⁵ “WHO Definition of Palliative Care” World Health Organization <<http://www.who.int/cancer/palliative/definition/en/>>.

³⁶ Interview with Ross Drake.

³⁷ Rod MacLeod, Jane Vella-Brincat, and Sandy Macleod *The Palliative Care Handbook: Guidelines for clinical management and symptom control* (6th ed, Soar Printers, Auckland, 2012) at 32.

³⁸ Brian Ensor and Daphne Cohen “Benchmarking benzodiazepines and antipsychotics in the last 24 hours of life” (2012) 125 NZMJ 19 at 19.

³⁹ MacLeod, Vella-Brincat, and Macleod, above n 37, at 32.

⁴⁰ Interview with Sinead Donnelly.

⁴¹ Interview with Sinead Donnelly.

⁴² Interview with Sinead Donnelly.

⁴³ “Euthanasia - our opinion” Hospice New Zealand <<http://www.hospice.org.nz/about-hospice-nz/euthanasia-our-opinion>>.

euthanasia would interfere with the development of palliative care”.⁴⁴ This tension between euthanasia and palliative care will be returned to in Part VII.

Belgium’s amendment expressly excludes psychiatric disorders from applications from minors. Mental suffering stems from a person’s psychological problems.⁴⁵ Already there are concerns around a child’s mental capacity; it is thus even more difficult to decide whether or not a mentally unwell child can make a sound decision about their own death.⁴⁶ Furthermore, there is greater public apprehension of children and mental suffering.⁴⁷ Giselle Bahr, clinical psychologist, argues that there is little evidence that mental health is actually incurable.⁴⁸ Thus it could never come within the ‘hopeless’ requirement. Mental illness is derived, in part, from the processes by which humans manage distress. She believes that there are techniques available for psychologists to help people learn how to manage that stress. Counselling is one such technique. New Zealand has an alarmingly high youth suicide rate, placed second highest of developed countries,⁴⁹ indicating that mental illness among young persons is prevalent. This makes it problematic to include minors with mental illness in euthanasia legislation when life will always be unbearable without the right help and treatment.⁵⁰

On the other hand, the line distinguishing between types of suffering appears arbitrary. In order to truly appreciate what “unbearable” means for one person, all types of suffering must be included.⁵¹ Such an argument supports the subjective test of “unbearable” and by claiming psychological suffering is not unbearable undermines this test. The law aims to be inclusive and to not discriminate against specific groups. Yet this is an expressly exclusionary element. However, an expansion of the criteria makes it more difficult to maintain tight regulations and enforcement in order to keep people’s safety a high priority.⁵²

⁴⁴ Jan Bernheim and others “Development of palliative care and legislation of euthanasia: antagonism or synergy?” (2008) 336 BMJ 864 at 864.

⁴⁵ Interview with Giselle Bahr.

⁴⁶ Interview with Jutte Van der Werf Ten Bosch.

⁴⁷ (12 December 2013) 5-130 Belgium Senate.

⁴⁸ Interview with Giselle Bahr.

⁴⁹ Ministry of Health “Suicide - International comparisons” (2007) Youth Statistics <<http://www.youthstats.mxd.govt.nz/indicator/healthy/suicide/international.html>>.

⁵⁰ Interview with Giselle Bahr.

⁵¹ Interview with John Kleinsman.

⁵² Interview with John Kleinsman.

On balance, Bahr offers persuasive arguments that the right treatment for mental health is required instead of an option for assisted suicide. It is difficult to diagnose the likes of grief and severe anxiety as “terminal”. Young people, in particular, need the support of their family, school and community to assist them during their time of high risk-taking and growing up.

D Competence

Skills that are helpful to assess and define competency in young children include “the capacity to persist, to be self-initiating...to handle the environment and to feel in control”.⁵³ The emphasis on the child’s personal competence strictly excludes “children with altered consciousness, intellectual disability, young children and neonates.”⁵⁴ Jean Cartmell, a member of the Voluntary Euthanasia Society, said that whether they fully understand the significance of a life-ending decision depends on the child: their intelligence and education.⁵⁵ Terminally ill children are likely to understand the concept of death after spending considerable time in hospital, making friends and seeing other children die.⁵⁶ They can be extraordinarily astute.⁵⁷ There must be as many people as possible who can estimate the child’s attitude in order to produce the most comprehensive assessment.⁵⁸ Repetition of requests to family and doctors with a waiting period will give a strong indication as to the child’s own views.

Generally, a competent child is “one who is able to understand the nature, purpose and possible consequences of the proposed investigation or treatment, as well as the consequences of non-treatment.”⁵⁹ *Gillick v West Norfolk and Wisbech Area Health Authority* articulated ‘the *Gillick* competence test’ which claims a young person to be competent once they achieve a “sufficient understanding and intelligence to enable him or her to understand fully what is proposed”.⁶⁰ When an attempt is made to apply the

⁵³ Anne Hendricks and Anne Meade “Competent Children: Influences of Early Childhood Experiences” (July 1993) NZCER at 1.

⁵⁴ Dan, Fonteyne and Clement de Clety, above n 21, at 672.

⁵⁵ Interview with Jean Cartmell

⁵⁶ Interview with Pam Oliver.

⁵⁷ Interview with Maryan Street.

⁵⁸ Interview with Maryan Street.

⁵⁹ Medical Council of New Zealand *Information, choice of treatment and informed consent* (March 2011) at 4.

