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ADVANCE EUTHANASIA DIRECTIVES, HELPFUL OR HARMFUL?

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Abstract

This paper carefully considers whether advance euthanasia directives (AEDs) should be permitted under the current legislative framework in New Zealand. After contemplating various arguments that support and oppose AED usage, such as the "then-self" versus the "now-self", elder abuse, and the legislative purpose(s) of the End of Life Choice Act (EOLCA) 2019, this paper concludes that the two sides of the debate may be largely reconciled if various safeguards are put into place.

Therefore, the section in the EOLCA prohibiting advance requests for euthanasia should be repealed, and replaced with two new sections which permit AED usage within limited circumstances and where strict requirements have been met. This paper proposes two draft sections which incorporate various new safeguards, such as requiring both a doctor and a legal professional to be involved during the creation of an AED, the inclusion of a statement of values in every directive, as well as certain formality requirements. It is suggested that when these legislative changes are in place, AED usage would safely uphold the purpose(s) enshrined within the EOLCA by enhancing the autonomy of incompetent patients and reducing their suffering, and should thus be permitted.

Keywords: *"Euthanasia", "Advance Directives", "Advance Euthanasia Directives", "Legislative Reform".*

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Subjects and Topics

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I Introduction

Refining the law on euthanasia requires care and critical thinking given the sanctity of human life and the potentially dangerous consequences for vague or ill-informed laws on the topic. In passing New Zealand's euthanasia law which is found in the End of Life Choice Act 2019 (EOLCA), many Members of Parliament stressed that one life lost due to uncertain euthanasia laws or lack of safeguards is one life too many.[1]

This essay argues that the same level of care must be applied when considering whether New Zealand should permit the current euthanasia legislation to extend to the use of advance directives and whether non-competent persons should be permitted to have their lives ended, or be assisted to end their lives in certain circumstances when it is their clear desire to do so.

Through carefully analysing the potential benefits and detriments of utilising advance euthanasia directives (AEDs) in New Zealand, this paper concludes AEDs should be permitted under the current legislative framework within limited circumstances and where various safeguards are in place. Permitting AED use is to uphold the purpose(s) of the EOLCA of enhancing patient autonomy and reducing suffering. This conclusion was reached by considering the current New Zealand law on euthanasia, focusing on the legislative purpose(s) of the EOLCA and issues relating to the "now-self" versus the "then-self", elder abuse, various case studies, as well as drafting two amendments to the EOLCA.

A Defining Types of Euthanasia

"Euthanasia" is derived from the Greek words of "eu" (good) and "thanatos" (death),[2] which depict the absence of severe suffering in death, thus a good death.[3] One type of this good death is active/positive euthanasia, which involves intentional act(s) that directly cause death with the object of eliminating suffering by assisting the dying person

[1] (31 July 2019) 739 (End of Life Choice Bill – In Committee, Part One, Jo Hayes).
[2] "Euthanasia" School of Medicine, University of Missouri <https://medicine.missouri.edu>.
[3] Karin Dufault "Active vs Passive Euthanasia – Where's the Distinction?" (1985) 41 AORN 1090 at 1090.

to end their life, or for a third party to cause their death.[4] Passive/negative euthanasia is characterised by either withdrawing treatment or an omission to act which indirectly brings about death, such as withholding treatment.[5] Both active and passive euthanasia may be brought about voluntarily or involuntarily.[6] Passive euthanasia arises where a patient has refused consent to treatment, or has withdrawn their prior consent to treatment.

This paper deals only with the case of voluntary, active euthanasia. This is because passive euthanasia is already permitted in New Zealand as patients may use advance directives to deny future treatment when they lose competency,[7] and the EOLCA relates to the direct administration of medication by a medical or nurse practitioner to hasten death, or the self-administration of such medication.[8]

B Defining Advance Directives and Enduring Powers of Attorney

Advance directives aid healthcare decisions when the "ravages of illness, disease, or injury have taken the ability to decide for oneself".[9] They allow medical professionals to consult the patient's prior wishes. The purpose behind these directives is to enhance patient autonomy.[10]

An advance directive is a written document which outlines the patient's wishes regarding future treatment should they become incompetent, and it can be made at any time. Similarly, an attorney with an enduring power assists with medical decision-making at

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[4] At 1090.
[5] At 1090.
[6] Robert Ho "Assessing Attitudes Towards Euthanasia: An Analysis of the Sub Categorical Approach to Right to Die Issues" (1998) 25 Pers Individ Differ 719 at 720.
[7] Pauline Wareham and others "Advance Directives: the New Zealand Context" (2005) 12 Nurs Ethics 349 at 349; and Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996, Schedule, cl 2, right 7(7).
[8] Section 4 definition of "assisted dying", paras (a) and (b).
[9] Robert Olick "Defining Features of Advance Directives in Law and Clinical Practice" (2012) 141 Chest 232 at 232.
[10] Roberto Adorno, Nikola Biller-Andorno and Susanne Brauer "Advance Health Care Directives: Towards a Coordinate European Policy?" (2009) 16 Eur J Health Law 207 at 208.

the end of life. The attorney is a person whom the patient has expressly nominated to make healthcare decisions on their behalf when they become incompetent.[11]

II Why This Issue is Important

This issue is important as the world's population is rapidly aging. It is estimated that by 2040 the amount of people older than 85 years old will almost be quadruple what it was in 2000.[12] In New Zealand, the older population is growing more rapidly than the younger population.[13] These statistics are relevant as older generations are more likely to face illnesses such as dementia which can cause incompetency. This is evidenced by statistics which note that approximately 70,000 kiwis currently live with dementia. By 2050 this number is expected to increase to 170,000.[14]

Research must be conducted to determine how to best care for patients who are facing terminal illnesses. Are competent individuals entitled to choose that their future incompetent selves be euthanised or assisted in euthanasia?

