Te Kāwanatanga o Aotearoa
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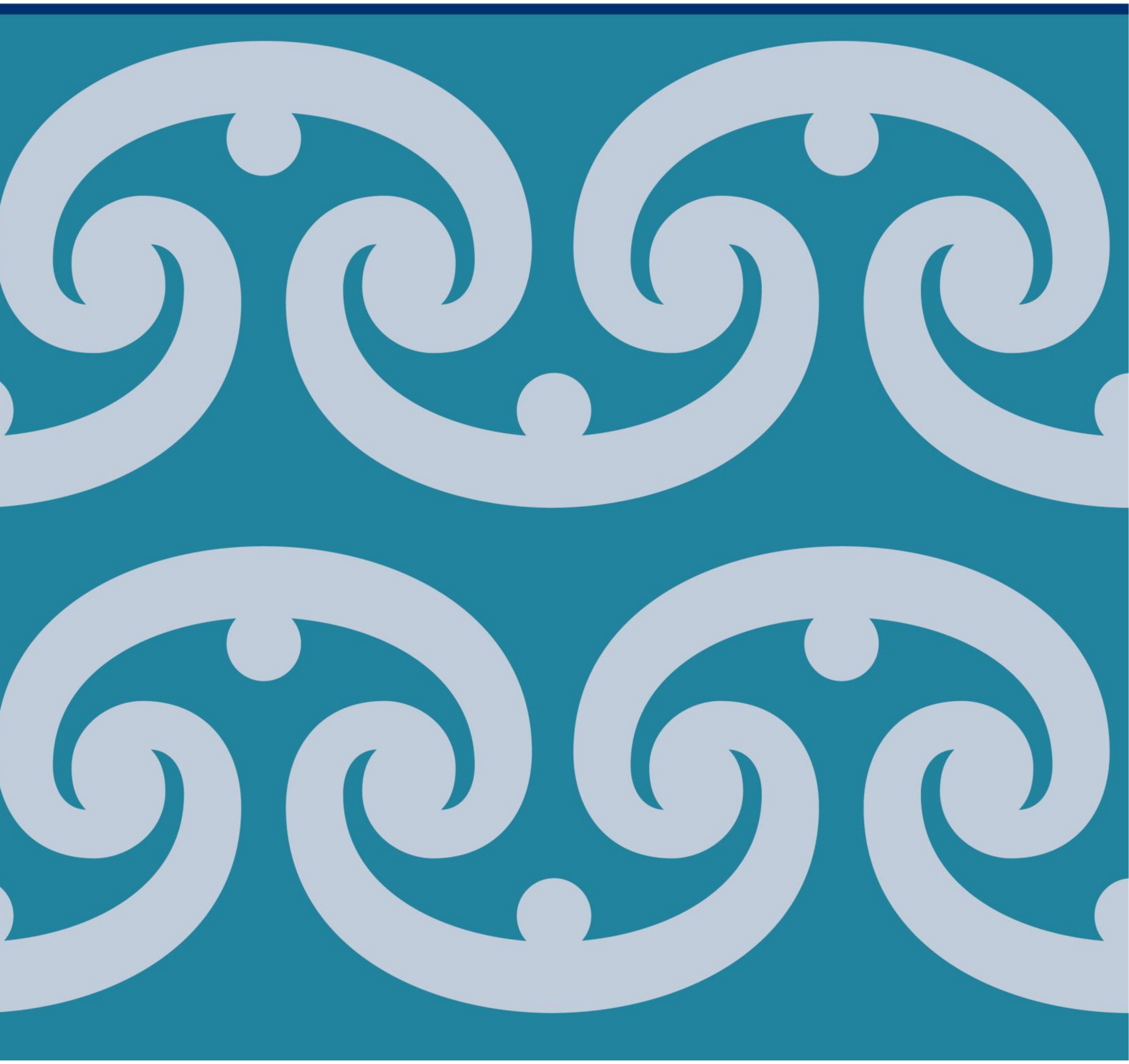
MINISTRY OF HEALTH
MANATŪ HAUORA

Summary of Online Submissions Received on the End of Life Choice Act 2019

2024



Summary of Online Submissions Received on the End of Life Choice Act 2019

2024

Presented to the House of Representatives
pursuant to section 30 of the End of Life Choice
Act 2019

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This report includes content that readers may find distressing, including detailed references to suffering at the end of life, and suicide.

Assisted dying is a sensitive topic and may be difficult for some people. Phone or text **1737** to speak with a counsellor anytime, for free.