⁶⁰ *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112 at 188 at 27.

assumption from *Gillick* to a child, “the true question which is to be confronted is whether *this* child, in *this* particular situation *in fact* has sufficient understanding and intelligence to be capable of making his own mind on the matter”.⁶¹ The test was applied in New Zealand in *ARB v KLB*.⁶² Such a test reinforces that the capacity of minors exists at varying ages depending on the minor and the decision at hand.⁶³ Thus if such a law similar to the Belgian one was passed in New Zealand, on a *Gillick* standard, it would be most appropriate that there is no minimum age set for euthanasia and that the issue turn on individual competence.

Alternatively, Dr Richard Hain, consultant in paediatric palliative medicine in Wales, suggests that the issue of euthanasia is not about whether individuals have a right to die but whether doctors should be given a right to kill. If that is true, the arguments do not depend on the capacity of a child to make decisions for themselves. Dr Hain believes, however, that children with a terminal illness have a greater maturity compared with a normal, healthy child of the same cognitive ability. Yet capacity depends on a much greater consideration than simply the nature of the individual. It also depends on the nature of the decision (both its complexity and arguably the seriousness of the potential outcome) and how well the healthcare team communicated with the patient so that they are truly informed. It is the specific context and set of circumstances that influences the child.

Dr Hain raises a further important debate. On one hand, paediatricians make constant pleas for recognition that children are much more autonomous than they are given credit for and that they are perfectly capable of making decisions, albeit within the context of friends and family. On the other hand, euthanasia for children is opposed on the basis that they are not yet able to make that decision. However, these two arguments are not completely at odds, since autonomy depends on the seriousness of the decision as well as the reasoning ability of the patient. It could be argued that the bar on autonomy for a decision as serious as euthanasia is much higher than that of any other procedure. He adds that there is no

⁶¹ BD Inglis *New Zealand Family Law in the 21st Century* (Brookers, Wellington, 2007).

⁶² *ARB v KLB* [2011] NZFLR 290 (FC).

⁶³ Professor W.R Atkin *New Zealand in International Encyclopaedia of Laws* (The Netherlands, Wolters Kluwer, 2012) at 30.

evidence that dying is preferable to living and “it is philosophically inept to assume that erasing a person equates to erasing their suffering”.⁶⁴

E Psychologist assessment

In order to determine that a child fulfils the competence requirement, a psychiatrist or psychologist must assess the child in order to ascertain their state of mind. Ms Bahr currently assesses children with suicide tendencies and therefore is in a position to consider the feelings of children around end of life choices. She believes it is possible to tease out why children are feeling like that and to assess the best procedure to relieve those death-associated emotions. Assessment depends on the child: it may take 1 hour or maybe a few weeks.⁶⁵

Biologically, however, the frontal lobe is not fully developed until aged 25. The frontal lobe is responsible for judgment, reasoning and acting without being unduly influenced by peers.⁶⁶ On this basis, arguably, children do not have the cognitive capacity to understand and make such decisions. Moreover, the lack of legal or scientific definition and content of the concept of “capacity of discernment” makes an objective assessment of this capacity very difficult for a child psychiatrist. The application may be arbitrary. There is also the concern that these assessors are not fully independent of doctors, thus being influenced by decisions made by other medical professionals. Yet there is a strong desire for the entire multidisciplinary team to be working together along with the family and child in order to make the most appropriate decision for that child. A fully independent psychological assessment may not be particularly advantageous either.

On the whole, a child psychologist is an important safeguard in order to add to the completeness of the child’s competence assessment.

⁶⁴ Interview with Richard Hain.

⁶⁵ Interview with Giselle Bahr.

⁶⁶ “About the lobes of the brain” (2011) ABI Rehabilitation <<http://www.abi-rehab.co.nz/lobes-of-the-brain-information-for-clients-and-families.html>>

F Parental consent

The Belgian law requires parental consent to all applications of persons under the age of 18 (with the exception of emancipated minors). In New Zealand at age 18, young people can vote, drink alcohol and enter contracts.⁶⁷ A parent's guardianship over their child ends when they turn 18.⁶⁸ The EOLC Bill defines a qualifying person as a person who is "aged 18 years or over".⁶⁹ Therefore in terms of parental consent, the discussion is based around 18 rather than 20. When asked of her opinion on parental consent, Street said that families are complicated institutions; it would be best that parental consent is not mandatory in order to ensure that a child was not being coerced into a decision. In the Bill for adults, family discussions are only encouraged. They are not mandatory. On the other hand, s 36 of the COCA states that consent, or refusal to consent, to "any medical, surgical, or dental treatment or procedure...to be carried out on the child for the child's benefit by a person professionally qualified to carry it out" if given by a child of or over the age of 16 years, has effect as if the child were of full age.⁷⁰ This indicates that parental consent for medically based decisions is not mandatory for a person over the age of 16. This is discussed in Part X.

Concerns arise around divorced parents and the complicated situation where one parent consents, while the other does not. If parents refused to come to an agreement on their child's best interests, it would be the most unlikely and unfortunate situation.⁷¹ If any such situation did arise that could not be resolved through discussion and counselling, an order can be made by the Court to help resolve the dispute. Paediatricians never treat the patient as independent; the family must also be dealt with.⁷²

In *ARB v KLB*, parents of 14-year-old R were conflicted about her medical care, in particular the choice of her doctor and dentist. The judge held that R was capable of making the decision for herself. She was so accustomed to the ongoing disputes between her parents that "she was able to express her own view in light of her parents' definite

⁶⁷ The Kiwi Families Team "Legal Age Guidelines" Kiwi Families
<<http://www.kiwifamilies.co.nz/articles/legal-age-guidelines/>>

⁶⁸ Care of Children Act 2004, s 28.

⁶⁹ End of Life Choice Bill, cl 4.

⁷⁰ Care of Children Act, s 36.