III Current New Zealand Law

A End of Life Choice Act (EOLCA) 2019

The EOLCA specifies various requirements to qualify for euthanasia. The key requirements are: the patient must be aged 18 or over, a New Zealand citizen or permanent resident, suffering from a terminal illness that is likely to end their life within six months,[15] experiencing *unbearable suffering* that "cannot be relieved in a manner that the person considers tolerable",[16] as well as being in "an advanced state of irreversible decline in physical capability".[17] The most relevant criterion for our purposes is the

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[11] Adorno, Biller-Andorno and Brauer, above n 10, at 208; and Protection of Personal and Property Rights 1988, Part 9.
[12] Paul Menzel and Bonnie Steinbock "Advance Directives, Dementia, and Physician-Assisted Death" (2013) 41 JLME 484 at 484.
[13] Stats NZ "National Population Projections: 2020(base)-2073" (8 December 2020) <www.stats.govt.nz>.
[14] Alzheimer's New Zealand "Facts and Figures" <https://alzheimers.org.nz>.
[15] End of Life Choice Act 2019, s 5(1)(a)-(b).
[16] Section 5(1)(e).
[17] Section 5(1)(d).

necessity of contemporaneous competency, as advance directives apply when the patient is no longer competent.[18] Competency is established when the patient can adequately understand, retain, and weigh information relating to the nature of assisted dying so far as necessary to make their decision, and is able to communicate their decision in some way.[19]

Two doctors are required to determine eligibility for assisted dying. The first opinion is given by the attending medical practitioner.[20] If they conclude the patient is eligible, a second opinion must be given by an *independent* medical practitioner.[21] If either (or both) decide competence is not established, they must obtain a third opinion by a psychiatrist as to competency.[22]

Section 33 of the Act expressly excludes AEDs, noting that an advance request will be invalid.[23] This paper seeks to challenge this section.

B New Zealand Code of Health and Disability Services Consumers' Rights 1996

The New Zealand Code of Health and Disability Services Consumers' Rights (the Code) sets out the right to make and use an advance directive in accordance with the common law.[24] Currently, individuals may write advance directives entirely by themselves. However, it is more likely to be honoured if it is made with a health worker, written, dated, signed, and regularly updated.[25] For an advance directive to be valid, at the time of writing the directive the individual must have been competent, free from undue influence, and adequately informed.[26]

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[18] Section 5(1)(f).
[19] Section 6(a)-(d).
[20] Section 13(2)(a)-(c).
[21] Section 14(1)-(4).
[22] Section 15(2)-(3).
[23] Section 33(1)-(3).
[24] Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations, Schedule, cl 2, right 7(7).
[25] "Advance Directives and Enduring Powers of Attorney" <www.hdc.org.nz>.
[26] Phillipa J Malpas "Advance Directives and Older People: Ethical Challenges in the Promotion of Advance Directives in New Zealand" (2011) 37 J Med Ethics 285 at 286.

C Protection of Personal Property Rights Act (PPPRA) 1988

The PPPRA allows a person (the donor) to appoint another as attorney under an enduring power. Section 94(2)(a) outlines that, when the donor lacks capacity to make or understand decisions relating to their personal care and welfare,[27] or is unable to "foresee the consequences of decisions about matters relating to his or her personal care and welfare or of any failure to make such decisions",[28] then the attorney can make healthcare decisions on the donor's behalf. Importantly, attorneys are subject to limitations outlined in the PPPRA. For example, attorneys cannot refuse consent to life saving treatments, or treatment which would prevent serious damage to the donor's health,[29] and are unable to request assisted dying on the donor's behalf.[30]

IV Purpose of the End of Life Choice Act 2019

To understand whether the EOLCA can encompass a situation involving AEDs, a purposive approach may be taken. There are various principles underlying the Act, the most relevant ones being alleviation of suffering and patient autonomy.

A Alleviation of Suffering and Patient Autonomy

When the EOLCA Bill was passing through Parliament, David Seymour MP (the Bill's sponsor) stated:[31]

> It is wrong… …[that] we tolerate a status quo where people suffer needlessly. We allow under our laws violent amateur suicide, barbaric suffering, and informal euthanasia, all perfectly legal, but the choice that we don't allow is the person in question who is suffering at the end of their life to make a choice, make their choice, safeguarded under the rule of law.

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[27] Section 94(2)(a)(i)-(ii).
[28] Section 94(2)(a)(iii).
[29] Section 18(1)(c).
[30] Section 18(1)(g).
[31] (13 December 2017) 726 (End of Life Choice Bill – First Reading, David Seymour).

The Act's purpose is to alleviate the pain of those suffering from a terminal illness. It intends to give the option to avoid a brutal finish to their lives, and to allow patients to choose. The EOLCA stands for patient autonomy, preventing "suffer[ing] until the bitter end, writhing in a body that lives on but gives no comfort",[32] when palliative care is not capable of providing adequate relief.[33]

The principle of autonomy outlines that each individual has the right to make their own decisions. The choice of when and how they die is not an exception, and preventing euthanasia would limit autonomy.[34]

V When an Advance Euthanasia Directive May Arise

AED usage arises when a person is incompetent and unable to make healthcare decisions for themselves. This can occur when individuals become permanently unconscious, such as the case of someone in a persistent vegetative state (PVS) or who is unconscious due to post-coma unresponsiveness (PCU). AEDs can arise where incompetent patients lose psychological connectedness in the case of dementia but remain conscious.[35] These people may be suffering immensely, "pleasantly demented",[36] or relatively neutral in disposition. Additionally, the case of terminal cancer may also lead to such suffering and incompetence as to employ an AED.[37] This paper does not consider mental illness as these individuals are excluded under the EOLCA.[38]

Dementia involves different levels of various cognitive deteriorations which cause memory loss. AEDs within a dementia context can be difficult to apply, given the

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[32] Above n 31.
[33] Above n 31, Chris Bishop.
[34] Sarah Mathieson "Live and Let Die: The Legalisation of Euthanasia in New Zealand" (LLB (Hons) Dissertation, University of Otago, October 2008).
[35] Leslie Francis "Advance Directives for Voluntary Euthanasia: a Volatile Combination?" (1993) 18 J Med Philos 297 at 305.
[36] Helga Kuhse "Some Reflections on the Problem of Advance Directives, Personhood and Personal Identity" in David Thomasma, David Weisstub and Christian Herve (eds.) *Personhood and Healthcare* (Kluwer Academic Publishers, 2001) 265 at 268.
[37] Francis, above n 35, at 307.
[38] Section 5(2)(a).