⁷¹ Interview with Pam Oliver.

⁷² Interview with Jutte Van der Werf Ten Bosch.

views and/or guidance”.⁷³ This lends itself to the view that minors are able to make decisions on their own, supporting the view of their sufficient competence. However, the judge narrowed the situation that “where consultations relate to complaints of a transitory and minor matter, these are not guardianship matters”.⁷⁴ Transitory and minor matters may include “treatment of transitory viral illnesses, wart removal, minor contrusions and abrasions arising from household, playground, and school time accidents, and acne management”.⁷⁵ Arguably, choice of doctor is not a transitory matter and R’s decision, at age 14, was decisive. Quite plainly, a decision to end life would not come within what is considered a ‘transitory and minor matter’. Therefore, on *ARB v KLB*, children, even at the age of 14, can potentially be autonomous individuals.

Consent, strictly speaking, is a guardian’s role under the COCA. Responsibilities of a guardian of a child include “determining for or with the child, or helping the child to determine, questions about important matters affecting the child”.⁷⁶ Important matters affecting the child include “medical treatment for the child (if that medical treatment is not routine in nature)”.⁷⁷ The procedure to euthanase would easily fit within this category. Guardianship generally ends when the child turns 18 years old.⁷⁸ When the exercise of guardianship is doubted, an eligible person such as a parent, grandparent, sibling or the child themselves,⁷⁹ may make an application to a court for an order placing a child under the guardianship of the court.⁸⁰ The Court then can consent to a procedure, whatever the views of the parents.⁸¹

V *A Māori perspective: whānau consent?*

The perception of pain by Māori is a “multidimensional experience”.⁸² As such, the assessment and treatment of pain from a multidimensional perspective is most appropriate

⁷³ *ARB v KLB*, above n 62, at [24].

⁷⁴ At [13].

⁷⁵ At [12].

⁷⁶ Care of Children Act, s 16(1)(c).

⁷⁷ Section 16(2)(c).

⁷⁸ Section 28(1)(a).

⁷⁹ Section 31(2).

⁸⁰ Section 31(1)(a).

⁸¹ Section 34(3).

⁸² Jane E Magnusson and Joyce A Fennel “Understanding the role of culture in pain: Maori practitioner perspectives relating to the experience of pain” (2011) 124 NZMJ 41 at 48.

within the Māori culture.⁸³ Te whare tapa whā is a model for understanding Māori health, considering the four core attributes that are physical health, spiritual health, family health and mental health.⁸⁴ New Zealand, unlike Belgium, has an extra consideration to uphold Māori tikanga in its legislation. Whānau can vary from the immediate family to much broader collectives, comprising of three (or more) generations.⁸⁵ It is difficult, therefore, to contain this concept of family within a narrow requirement like parental consent. A clause could read “consent to a euthanasia procedure of a minor must be obtained by the child's or young person's parents, whanau, hapu, iwi, or family group.” That said, this essay considers parental consent to be an unnecessary requirement for young people over the age of 16. Patients under that age who are still suffering are to be provided with aggressive palliative care, which is in agreement with the multiple dimensional phenomena, as described by Māori. Palliative care serves to treat physical and emotional pain of the patient as well as support for their family.

VI *Coercion and vulnerability*

Undue influence may take a direct or indirect form of families putting pressure on a child to apply for euthanasia. Families may be tired, stressed and emotionally exhausted, irrationally seeking an easy way to end the grief and let their child die faster. Though children can be very clear in their requests, the significant difference, compared to that of an ordinary mature person, is coercion. Children are particularly vulnerable to people in their surroundings, especially their family. John Kleinsman, director of the Nathaniel Centre and advocate against the legalisation of euthanasia, argues that it would be difficult to protect them from the pressure of family. That pressure may be real and imposed on them by the outside or it may simply be self-perceived.⁸⁶ A child may consider themselves to be a burden on their parents, siblings and wider relatives. Professor Van der Werf Ten Bosch, on the other hand, quickly dismisses the point and believes that it would be

⁸³ Magnusson and Fennel, above n 82, at 48.

⁸⁴ “Maori health models - Te Whare Tapa Wha” (27 March 2012) Ministry of Health < <http://www.health.govt.nz/our-work/populations/maori-health/maori-health-models/maori-health-models-te-whare-tapa-wha>>.

⁸⁵ Tai Walker “Whanau - Maori and family - Contemporary understands of Whanau” Te Ara - The Encyclopedia of New Zealand (5 February 2014) < <http://www.teara.govt.nz/en/whanau-maori-and-family/page-1>>.

⁸⁶ Interview with John Kleinsman.

“inconceivable” for a family to want to push their child towards death.⁸⁷ Though this may be true, the possibility of coercion is an argument against parental consent as a pre-condition.

VII *A child’s best interests*

Dr Hain of Wales argues that, in Western countries, the interests of the child are considered separable from those of the parents, and parents are expected to attend to those interests. By amalgamating those two focuses, parents cannot insist on doctors performing a particular treatment on their child that is not in the child’s interest, nor can they refuse a procedure that is in their child’s best interests. If euthanasia were in the child’s best interest, then refusing it would be a child protection issue. But, in reality, it is difficult to make any argument that euthanasia would better serve a child than another medical option. Euthanasia does not relieve suffering, whereas good palliative care may. Those who support the legalisation of euthanasia rely less on the argument about a patient’s best interests. Instead, supporters argue that a competent individual should be able to request it, whether it is in their best interest or not. Therefore, if Dr Hain’s argument is true, euthanasia is wholly inappropriate for children because “the welfare and best interests must be the paramount consideration for a child”.⁸⁸ This is an important distinction between adults and children.

VIII *Advanced directives: The Netherlands*

Belgium was surprised by the international criticism of its amendment.⁸⁹ They were simply doing what the Dutch had done. The Netherlands legalised euthanasia in 2002, setting a minimum age of application at 12 years old. Most notably, an addition in its law is that, if a patient, aged 16 years or older, prior to reaching their incompetent condition, was deemed to have a reasonable understanding of their own situation, that person may make a written statement containing a request for termination of life. This is known as an advanced directive or an End of Life Directive (ELD). Their request cannot then be

⁸⁷ Interview with Jutte Van der Werf Ten Bosch.

⁸⁸ Care of Children Act, s 4.

⁸⁹ Robert-Jan Bartunek “Belgium surprised at international euthanasia backlash” Reuters (online ed, Brussels, 14 February 2014).

cancelled on the basis that their condition has deteriorated.⁹⁰ In the EOLC Bill, “a qualifying person may request, by means of a registered ELD, to be provided with medical assistance to end his or her life if he or she is mentally competent at the time of making the ELD.”⁹¹ Though in favour of euthanasia itself, Street opposes it for children. She believes that allowing children to make advanced directives is “contrary to the usual order of things”.⁹² A young person “should not have to think about” making a written request in advance of their inevitable death.⁹³ On this basis, advanced directives are not suitable for minors. This is consistent with the Wills Act in New Zealand, which permits only persons over the age of 18 to make, change or revoke a will (except under certain conditions).⁹⁴

On the issue of consent in the Netherlands, 12-15 year olds must obtain parental consent for euthanasia to be performed, while 16-17 year olds are able to make the decision independently. For the latter, it is prescribed that parents must be involved in discussions.⁹⁵

IX *Fitting child euthanasia within the EOLC Bill*

As mentioned, the EOLC Bill limits its application to patients over the age of 18. Street’s reasons for this are political and personal. She argues that New Zealand is conservative on this issue and thus progress will be slow. Therefore, the public must be taken gently and only people who have thought about it for a long time will be comfortable with the matter. Secondly, the inclusion of young people may be a distraction from what the Bill aims to achieve and thus it is best not to provoke further debate. On a personal level, she struggles to contemplate assisted dying for children because the Bill targets autonomous, self-determining people who are still so at the end of their life. “Children are not autonomous or self-determining; their lives are circumscribed by parents and wider family and thus they have not exercised their own minds sufficiently to be self-determining.”⁹⁶

The Bill is not limited to physical suffering and thus differs from the Belgian amendment in this way. Clause 6 states a person is eligible if they “suffer from an irreversible [and

⁹⁰ Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002, art 2(2).

⁹¹ End of Life Choice Bill, cl 11.

⁹² Interview with Maryan Street.

⁹³ Interview with Maryan Street.

⁹⁴ Wills Act 2007, s 9(1).

⁹⁵ Netherlands Ministry of Foreign Affairs, above n 31, at 19.

⁹⁶ Interview with Maryan Street.

unbearable] physical *or* mental condition”.⁹⁷ See part IV(C) for discussion of mental health and its inappropriateness to be included in legislation for children. The End of Life Choice Bill is, therefore, not satisfactory for expansion to young people.

John Kleinsman strongly opposes the Bill arguing that it is inevitable that the legislation would extend to children in time, just as Belgium has 12 years on. It is illogical and irrational to limit euthanasia to certain groups when the key argument is based around suffering and the alleviation of suffering.⁹⁸ The line is arbitrary. Euthanasia should thus not be legalised because, when the criteria expand, there are greater difficulties in control and management and, ultimately, keeping people safe. The focus must be on its social effects and what is for the common good, rather than focusing on an individual’s rights.

Yet those in favour support a change in people’s opinion and the social conversations which are occurring. If overseas euthanasia laws applying to adults have not been as frequently accessed as thought with no instances of abusing the process, it is thought it may be safe to apply to children.⁹⁹

X An analysis of s 36

A Clarifying the law on consent

Informed consent is an “external expression of a practitioner’s pivotal ethical duty to uphold and enhance their patient’s autonomy”.¹⁰⁰ The Ministry of Health defines autonomy as “the ability to think, decide and act on one’s own deliberation freely and without coercion”.¹⁰¹ In order to be autonomous and give consent, regardless of age, a person must be able to understand:¹⁰²

- That they have a choice
- Why they are being offered the treatment

⁹⁷ End of Life Choice Bill, cl 6.

⁹⁸ Interview with John Kleinsman.

⁹⁹ Interview with Maryan Street.

¹⁰⁰ Ministry of Health *Consent in Child and Youth Health: Information for Practitioners* (2 December 1998) at 2.

¹⁰¹ At 3.

¹⁰² At 3-4.

- What is involved in what they are being offered
- What the probative risks, side effects, failure rates and alternatives are.

As mentioned in part IV(F), discussion around consent focuses on young people under the age of 18. This is the time when guardianship ceases. However, the law makes a further provision that when a young person reaches 16, for the purposes of medical consent, their status is the same as that of an adult.¹⁰³ As with an adult, a health care practitioner can reverse this right if they reasonably believe that a person is not sufficiently competent and thus incapable of providing consent.¹⁰⁴

The Ministry of Health in *Consent in Child and Youth Health*, a document for practitioners, states that good practice is to seek the consent of parents and their competent child.¹⁰⁵ In line with *Gillick*,¹⁰⁶ the health practitioner's role is to encourage (not coerce) parents' involvement.¹⁰⁷ Inclusion is favoured to allow the young person to receive adequate support and guidance. Moreover, doctors must "deal with anxious parents or guardians who, not unnaturally, want to know about the situation."¹⁰⁸ But, currently, parents do not have an automatic right to view or hear confidential information concerning their children. The Privacy Act 1993 simply "adopts existing notions that children have a degree of autonomy" and that autonomy is not dependent on a particular age.¹⁰⁹ If the child approaches a health practitioner in confidence, but the practitioner is not satisfied the child is capable of giving informed consent, then the practitioner is required to obtain consent from a legal guardian.¹¹⁰ If the child appears to have the "understanding and maturity to form a balanced judgment about the proposed treatment" then the doctor can proceed to advise and treat the child.¹¹¹ The *Gillick* competence test is an important tool to make such an assessment.