progressive nature of the disease and its various outcomes. Dementia ranges from ‘mild’ to ‘very severe’, the former encompassing shortfalls in the patient’s daily functioning, the latter including loss of psychomotor skills, verbal ability, and an inability to recognise people they once knew and cared for.[39]

Instances of terminal cancer or permanent unconsciousness are arguably more straightforward, as it can be easier to discern when a (well-articulated) advance directive is intended to apply as these contexts do not typically lead to the drastic personality change which can permeate dementia.[40]

VI Arguments Supporting Advance Euthanasia Directive Use

This paper will now put forward arguments in support of AEDs, namely Dworkin, Menzel and Steinbock’s arguments in relation to the now (incompetent) self, and the then (competent) self, focusing on the concept of patient autonomy, which is in line with purpose of the EOLCA. Also analysed is Kuhse’s assertion that the now-self is no longer a person, the argument that there is no real moral distinction between active and passive euthanasia, as well as various case studies.

A AED Use is Consistent with the EOLCA’s Purpose

Upholding patient autonomy is the at the core of the EOLCA. Therefore, we should not exclude individuals from having their autonomy upheld due to incompetence. Requiring competence at the time of euthanasia excludes incompetent persons who suffer from terminal illness(es), are victims of unbearable suffering and who have expressed their desires for euthanasia in advance.[41] This exclusion is contrary to the Act’s purpose as the desire to relieve unbearable suffering is not limited to competent persons alone.

AED use would properly uphold the EOLCA’s legislative purpose by honouring the wishes of those who would otherwise meet the Act’s criteria. Some submissions on the

[39] Menzel and Steinbock, above n 12, at 486.
[40] At 486.
[41] At 484.

Bill expressed a similar view by stating that AED use would positively contribute to upholding autonomy and choice.[42]

B *The Now-Self Versus the Then-Self*

The most controversial issue requiring resolution is the question of whose autonomy we must uphold. Is it the autonomy of the then-competent patient, or the now-incompetent patient who may display contrary interests? Dworkin argues it is the autonomy of the formerly competent patient that must be upheld.[43] The basis of his argument is formed upon the distinction between critical interests and experiential interests.

Critical interests on Dworkin's view are grounded in "character, convictions, and the value one sees in one's life as a whole",[44] whereas experiential interests concern "the quality of the person's experience, her state of mind".[45] He asserts critical interests are the crucial consideration as it is these interests that make us who we are,[46] and should therefore be prioritised.[47] Dworkin believes, a patient with Alzheimer's disease for example may be able to experience experiential interests, but they are unable to create new critical interests as they do not have a sense of their life in its entirety.[48] Due to their inability to create critical interests, the incompetent person retains the critical interests of their formerly competent self.[49] Dworkin sees the competent and incompetent patient as being the same person, despite any personality changes occurring due to the terminal illness.[50]

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[42] Justice Committee *End of Life Choice Bill* (9 April 2019) at 26.
[43] Rebecca Dresser "Dworkin on Dementia Elegant Theory, Questionable Policy" (1995) 25 Hastings Cent Rep 32 at 33.
[44] Menzel and Steinbock, above n 12, at 491.
[45] Agnieszka Jaworska "Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value" (1999) 28 Philos Public Aff 105 at 110.
[46] Kuhse, above n 36, at 270.
[47] Dresser, above n 43, at 33; and; Menzel and Steinbock, above n 12, at 490.
[48] Jaworska, above n 45, at 113.
[49] At 111.
[50] Dresser, above n 43, at 35.

On this view, prioritising a patient's experiential interests over their critical ones expressed in their AED would violate their autonomy, as that person had decided under what circumstances they wanted to live, and detailed it as such in their AED. [51] It is through this distinction between interests that it can be concluded that it is in an incompetent patient's best interest to uphold their AED, as "making someone die in a way that others approve, but he [or she] believes a horrifying contradiction of his life, is a devastating, odious form of tyranny".[52]

The earlier self may strongly desire to not live on in a suffering, demented state for various reasons. For example, if a person strongly values independence, being forced to live in a state of co-dependence may cause them unbearable suffering. Dworkin would consider such continued living as contrary to their critical interests, and thus a violation of autonomy.

Menzel and Steinbock echo this view by outlining that experiential interests in dementia, even if contrary to critical interests that are no longer being outwardly expressed, does not conclusively mean that the patient has altered their view about the value their life would have while demented. It is on this basis they believe the demented patient retains their competent self's critical interests. We should therefore uphold the desires expressed in their AED to honour their ability to choose.[53] This argument could not apply in New Zealand as patients must be suffering unbearably to qualify for assisted dying. Therefore, where their experiential and critical interests conflict, the patient is likely not suffering unbearably.[54]

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[51] Menzel and Steinbock, above n 12, at 490.
[52] At 490.
[53] At 491.
[54] End of Life Choice Act, s 5(1)(e).

C The Now-Self is No Longer a Person

Kuhse contends that, when there is a lack of memories, intentions, beliefs, and/or desires in the now- compared to the then- self, this suggests lack of connection between the two persons. Therefore, we can conclude that they are two different people.[55]

This assertion requires considering whether competent person A is entitled to make decisions for incompetent person B who are two different persons in an AED context. To answer this, Kuhse puts forward the reasoning of Tooley and concludes that the incompetent self is not a person at all. Therefore, it is permissible. She asserts that to be considered a person, and as having a right to life you must possess the faculties to see yourself existing over time.[56] Someone suffering with severe dementia, or who is permanently unconscious would not meet this criterion. On this reasoning, it is not morally wrong to cause that later human to die at their prior request, as they no longer have an interest in continuing to live.[57]

The above argument can be critiqued as a weak one in regards to supporting AED use within a *safe* context. To a degree, it implies that it is okay to provide the lethal injection to any person who loses the ability to see themselves as existing over time, even without an AED. Further, the views of Dworkin and Kuhse do not appear to allow for a genuine change in mind once the patient has been rendered incompetent. This is not something that is likely to be supported in New Zealand due to the emphasis on the importance of the sanctity of life within a euthanasia context, as well as the focus on autonomy.