Medical procedures that can be consented to, or refused, under section 36 include chemotherapy, blood transfusions and hormone therapy for a transgender procedure.

¹⁰³ Care of Children Act, s 36.

¹⁰⁴ Ministry of Health *Consent in Child and Youth Health: Information for Practitioners*, above n 100, at 11.

¹⁰⁵ At 12–13.

¹⁰⁶ See part IV(D) *Competence*.

¹⁰⁷ Ministry of Health *Consent in Child and Youth Health: Information for Practitioners*, above n 100, at 13.

¹⁰⁸ At 58.

¹⁰⁹ At 58.

¹¹⁰ Justice and Electoral Committee *Report on the Care of Children Bill* (29 June 2004) at 15.

¹¹¹ Ministry of Health *Consent in Child and Youth Health: Information for Practitioners*, above n 100, at 12.

B An example of s 36: transgender

Gender dysphoria “refers to the unhappiness that some people feel with their physical sex and/or gender role”.¹¹² It is common for the majority of children with gender dysphoria to outgrow it.¹¹³

Giselle Bahr described the implications of transitioning for transgender children. She explained, on a medical basis, if a person takes hormones for sex change before puberty, only a small a dose is required; if a person must wait until after puberty, the quantity of hormone therapy is significantly greater. Such large doses can cause health complications later on in life, such as heart difficulties. Therefore, it would be safer for therapy to be administered earlier in order to protect that person from those health risks. However, only 10% of children who meet the criteria for a gender identity disorder pre-puberty still meet the criteria *after* puberty. This means that 90% of the children who wanted it *pre*-puberty would be wrongly treated.¹¹⁴ Implicitly, this recognises that pre-puberty youngsters are in an indecisive, confused and easily influenced stage in their life. An inability to make reversible decisions like changing gender is complicated enough for young people. Allowing them to make decisions to end life is even more difficult.

Confusion in young people on this topic is illustrated in the case of *Chief Executive of the Ministry of Social Development v Young Person X*, where a 15 year old had applied to the Court to begin the hormone process to block the progression of masculinsation.¹¹⁵ It was held that X was uncertain about her choice and thus “there was inadequate information as to when, how and by whom the ultimate decision to begin treatment would be made”.¹¹⁶ This serves as an example of a young person’s period of indecision, proving to have great “enthusiasm” at one point, and “abscond” the next.¹¹⁷

¹¹² Kevin Alderson “*Psychology Works*” *Fact Sheet: Gender Dysphoria in Children* (Canadian Psychological Association, Occasional Paper 2014) at 1.

¹¹³ Kenneth Zucker and Susan Bradley “Gender identity disorder and psychosexual problems in children and adolescents” (2005) 3 *Focus* 598 at 613.

¹¹⁴ Interview with Giselle Bahr.

¹¹⁵ *Chief Executive of the Ministry of Social Development v Young Person X* HC Auckland CIV-2013-404-004621, 18 November 2013 at [1].

¹¹⁶ At [10].

¹¹⁷ At [3].

The issue of transgender children indicates that competence and rationality are more likely to be gained in a person post-puberty than pre-puberty. Though puberty ranges from person to person, generally young people have gone through some, if not all, stages of puberty by the age of 16. Thus, maintaining such an age qualification would be most suitable. By analogy, the same age should apply to a law on euthanasia.

C The exception to s 36: abortion

There is a single statutory exception to the general rule that a young person over the age of 16 can consent to a medical procedure independently of their parents. That is, when a female seeks the termination of her pregnancy. This concession is prescribed in s 38 of the COCA, which states that a female child of whatever age may consent to a medical procedure for the purpose of terminating her pregnancy.¹¹⁸ She may also refuse consent. Choices such as whether to terminate a pregnancy or not are mature decisions with emotional consequences. It may be out of fear that such a decision is made.¹¹⁹ Fear of judgment or the prospect and responsibility of bringing up a child. It is odd that a parent or guardian must consent to excursions like a school trip,¹²⁰ while their child can have an abortion without their knowledge.¹²¹ The Justice and Electoral Committee expressed its concern that “non-notification of parents is used as a shield by abusers of young girls and leaves young girls without support at a particularly vulnerable and difficult time of their lives”.¹²² However, it is difficult to see how else it could be done. If, hypothetically, a 12-year-old girl is pregnant or seeking contraception, it is likely to be a complicated affair to involve her parents. If a child is living a life that is that unsupervised and unsafe, they should be in a position to best look after themselves.¹²³ Jean Cartmell raised the argument that there should be some intervention if the child’s physical development is at risk in giving birth. However, in reality and in law, a doctor could only ever give this as advice, not as instruction.

¹¹⁸ Care of Children Act, s 38.

¹¹⁹ Interview with Jean Cartmell.

¹²⁰ See Education Outside the Classroom Guidelines.

¹²¹ Interview with John Kleinsman.

¹²² Justice and Electoral Committee, above n 110, at 19.