D No Real Moral Distinction Between Active and Passive Euthanasia

Another argument advanced in favour of advance euthanasia directives is the idea that there is no real moral distinction between active and passive euthanasia. The underlying rationale for allowing passive but not active euthanasia is typically found in the cause of death. If we administer a lethal injection, the contents of the injection causes the death,

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[55] Kuhse, above n 36, at 270.
[56] At 275.
[57] At 276.

whereas if we do nothing or use palliative care, the underlying disease will be the cause.[58] It is therefore suggested that allowing a patient to die is morally permissible, whereas killing them is not.

Some argue that this is not sufficient to justify a moral difference. Where a doctor allows a patient to die, or administers a lethal injection to speed up the dying process and does either act with the positive intention of relieving suffering, the moral position in both instances is arguably the same.[59] Further, in New Zealand we permit treatment withdrawal and palliative care, which are both just as much of a positive act as administering a lethal injection is.[60]

When this issue is looked at from the context of the aims of euthanasia, that is to promote a *good* death, it is suggested that the most painless death best achieves this goal. Withdrawal or withholding of treatment can elicit a slow and painful death, whereas the lethal injection is likely to achieve a faster and less painful death than other alternatives.[61]

E AEDs as a Protection Against Lying Family Members

Written AEDs also serve as a way to mitigate one of the arguments against them, being the risk of elder abuse and undue influence (this is discussed in more detail later in this paper). This is because when an AED is written clearly and has requisite specificity as to the circumstances it is intended to be invoked in, it may serve as a long-lasting extension of the patient, and can greatly assist healthcare professionals when making end of life decisions.

Without the protection of an AED family members may make decisions that may not be in the patient's best interests. Given the prevalence of financial and psychological elder

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[58] Dufault, above n 3, at 1090.
[59] Nancy Jecker, Albert Jonsen and Robert Pearlman *Bioethics: An Introduction to the History, Methods, and Practice* (2nd ed, Jones and Bartlett Publishers, Massachusetts, 1997) at 67.
[60] Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations, Schedule, cl 2, right 7(7).
[61] Jecker, Jonsen and Pearlman, above n 59, at 65.

abuse in New Zealand, it is essential to prevent family members from making decisions relating to euthanasia on a patient's behalf without healthcare professionals being assured that the patient would have echoed those preferences.

A valid AED puts the patient's values at the centre of the discussion. Once an AED has been made, and safeguards to prevent undue influence within its creation have been followed, the opportunity for family members to make decisions with their own interests in mind is lessened. This paper proposes safeguards to minimise AED risks in Part 9 as the current code on advance directives is too vague.

F Successful Case Studies

Lastly, there are situations where AEDs have been successfully implemented and yielded positive results. In the Netherlands, there was a 64 year old woman who had been diagnosed with dementia. Before the dementia, she wrote an advance directive which requested active euthanasia instead of being required to live in a nursing home. Despite consequential memory loss, she reiterated this request whenever she saw her doctor. Additionally, she was visibly suffering as it was noted she frequently cried, was often angry and confused. In this situation the physician deemed it appropriate to administer the lethal injection, honouring her autonomy. It was emphasised in this instance that the doctor had not strayed from the due care requirements in Dutch law.[62] It is important to note there is no 6 month prognosis requirement in the Netherlands for euthanasia.[63]

Another instance of success involves a Netherlands case where an AED helped a patient who had suffered a stroke which lead to speech and functioning disabilities, as well as dementia, recall her prior wishes. The patient retained her executive functioning, although slightly impaired, which is an important component of decision-making. Under these circumstances she was able to repeatedly reiterate her desire to die after recognising

[62] Menzel and Steinbock, above n 12, at 486.
[63] Theo Boer "Euthanasia and Addiction: A Comment from the Netherlands" (2017) 113 J Addict 1184 at 1184.

her previous wishes in her AED. It was through these discussions that the physician was able honour her AED.[64]

VII Arguments Against Advance Euthanasia Directive Use

Despite many arguments in favour of AEDs, there are also compelling arguments to the contrary. Dresser and Jaworska oppose AED use due to their views on the now- and then-self, which are contrary to Dworkin's as outlined above. Further, AEDs may limit patient freedom by tying them to their past decisions, are at risk of bias due to lack of foresight into the future, and may create risk for elder abuse and undue influence in their preparation and execution. Additionally, in New Zealand it is crucial to consider a tikanga perspective where dying is considered "a process of whānau".[65] There are also case studies that have yielded detrimental results.

A The Now-Self Versus the Then-Self

Dresser believes that where prior wishes expressed in an AED are contrary to the current desires of the patient (experiential or otherwise) they should not be considered. This is because the person when incompetent is not always the same person as they were when competent due to psychological changes or perhaps memory loss.[66] Caregivers should honour the wishes that the patient currently expresses, even where these wishes are contrary to their formerly expressed critical interests. [67]

She criticises Dworkin's differentiation between experiential and critical interests in the context of dementia. Dresser states that the patient's experiential interests should be prioritised because, where someone remains contented in circumstances which contradict

[64] C M P M Hertogh "The Role of Advance Euthanasia Directives as an Aid to Communication and Shared Decision-Making in Dementia" (2009) 35 J Med Ethics 100 at 102.
[65] (13 December 2017) 726 (End of Life Choice Bill – First Reading, Nuk Korako).
[66] Dresser, above n 43, at 35.
[67] Jaworksa, above n 45, at 108.

their critical interests contained in their AED, it would harm that individual to execute their directive.[68]

Similarly, Jaworska wants the needs of the incompetent patient to be considered. Dworkin assumes the now-self is incapable of creating new critical interests and that autonomy is based on decision-making capacity, whereas Jaworska asserts that the now-self can retain autonomy when they can *value* and thus have an interest in continued life, as they can live in accordance with such values.[69] The ability to value is present where a person believes their wants are correct, acquiring these wants is linked to that person's self-worth, and this is independent from their own experience.[70] It is evident that Jaworska interprets Dworkin's term "critical interests" as referring to the things that that person values.