¹²³ Interview with Giselle Bahr.

On the whole, it is essential that “the welfare and best interests of a child, in his or her particular circumstances, [are] the first and paramount consideration”.¹²⁴ This means that in some circumstances, a child’s best interests are to allow them to receive advice from health professionals rather than involve the family. In other situations, a child will volunteer to involve her parents. This lends itself to the requirements of (a) no minimum age and (b) no parental consent for a potential child euthanasia law in New Zealand.

D Contraception and pregnancies

On the other end of the scale is the situation where young people decide to continue the pregnancy until the birth of the child. The New Zealand teenage fertility rate in 2001 was the third highest among Organisation for Economic Cooperation and Development (OECD) countries.¹²⁵ Consent to sexual intercourse is allowed by law at age 16. This, therefore, is the time at which a person can safely, as prescribed by the law, bear a child. Being a parent has its emotional and physical pressures. Thus the legislature must consider 16 year olds to be able to make rational decisions at that time about contraception (or lack of it). Though the Contraception, Sterilisation and Abortion Act 1977 allows for some young people under the age of 16 to be given contraceptive information, services and prescriptions, it is limited to females who are mentally subnormal and complainants of sexual violence.¹²⁶

There is no statute explicitly restricting any health provider from giving information or advice on contraception. However it is expected that they take into account the competence of a young person to make an informed decision. The Fraser guidelines, as set out by Lord Fraser in *Gillick*, apply specifically to contraceptive advice. He stated that a doctor is justified in proceeding without the parents’ consent (or knowledge) if he is satisfied:¹²⁷

- 1 that the girl (although under 16 years of age) will understand his advice;

¹²⁴ Care of Children Act, s 4(1).

¹²⁵ Countries who have signed the Convention on the Organisation for Economic Co-operation and Development.

¹²⁶ Contraception, Sterilisation and Abortion Act 1977, ss 4 and 5.

¹²⁷ *Gillick v West Norfolk & Wisbech Area Health Authority*, above n 60, at 12.

- 2 that he cannot persuade her to inform her parents or to allow him to inform the parents that she is seeking contraceptive advice;
- 3 that she is very likely to continue having sexual intercourse with or without contraceptive treatment;
- 4 that unless she receives contraceptive advice or treatment her physical or mental health or both are likely to suffer;
- 5 that her best interests require him to give her contraceptive advice, treatment or both without the parental consent.

This, therefore, does not support any minimum age or parental consent but centralises understanding, risk and best interests of the young patient.

XI A holistic view of other ethical issues

This essay has considered issues of abortion, contraception, pregnancy and transgender children. There are some difficulties in extrapolating end of life choices from other areas.¹²⁸ It is appreciated that all other events or decisions must be analysed independently with proper consideration for legal protection. With this in mind, it is still helpful to look at how society, the legislature and the judiciary have responded to these legal and ethical issues.

A summary so far,

	Minimum age?	Parental consent?
Section 36 of the COCA	16	No for 16+
Transgender children	>15 (<i>Chief Executive v X</i>)	n/a
Abortion (s 38 of the COCA)	No	No
Child pregnancy and contraception	Apply <i>Gillick</i> (roughly: post puberty)	No

As shown in the table, a young person is considered competent and capable of understanding the consequences of a significant decision like euthanasia at age 16. For patients aged 15 or younger, euthanasia is not an appropriate option to deal with their

¹²⁸ Interview with Maryan Street.

suffering. The decision to end life prematurely is so weighty for those young minors with complications of competence, consent and possible coercion. It is unsuitable for the law to intervene on those vulnerable and uncertain grounds. Intense and equitable palliative care should instead be available to deal with their unbearable suffering.

XII Paediatric Palliative Care in New Zealand

A The current situation

There is only one specialist paediatric palliative care service in New Zealand, which is located at Starship Children's Health in Auckland. There is a need for services outside of Auckland, as families are simply relying on local primary health care, community services and non-governmental organisations for the provision of palliative care.¹²⁹ Places of palliative care include a hospital, a hospice or in the patient's own home. Home is a favourable place of care for children as it reduces disruption to the child and family's usual activities and somewhat normalises the dying process.¹³⁰ However, it can be much more stressful for family members within the home to provide such demanding care.¹³¹ Paediatric palliative care has not kept pace with adult palliative care.¹³² The World Health Organisation describes palliative care for children as "the total active care of the child's body, mind and spirit, and also involves giving support to the family. It begins when the illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease."¹³³

Palliative care is an avenue which offers relief for both physical and mental suffering. The care should be intensive and coordinated from a high level. It is common knowledge that all humans are going to die. Therefore the focus should be on *how* people are dying and how they can best be *supported*.¹³⁴

¹²⁹ Ministry of Health *Guidance for Integrated Paediatric Palliative Care Services in New Zealand* (September 2012) at 11.

¹³⁰ At 23.

¹³¹ At 24.

¹³² At 11.

¹³³ "WHO Definition of Palliative Care", above n 35.

¹³⁴ Interview with Sinead Donnelly.

B Paediatric Palliative Care: the most comprehensive and undisputed framework for suffering young people

An explanation for paediatric palliative care is described as follows:¹³⁵

Although a child can surely feel pain, concepts like loss of dignity or the fear of losing self-determination are outside the realm of young children's capacities. Ensuring adequate pain control is thus a more reasonable response to their needs rather than seeking to involve them in decisions about euthanasia that exceed their experience and abilities.

Interventions, like palliative sedation and other aggressive palliative care, are far more ethical options than allowing doctors to euthanase children who do not possess the cognition and sophistication to comprehend the consequences of euthanasia.¹³⁶ Aggressive pain management is best for those whose dying solely entails the relief of their pain, which is the case for young people.¹³⁷

The International Children's Palliative Care Network issued a declaration on 12 February 2014 (Appendix 3) which strongly opposes the Belgian child euthanasia law and strives for good access to pain and symptom management as well as providing high quality support for the child and family.¹³⁸ The Palliative Care Nurses New Zealand Society advocates that:¹³⁹

Palliative care should be routinely available to all who need it, and Government should prioritise and ensure that public funding is made available to increase the availability of palliative care, whether provided by hospital, at home (by the primary health care team), in residential aged care facilities or hospices.

¹³⁵ Andrew Siegel, Dominic Sisti and Arthur Caplan "Pediatric Euthanasia in Belgium: Disturbing Developments" (2014) 311 American Medical Association at E1.

¹³⁶ At E2.

¹³⁷ At E1.

¹³⁸ International Children's Palliative Care Network Mumbai Declaration 2014.

¹³⁹ Palliative Care Nurses New Zealand "Position Statement to euthanasia and assisted dying" (September 2012).

Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; and intends neither to hasten nor to postpone death.¹⁴⁰

The End of Life Plan (Appendix 4), provided by Starship Hospital, focuses on discussions and goals. The care is holistic and personable and thus suitable especially for vulnerable young patients. Goals for the child include being independent, controlling symptoms and being involved in decision-making.¹⁴¹ Family goals reach from providing information about their child's condition, prognosis and available options to connecting with health care professionals and providing support for daily living problems.¹⁴² Starship's focus is on young people up to the age of 15. A "transition" is the word used "when a young person with a health condition moves from a child healthcare service to an adult [one]".¹⁴³ Hospice is one such adult healthcare service which also has a unique whole person approach.¹⁴⁴

C *A solution*

From a legal perspective, it is difficult to implement legislation to raise the standard of palliative care provided to minors. The best avenue may be through a special committee that tightly regulates and supports providers of palliative care. Regular reporting, such as 2 yearly self-reviews,¹⁴⁵ and feedback from patients make providers publicly accountable. Greater education and awareness among the public through the likes of an annual flagship event for paediatric palliative care (like Red Nose Day or Daffodil Day) may move towards more equitable access nationwide.¹⁴⁶ Such campaigns would also increase funding available in order to help families who are ineligible for public funding healthcare.

¹⁴⁰ "Palliative Care" World Health Organization < <http://www.who.int/hiv/topics/palliative/PalliativeCare/en/>>.

¹⁴¹ Ministry of Health *Guidance for Integrated Paediatric Palliative Care Services in New Zealand*, above n 129, at 22.

¹⁴² At 22.

¹⁴³ "What is transition" Starship < <https://www.starship.org.nz/patients-and-families/youth-transition/what-is-transition/>>.

¹⁴⁴ "What is hospice?" Hospice New Zealand < <http://hospice.org.nz/hospice-care/what-is-hospice/>>.

¹⁴⁵ Hospice New Zealand *Hospice New Zealand Standards for Palliative Care* (13 April 2012) at 46-47.

¹⁴⁶ Red Nose Day raises funds for Cure Kids; Daffodil Day supports the Cancer Society.

XIII Conclusion

Child euthanasia is a sensitive topic brought to fruition by Belgium earlier this year. After close analysis of each criterion, this essay concluded that, in New Zealand, *if* euthanasia were legalised, it should only be available to patients 16 or over. This adheres to section 36 of the Care of Children Act. The *Gillick* test is a helpful aid to assessing competence of a minor, ensuring they have the capacity to understand the implications of euthanasia. Like the Belgian law, the suffering of a minor must be unbearable and result from a physical incurable illness. Family discussions for all eligible minors (16-19 year olds) would be encouraged, though not a pre-condition. It is sufficient that the minor is competent.

Whether there is euthanasia or not, palliative care is a positive approach to the child's end of life. It offers both physical and mental relief through careful pain and symptom management as well as strong support for the family. Palliative care strives to help a patient live as normal and long life as possible. Care can be administered through a hospital, hospices or a patient's own home. Regular reporting and a new campaign initiative are ways to raise funds and make people aware of the importance of paediatric palliative care. Although Starship centralises its services to patients up to the age of 15, 16-19 year olds can receive care through adult hospices. The law must strike a careful balance with children. They need to be carefully considered and guided through their growing up but not be undermined in their ability to be capable and aware of themselves.

IX Appendices

Appendix 1: List of interviewees

Giselle Bahr (18 June)

Clinical Psychologist, Wellington

Jean Cartmell (28 May)

Member of Voluntary Euthanasia Society

Dr Sinead Donnelly (3 June)

Palliative Care Specialist (Wellington Hospital)

Dr Ross Drake (19 June)

Paediatrician in Palliative Care (Starship Hospital) by phone

Dr Richard Hain (2 July)

Paediatric Palliative Medicine Consultant (Wales) by email

John Kleinsman (27 May)

Director of Nathaniel Centre

Pam Oliver (11 June)

Completing a PhD in Assisted Dying (NZ)

Dr Hilary Stace (20 June)

PhD and interest in Disability Services; Mother of a child who had leukaemia

Hon Maryan Street (27 May)

Member of Parliament: End of Life Choice Bill

Professor Jutte Van der Werf Ten Bosch (17 June)

Paediatric oncology (Belgium) by email

Appendix 2: The Child Euthanasia Bill in Belgium

A Projet de loi modifiant la loi du 28 mai 2002 relative à l'euthanasie en vue de l'étendre aux mineurs (7 février 2014) DOC 53 3245/004

Cette proposition vise à étendre aux mineurs la loi de 2002. Elle pose plusieurs conditions. Le mineur doit être, à cause d'une maladie incurable, en situation de souffrance physique intolérable et qu'on ne peut soulager. Le mineur doit, lorsqu'il formule la demande, être en capacité de discernement attestée par un tiers. Tant la demande du mineur que l'accord des représentants légaux doivent être actés par écrit. Un accompagnement tant du patient que des parents est proposé dès que la demande est entendue.