In dementia, the hippocampus tends to be impacted first, which is the brain region which relates to memory. Jaworska argues it is only when other brain regions that relate to reasoning and decision-making are impacted later in dementia that this ability to value can become impaired.[71]

Jaworska also believes incompetent patients are capable of being autonomous. Autonomy does not require independence, and getting assistance in living according to their values does not diminish a person's autonomy.[72]

Therefore, where these other brain regions remain intact and the patient has capacity to value, there is no reason to prioritise the values they expressed in their AED over the ones they appreciate now, even if they need assistance in carrying them out.[73] Although the

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[68] Dresser, above n 43, at 36.
[69] Jaworksa, above n 45, at 109.
[70] At 116.
[71] At 121-122.
[72] At 126.
[73] At 125.

patient lacks legal capacity, Jaworska contends that they can still exercise some autonomy.

B Advance Directives Limit Patient Freedom

Arguably, AEDs are detrimental as they limit patient freedom by tying individuals to past decisions. There is considerable fear that once incompetent, patients will not be permitted to change their mind and they will be bound by the choices of their previous self.[74]

However, this argument is persuasive only to the extent that a patient is unable to express a change in mind. This is because, if there is a genuine change of mind, say perhaps a patient retains the capacity to value and their expressed values no longer align with their AED, we should not bind them to previous desires (according to Jaworska's view, not Dworkin's). The EOLCA requires a patient to be suffering unbearably in order to qualify.[75] If an incompetent patient has changed their mind about wanting euthanasia they are arguably not suffering unbearably as they have retained their desire to live.

In the context of late-stage dementia it may become difficult to discern a change of mind due to the degeneration of speech and motor skills. Discussed below in Part 9 are some safeguards that would allow a doctor to notice a change of mind, such as the inclusion of a personal statement of values into an advance directive, as well as requirements to keep the directive up to date.

C Lack of Foresight into The Future

Another hurdle to overcome when it comes to considering the use of AEDs is our inability to predict the future. Studies demonstrate the presence of a disability bias in the majority of people, whereby participants rated being disabled as significantly worse than

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[74] Marta Spranzi and Veronique Fournier "The Near-Failure of Advance Directives: Why They Should Not be Abandoned Altogether, but their Roles Radically Reconsidered" (2016) 19 Med Health Care Philos 563 at 565.
[75] Section 5(1)(e).

those who actually live with a disability consider it to be.[76] A person is unlikely to accurately predict how they would feel in the circumstances outlined in their AED.

Additionally, people adapt very well to different conditions. For some, it may seem that receiving euthanasia should they become seriously terminally ill and incompetent is something that their future self would desire, but find that when they are in that situation they adapt well and are able to retain their happiness without suffering in the way they anticipated.[77]

It is important to note that some of the bias against certain illnesses can be attributed to a lack of education on the illness itself, and ignorance of the ability to adapt to new situations.[78] Thus, increasing education on the topic of adaptation and better informing people of what the illness may entail could prevent ignorant AEDs from being made and implemented.

D Elder Abuse in New Zealand

The biggest concern in relation to the use of AEDs pertains to the risk of elder abuse. Elder abuse is a pervasive issue in New Zealand, the most common forms being financial and psychological abuse, and the most frequent perpetrators being family members.[79] This is concerning given that when someone dies their assets are commonly distributed among family members, thus putting the elderly in a vulnerable situation when it comes to creating and implementing AEDs.

There were many submissions to the Select Committee which did not support the End of Life Choice Bill on this basis.[80] Concerns were also raised in Parliament about the right to die becoming a *duty* to die for these vulnerable individuals.[81]

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[76] Jonathan Wolf "Dementia, Death, and Advance Directives" (2012) 7 Health Econ Policy Law 499 at 503.
[77] Menzel and Steinbock, above n 12, at 487.
[78] At 487.
[79] "Elder Abuse 'Rampant' in New Zealand" Nursing New Zealand (2017) 23 8 at 8.
[80] Justice Committee, above n 42, at 12.
[81] (26 June 2019) 739 (End of Life Choice Bill – Second Reading, Maggie Barry).

The possibility of elder abuse is a reason to object to AED use due to the risk of people influencing their elderly relatives to request euthanasia. Such influencing may be motivated by family members not wanting to incur palliative care or rest home costs if they stand to benefit from the death of the person.

If an AED is not the autonomous decision of the patient it should be rendered invalid, as it is contrary to the ideas which justify active euthanasia.[82] Cressida Auckland asserts that a base level of autonomy demands that the decision made is free from coercion.[83] Without appropriate safeguards, there is no way of determining whether an AED was created due to undue influence as the patient will be incompetent during the circumstances where the directive arises. Therefore permitting AEDs under circumstances that may permit elder abuse and coercion should not be allowed.[84]

E Tikanga

Additionally, any consideration of law reform requires that tikanga Māori also be considered. The Māori perspective asserts:[85]

> We bring people into this world. We care for them right from the time they are conceived, born, bred, in health, sickness, and death. The rituals still exist for every part of their lives.

Each step of this process, including death, is a whānau process.[86] The EOLCA and the current law underpinning advance directives presently undermines tikanga, as there is no family consultation requirement.

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[82] Cressida Auckland "Protecting Me from My Directive: Ensuring Appropriate Safeguards for Advance Directives in Dementia" (2018) 26 Med L Rev 73 at 76.
[83] At 76.
[84] (31 July 2019) 739 (End of Life Choice Bill – In Committee, Part One, Jo Hayes).
[85] (13 December 2017) 726 (End of Life Choice Bill – First Reading, Nuk Korako).
[86] Above n 85.

Permitting AEDs would allow individuals to make future decisions about their life which may prevent family members from taking care of them in death and in dying, or fail to incorporate their whānau into the decision-making process. Therefore, these collective relationships which are fundamental to tikanga Māori would be further ignored if AEDs were allowed under the current law.[87]

F Unsuccessful/Harmful Case Study

Lastly it is crucial to consider cases where AEDs resulted in harmful outcomes for those involved. Poorly written advance directives pertaining to a request for active euthanasia coupled with negative actions on the part of the physician unfortunately caused extreme harm to Mrs A and her family.