La ministre souligne que le mineur doit disposer de la capacité de discernement nécessaire pour pouvoir faire une demande d'euthanasie. Aucun âge n'a été fixé, car un enfant n'est pas l'autre, un cas n'est pas l'autre et la médecine aborde chaque situation et chaque patient de manière individuelle. Il appartient au médecin d'évaluer la demande du malade mineur en fin de vie au cas par cas. Le législateur a décidé de faire évaluer la capacité de discernement par un tiers, qui doit être un spécialiste.

Le rôle des parents a fait l'objet de discussions approfondies. Finalement, on a considéré qu'il était préférable de les associer à la décision. Il serait impensable qu'un médecin pratique une euthanasie sur un mineur, alors que ses représentants légaux opposent leur veto.

B The Bill amending the Euthanasia Law of 28 May 2002 to extend to minors

This proposal would extend to minors the 2002 Act but imposes several conditions. The minor must have an incurable disease, with intolerable physical suffering that cannot be relieved. The minor must, when making the request, be in a capacity of discernment as certified by a third party. Both the application of the minor and the agreement of the legal representatives must be recorded in writing. Counselling for both the patient and parents is available when the application is heard.

The Minister stressed that the minor must have the mental capacity needed to make a request for euthanasia. No age has been set because a child is not like any other, a case is not like any other and medicine approaches each situation and each patient individually. It is for the doctor to assess the patient's request to die on a case by case basis. The legislature decided to assess the ability of discernment by a specialist third party.

The role of parents has been the subject of extensive discussions. Finally, we considered it best to involve them in the decision. It would be unthinkable that a physician practice euthanasia on a minor, while its legal representatives vetoed.

*Appendix 3: International Palliative Care Network Declaration**12 February 2014*

We believe that all children (neonates, children and young people) have the right to the best quality of life. When they have life-limiting conditions they have the right to high quality palliative care to meet their needs.

We believe that euthanasia is not part of children's palliative care and is not an alternative to palliative care. It is imperative that we work together to improve access to children's palliative care around the world, including ensuring access to appropriate pain and symptom control.

We call on all governments to transform children's lives through the development of children's palliative care, and in particular we urge the Belgian government to reconsider their recent decision to allow euthanasia of children.

This includes:

- 1 Access to children's palliative care within the children's health care system
- 2 Access to appropriate pain and symptom management (including medications) for all children
- 3 Supporting children and their families to be able to live their lives to the best of their ability for as long as possible.

Appendix 4: End of Life Plan - Starship Hospital

**Starship Children's Health
End of Life Care Plan**

SURNAME: _____ NHI: _____

FIRST NAMES: _____

DATE OF BIRTH: ____ / ____ / ____ SEX: _____

Please attach patient label here

Primary Consultant _____

Ward _____ Date of Admission _____

A discussion about end of life care and allowing a natural death in relation to

_____ (name of child) whose diagnosis is

was held on _____ (date). The following people were involved in the discussion:

Allowing a natural death (AND) and providing palliative care does not indicate a withdrawal of care, but the provision of symptom management; psychosocial and spiritual support and comfort during the end of life period.

The following goals of care were identified:

Symptom management

Treatment

Psychological / Social / Spiritual support

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CR8873

SURNAME: _____ NHI: _____
 FIRST NAMES: _____
 DATE OF BIRTH: ____/____/____ SEX: _____
 Please attach patient label here

Acute Deterioration Measures

In the event of an acute deterioration, the care to be provided may include, as appropriate:

Response	Yes	Withhold
Call to arrest team (Code Blue)		
Nasopharyngeal suctioning		
Oxygen – passive		
Oxygen – bag and mask		
Intubation		
Cardiac compression		
Electrical cardioversion		
Arrest medications		
Antibiotics		
Other (specify)		

Is a referral to the Palliative Care Team needed for symptom management and or psychological / social or spiritual support of the child and family?	☐ Yes	☐ No
If yes, has the referral been made?	☐ Yes	☐ No

Have the parents agreed to the acute deterioration measures (above) being a standing order?	☐ Yes	☐ No
Parents have agreed that this care plan and the acute deterioration measures will be reviewed in (timeframe _____)		

This reflects the care options discussed and agreed. It is understood that these decisions can change after discussion at any time.

Senior Medical Officer completing this form

Print Name _____ Designation _____
 Signature _____ Date _____
 Contact Number _____

The arrangements for end of life care and allowing a natural death must be reviewed according to the timeframe previously specified, unless the parents have requested a standing order. If the order changes, a new form must be completed and placed in the clinical record.

Date of Review	Order remains the same? If no, complete a new form	Signature of Medical Officer completing review	Print Name and Contact Number
	Yes / No		
	Yes / No		
	Yes / No		
	Yes / No		

When form is complete fax immediately with the CR0008 Clinical Alert Notification/Cancellation form to the Clinical Record Department for scanning and place file original into patient's clinical notes. ☐

Copy of EOL plan sent to GP ☐

Copy of EOL plan given to family ☐

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XV Word count

The text of this paper (excluding cover page, contents, abstract, non-substantive footnotes, appendices and bibliography) comprises approximately 7,994 words.

XVI Bibliography

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