Mrs A had written two AEDs, the first being written shortly after her initial Alzheimer's diagnosis and the second 3 years later. In essence, Mrs A's first request expressed a desire for euthanasia in circumstances where she is still competent enough to request it herself, and when she is required to live at a rest home. [88]

Her second AED requested euthanasia "… whenever I think the time is right for this",[89] and "when the quality of my life has become so poor".[90] It is evident that her two AEDs are contradictory, the second request in part revoking the first one. It can also be noted here that there were doubts about the level of her competency at the time this second request was written.[91]

Eventually Mrs A was admitted into a nursing home and it was said that she appeared very unhappy for the most part while she was there, particularly after her husband's visits

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[87] Joseph Williams *Lex Aotearoa: An Heroic Attempt to Map the Maori Dimension in Modern NZ* Law (Waikato Law Review, 2013) at 23.
[88] David Miller, Rebecca Dresser and Scott Kim "Advance Euthanasia Directives: a Controversial Case and its Ethical Implications" (2019) 45 J Med Ethics 84 at 84.
[89] At 84.
[90] At 84.
[91] Jonathan Hughes "Advance Euthanasia Directives and the Dutch Prosecution" (2021) 47 J Med Ethics 253 at 253.

ended.[92] On this basis, her physician decided to execute her AED. The geriatrician sedated Mrs A without her knowledge, and then began to administer the lethal dose. In the middle of the process Mrs A sat up and her family restrained her while the rest of the dose was administered seemingly against her will.[93]

The Netherlands Regional Review Committee held that Mrs A's AED was too vague, and that Mrs A exhibited signs of potential resistance. Despite this, the doctor was acquitted by the criminal court of wrongdoing because it was clear Mrs A was suffering and she was also unable to consent due to her incompetency.[94]

VIII Should Advance Euthanasia Directives Be Allowed?

There are strong arguments both for and against AEDs. Arguably, the two sides of the debate may be largely reconciled through the use of appropriate safeguards in both the creation and execution of such directives.

The views of Jaworksa and Dresser are that AEDs should only be permitted in certain circumstances. For example, Jaworska disagreed with AED use only where the suffering person no longer has the capacity to value their life, and Dresser explicitly stated that directives should influence outcomes only where the patient's critical and experiential interests do not conflict.[95] The majority of arguments in the literature are against AED use in the case of the pleasantly demented person, or where someone is still enjoying life. This opposition is in line with the current New Zealand legislation, as the patient must be suffering unbearably to be eligible.[96] This means that an advance directive would not apply where the patient is not suffering, and is displaying a continued desire to live.

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[92] Miller, Dresser and Kim, above n 88, at 85.
[93] At 85.
[94] Hughes, above n 91, at 253.
[95] Dresser, above n 43, at 37.
[96] End of Life Choice Act, s 5(1)(e).

In terms of AEDs limiting patient freedom, it could be said that a change in mind would result in a conflict between experiential and critical interests whereby the patient would not be visibly suffering and denying euthanasia. Therefore in New Zealand active euthanasia could not be permitted under these circumstances.

While AEDs have associated risks, it is arguable that such risks can be mitigated through the use of safeguards. The following reform suggestions are aimed to ensure that those who create AEDs are competent, well-informed on the matters contained in their directives, and are free from undue influence in order to ensure the directive enshrines the patient's autonomous choice.[97]

IX Safeguards Required

A Involvement of Doctors and Lawyers

Both a doctor and a lawyer must be directly involved in the creation of the AED. Currently, the EOLCA requires that the person must understand information relating to assisted dying, retain the information, be able to weigh information when making their decision as well as be able to communicate their final choice.[98] The requirements this paper suggests go beyond the current safeguards contained in both the EOLCA and the Code as outlined above in Part 3.

For AEDs, the EOLCA requirement should be extended to require that the patient is also able to understand the nature of the terminal illness their directive requests euthanasia for, the relevant stages and possible symptoms, and understand the outcomes which may arise.[99] For example, if a person knows they are more likely to develop certain terminal illnesses due to a genetic predisposition, they may make an AED requesting euthanasia under certain circumstances should they receive that diagnosis. This person must also know about the nature and stages of that illness. This goal can be accomplished by increasing medical and legal professional involvement. For example, in Austria the

[97] Dresser, above n 43, at 34.
[98] Section 6(a)-(d).
[99] Auckland, above n 82, at 85.

author of the AED must seek legal and medical advice, where the doctors must detail the nature and consequences of the AED, as well as provide other possible courses of action to the patient. Additionally, the doctor must ensure the author has adequately understood the advice.[100]

This paper suggests a similar obligation, where a doctor must be present with the patient as they write their advance directive to inform the patient of all of the potential outcomes of their diagnosis, and ensure they understand the consequences. They can do this by testing patient understanding, encouraging the patient to ask questions, and by asking probing questions as to why the patient has included certain elements in their directive.[101] Further, the doctor must ensure the patient is well informed as to disability bias, as well as a human's ability to adapt to circumstances as discussed above. A lawyer must read over the completed advance directive with the patient to ensure sufficient clarity in the document. Lawyers can also help ensure that the directive was created autonomously and that the patient was competent to make the AED.

This requirement allows professionals to verify that the patient created their AED from a place of knowledge and understanding. This will protect against disability bias and ensure a degree of foresight into the future, as the patient will be in communication with an experienced doctor (ideally the patient's general practitioner) who is familiar with the nature of the illness(es) contained in the directive. This requirement is needed for any AED, whether it is created years in advance of receiving a 6-month prognosis or afterwards. This safeguard may also serve as a check on undue influence, as it would give the doctor the ability to learn about the patient's own views, and thus can aid in discerning whether the directive reflects their life values.

[100] At 86.
[101] At 86.

B Support Person for the Elderly

Supplementary Order Paper 321 suggested adding a clause into the EOLCA which would apply to elderly persons aged 65 and above. The suggested clause requires eligible elderly persons under the EOLCA to be offered support from an independent support person who "possesses in-depth knowledge of the cultures and practices within the community the vulnerable elderly person is from".[102] This clause would provide extra protection against those elderly persons who are prone to abuse and may be in a particularly vulnerable situation.

C Formality Requirements

Currently advance directives can be made without sufficient clarity and detail for doctors to be able to discern the patient's intentions. Therefore, this paper suggests AEDs must be in writing, signed, and dated to be considered valid. This is because instructions are clearer, and more likely to be taken seriously when written.[103]

Further, AEDs must be frequently updated to remain valid. Within the context of the EOLCA where a 6 month prognosis is required,[104] if the patient has already received that prognosis before writing their AED, their directive must be frequently revisited while they remain competent to ensure they have not changed their mind. If the AED was written well in advance of such a prognosis, the directive should be updated yearly. This is because an AED that is recent is more authoritative as it is more likely to be a reflection of that person's current values.[105]

AEDs must have requisite specificity to ensure the author's wishes have been properly set out to avoid it being executed in circumstances the patient did not intend. Therefore, AEDs must be written with such clarity and specificity that relevant medical

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[102] (21 August 2018) 740 (End of Life Choice Bill, — In Committee, Part Two, Alfred Ngaro).
[103] Auckland, above n 82, at 87.
[104] Section 5(1)(c).
[105] Auckland, above n 82, at 88.

professionals can accurately understand the patient's intentions.[106] Illnesses have various stages so it would be insufficient to note "I would like to receive euthanasia if I contract X illness". Lawyer consultation can assist in ensuring the directive has the specificity that such an important decision requires.

D Statement of Values

Within every directive a statement of values must be included.[107] This statement would describe the patient's critical values, such as the things that are important to them, why they want their life to end under certain circumstances, as well as how they self-identify.

Such a statement would assist the doctors in understanding who the patient is, and why they make the choices that they do. This will help medical professionals decide whether the lethal injection should be given under circumstances where there might be a slight degree of uncertainty. Perhaps a situation may arise where the patient is suffering unbearably, but the situation was not explicitly contemplated by the AED. The statement of values would aid medical professionals in determining whether that patient would desire euthanasia in that situation. It could also enhance the credibility of someone who is an attorney with an enduring power, whereby the attorney's healthcare choices on the patient's behalf echo those values as written.

More importantly, this would greatly help in the context of dementia when determining if the patient has undergone a personality change which would render their AED void. It would highlight whether a patient's critical and experiential interests are in conflict with each other, or whether (contrary to Dworkin's view) such critical interests had changed. This could be determined by comparing the patient's current disposition and apparent beliefs to those that are enshrined in the directive.

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[106] At 77.
[107] At 78.

E Introduction of a Pro Forma (Non-Statutory)

Additionally, an AED pro forma could be introduced so there is a standardised form for each type of disease. A pro forma could demonstrate different treatment options, various stages of the disease, and possible outcomes. This could allow patients to be more specific as to which stage of the illness and under what circumstances they want to receive euthanasia.[108]

An example of such a prescribed form was outlined by Cressida Auckland, where she noted the pro forma should describe when the AED should and should not be triggered, possible future events which may alter or void their AED, as well as a statement of values outlining the patient's character and values.[109] Additionally, this paper suggests that the assisted dying request form that is required under the EOLCA should also be a part of this pro forma so that patient can sign it in advance.[110] This request form would then become operational under the circumstances described in the AED.

Such a requirement in conjunction with doctor consultation would assist in educating people as to the nature of the disease they are requesting euthanasia for, and thus increase the likelihood of the AED being executed and therefore upholding patient autonomy.

F Due Care Principles from the Netherlands

Criterion one requires that "the physician must be convinced that the request of the patient was voluntary and well considered".[111] This criterion works well in conjunction with the EOLCA as the Act requires the attending physician to decline the euthanasia request where on reasonable grounds they suspect pressure from a third party.[112] This criterion would further add the requirement that the decision was a well-considered one, which is important given the patient's lack foresight into the future. It has been argued

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[108] At 90.
[109] At 90-91.
[110] Section 33(1).
[111] J J M Van Delden "The Unfeasibility of Requests for Euthanasia in Advance Directives" (2004) 30 J Med Ethics 447 at 448.
[112] Section 24.

that this criterion is unachievable in the Netherlands due to difficulties obtaining information from when the directive was written.[113] This requirement could be fulfilled in New Zealand where the AED was crafted while competent, and made with the relevant doctor(s) and legal professional(s) who provided education and documented the interaction.

G Introduction of a Family Consultation Requirement.

Adding a family requirement is one of the most important additions to the law. This is for various reasons, some tikanga related, others due to the fact that it is the family members who are left behind with the grief.[114] Further, given that tikanga forms part of the law of Aotearoa,[115] it is important to acknowledge it within the context of death where life is considered as a taonga.[116] Family consultation allows for the family to be let in on the patient's decision-making process, and gives them the opportunity to express their opinions. This requirement will not apply people who have no living family, or who are largely estranged from their family.

Family members need not agree on a directive to make it valid. This requirement merely provides the opportunity for family to discuss about the motives of such a decision, alternative options, and avoids the risk of patients being administered a lethal dose without their broader whānau knowing.

H Capacity Assessment

Competency is essential at the time the AED is created. This is because if the patient is not competent, it cannot be said that the requests within the AED are their autonomous decisions.[117] The test to be applied is what is currently outlined in the EOLCA for requisite capacity.[118]

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[113] Van Delden, above n 111, at 448.
[114] (31 July 2019) 739 (End of Life Choice Bill – In Committee, Part One, Poto Williams).
[115] *Ellis v R,* [2022] 1 NZLR 239, [2022] NZSC 114, 240-337, At 241.
[116] Justice Committee, above n 42, 19.
[117] Auckland, above n 82, at 81.
[118] Section 6(a)-(d).

I Attorneys Can Request Euthanasia With Prior Consent

Additionally, attorneys should be able to request euthanasia on behalf of the donor when the donor's consent is expressly contained in an AED. This is because it must be the direct choice of the donor to undergo euthanasia as the central purpose of euthanasia is preserving patient autonomy. It may be argued that the donor consented to any and all healthcare choices the attorney chooses to make, as the donor appointed the attorney for that purpose. This is not a strong argument as an attorney is at risk of making a choice that reflects their own values, not the donor's.[119]

With donor consent, the attorney would need to sign the euthanasia request form on the donor's behalf in order to fulfil the requirements under the EOLCA.[120]

J Not Legally Binding

Lastly, AEDs should not be held to be legally binding. This is because we want to give professionals the option to evaluate AEDs to avoid situations where a doctor may be forced to administer the lethal injection under circumstances where there may be uncertainty. AEDs should be considered to be persuasive where valid, and will be invalid unless all of the aforementioned requirements have been met.

As Dresser stated:[121]

> A policy of absolute adherence to AEDs means that we deny [people] the freedom we enjoy as competent people to change our decisions that conflict with our subsequent experiential interests.

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[119] Francis, above n 35, at 301.
[120] Section 33(1).
[121] Dresser, above n 43, at 35.

X Conclusion

In conclusion, s 33 of the EOLCA should be repealed and replaced with new provisions which permit AED usage where the above conditions have been met. To exclude AEDs prevents people from making their own autonomous decisions about what they would like their life to look like in death, thus undermining the purpose of the EOLCA. What follows next are draft provisions of what a new s 33 and an additional s 33A may look like after the above safeguards have been incorporated.

A Proposed New Sections

Section 33

(1) To the extent that any provision expressing a wish for assisted dying is included by the person in a written advance directive, that provision is invalid **except** as provided for in this section.

(2) Where the advance directive satisfies the criteria outlined in subsections (5)-(12), the directive is not binding on any medical practitioner acting under this Act.

(3) In exercising their discretion under this Act medical practitioners must consider:
   (a) The recency of the document; and
   (b) Whether the current circumstances were contemplated by the author of the directive when the directive was made or updated.

(4) An advance directive is valid and thus capable of being executed where the requirements set out in subsections (5)-(12) are satisfied.

(5) The advance directive must include a statement of values.

(6) The advance directive must comply with the following formality requirements—
   (a) It is in writing, signed, and dated; and
   (b) It is written with requisite specificity; and

(c) The directive has been updated yearly until the author was diagnosed with a terminal illness; and

(d) The directive has been frequently revisited after the author of the directive has been diagnosed with a terminal illness and remained competent.

(7) The author of the advance directive has consulted a medical doctor who—

(a) Was present when the advance directive was written; and

(b) Had explained the nature of the terminal illness outlined in the directive to the author, including:

(i) The relevant stages of the illness; and

(ii) The possible symptoms of the illness; and

(iii) The possible outcomes of the illness; and

(iv) Alternative care options to assisted dying; and

(c) Had explained to the author what a disability bias is; and

(d) Had informed the author that humans tend to adapt well to new circumstances; and

(e) Was satisfied that the author of the advance directive has comprehensively understood the information they have provided; and

(f) Was satisfied that the directive was created voluntarily and free from undue influence.

(8) The author of the directive has consulted a lawyer who was satisfied that—

(a) The wishes contained in the directive are conveyed with sufficient clarity; and

(b) The author of the directive has legal competence to write a valid directive; and

(c) The directive was created voluntarily by the author and free from undue influence; and

(d) The author of the directive was competent in accordance with section 6 at the time they wrote their directive.

(9) The author of the directive has discussed the contents of their advance directive with their family.[122]

(10) In addition to subsection (4) the author of the directive must sign and date the approved form referred to in section 12(3) (the request form) after they have written their advance directive and while they are still competent.

(11) If the author of the directive was aged 65 and above when writing the directive—

(a) They must have been offered the support from an independent support person during the creation of the directive; and

(b) The independent support person possessed in-depth knowledge of the cultures and practices within the community the person is from.

(12) Subsection (9) is not required where:

(a) The author of the directive had no living family at the time the advance directive was written; or

(b) The author of the directive was estranged from their family at the time the advance directive was written

(13) **A statement of values** is a statement which outlines a person's values such as:

(a) what they consider to be important to them; and

(b) why they would want to undergo euthanasia under the circumstances described in their advance directive; and

(c) what personal values informed their decision-making process.

(14) **Family includes—**

(a) Those whom the author of the directive genuinely considers to be a part of their family; and

[122] Note the term "whānau" has been deliberately omitted to avoid the threshold for a valid AED being too high, as whānau is very broad concept.

(b) Those family members whom the author of the directive considers would be harmed or impacted by the execution of their directive; or

(c) Those family members whom the author of the directive considers to have a real interest in discussing the contents of such a directive with them.

(15) **Advance directive includes—**

(a) A will; or

(b) A contract; or

(c) Any other document that satisfies the requirements of this section.

Section 33A

(1) An attorney with an enduring power may validly request assisted dying on behalf of the donor of an enduring power in the following circumstances—

(a) The donor has written an express clause into an advance directive giving their express consent for the attorney to make such a request on their behalf; and

(b) The relevant medical practitioners believe that the attorney's request is in line with the patient's best interests, with specific consideration to be given to the statement of values contained in the advance directive; and

(c) The advance directive complies with the requirements of section 33(4), except for section 33(3)(b) and (4)(c)(ii).

(2) Where the advance directive satisfies the criteria outlined in subsection (1), the directive is not binding on any medical practitioner acting under this Act.

B Subsequent Edits to the Current Legislation

Changes would also need to be made to existing legislation in order to ensure coherence with the proposed new law. Some examples of changes that are required for the EOLCA would include, altering s 5(1)(f) to exclude the contemporaneous competency requirement where the patient has an AED that complies with the new s 33, and adding the requirement to s 24 that the doctor must also be convinced that the request for

euthanasia was well-considered. Additionally, the old s 33(2) and (3) will need to be contained in a different section in the EOLCA, and be amended to permit AED usage. Lastly, s 18 of the PPPRA needs an additional subsection which allows an attorney to request assisted dying where ss 33A and 33 of the EOLCA are complied with.

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