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Contents

List of Tables

Glossary of terms

Term	Meaning
Attending medical practitioner	A person's primary practitioner who provides assisted dying services.
Attending nurse practitioner	A nurse practitioner who, under the instruction of an attending medical practitioner, may undertake the prescription and administration of assisted dying medication.
Assisted dying	The End of Life Choice Act sets out that assisted dying, in relation to a person, means: • the administration by an attending medical practitioner or an attending nurse practitioner of medication to the person to relieve the person's suffering by hastening death; or • the self-administration by the person of medication to relieve their suffering by hastening death.
Assisted Dying Secretariat (the Secretariat)	Part of the Regulatory Assurance team in the Ministry's Regulation and Monitoring – Te Pou Whakamaru directorate. The Secretariat supports statutory bodies established under the End of Life Choice Act, and has a regulatory and monitoring function to ensure compliance with the Act.
Assisted Dying Service	The service that delivers assisted dying in New Zealand. This service is provided by Health New Zealand – Te Whatu Ora. Clinical advisors (Senior Nurses) in Health New Zealand provide information and support, alongside practitioners, to help a person and their whānau navigate the assisted dying process.
Code of Health and Disability Services Consumers' Rights	Establishes the rights of consumers, and the obligations and duties of providers to comply with the Code. It is a regulation under the Health and Disability Commissioner Act 1994.
End of Life Choice Act 2019	The legislation that provides the legal framework for assisted dying in New Zealand. The Act sets out who is eligible for assisted dying, the process to access assisted dying, and some important safeguards.
End of Life Review Committee (the Review Committee)	A statutory body under the End of Life Choice Act responsible for considering the death reports sent to it by the Registrar (assisted dying) under section

Term	Meaning
	21(3) of the Act. The Review Committee decides whether the death report shows satisfactory compliance with section 21(2) of the Act. Its function is to make recommendations to the Registrar (assisted dying) about the death report information should that be necessary.
Independent medical practitioner	The practitioner that undertakes a second, independent assessment of the person seeking assisted dying.
Pae Ora (Healthy Futures) Act 2022	Health legislation that provides for the public funding and provision of services in order to: • protect, promote, and improve the health of all New Zealanders • achieve equity by reducing health disparities among New Zealand's population groups, in particular for Māori • build towards pae ora (healthy futures) for all New Zealanders. The Act establishes a set of health system principles to provide common expectations across the health system.
Registrar (assisted dying) (the Registrar)	A statutory role under the End of Life Choice Act. The Registrar's responsibilities under the Act include: • reviewing the assisted dying forms completed by practitioners to ensure compliance with the Act before the prescription is released • establishing and maintaining a register of approved forms for the assisted dying process, including consulting the Privacy Commissioner as required under the Act • receiving and managing complaints, including referring them to the Health and Disability Commissioner, New Zealand Police and/or other appropriate authorities • taking any action as directed by the End of Life Review Committee.
Support and Consultation for End of Life in New Zealand Group (the SCENZ Group)	A statutory body under the End of Life Choice Act. Members are appointed by the Director-General of Health for a period of two years. The SCENZ Group maintains a list of health practitioners willing to provide assisted dying services in New Zealand and is responsible for the clinical guidelines for administering medication for an assisted death and the standard of care for assisted dying in New Zealand.

Introduction

In 2024, the Ministry of Health – Manatū Hauora carried out a review of the End of Life Choice Act 2019 (the Act). The review was run in two parallel streams:

- a review of the operation of the Act by the Ministry
- an online process to gather public opinion about changes that could be made to the Act.

The Ministry also provided an online process to give the public an opportunity to share their views on what changes could be made to the Act. This report summarises feedback received though the online process.

This report is provided for consideration alongside the Ministry's review of the operation of the Act.

The Ministry would like to acknowledge and thank those who made a submission to the online process.

Background

The End of Life Choice Act 2019 (the Act) came into force on 7 November 2021. The Act enables a New Zealand citizen, or permanent resident, the option of requesting medication to end their life. It includes provisions that provide:

- eligibility criteria for people seeking assisted dying
- requirements for practitioners that provide assisted dying, including provisions allowing for conscientious objection
- a process that must be followed for someone to seek and receive an assisted death
- a number of requirements that are intended to act as safeguards
- entities to oversee and support the provision of assisted dying
- offences for breaching requirements in the Act and immunity provisions to protect practitioners who meet the requirements of the Act.

The Ministry of Health – Manatū Hauora (the Ministry) administers and regulates the Act, while Health New Zealand – Te Whatu Ora (Health New Zealand) manages the delivery of the Assisted Dying Service.

The Act includes a requirement that the Ministry must review the operation of the Act within three years after the commencement of the Act, and then at subsequent intervals of not more than five years, and consider whether any amendments to the Act, or any other enactment, are necessary or desirable. The Ministry also provided an online process to give the public an opportunity to share their views on what changes could be made to the Act.

This report provides a summary of the submissions received through the online process. The Ministry's review of the operation of the Act is provided in the report *Review of the End of Life Choice Act 2019*, which has been provided alongside this report.

About the process to gather public opinion on the Act

The submissions process

An online portal for feedback on the Act was set up on the Ministry website from 1 August 2024 until 26 September 2024, a period of eight weeks. The Ministry received **2759 submissions** from organisations and individuals, with a small number of individuals (less than 100) submitting more than once.

This report provides a summary of those online submissions, organised by theme, garnered from qualitative data. Some quantitative data was collected on submitters' demographic information.
A small number of submissions were received by email where submitters were unable to navigate the portal. These submissions were entered into Citizen Space by Ministry staff, to ensure they could be analysed alongside online submissions.

All care has been taken to accurately represent the views of submitters, but this may not have occurred in all cases and some errors, omissions, or inadvertent misrepresentations may have been made.

Structure of the questions

The online portal used a questionnaire, which canvassed information and opinions on the following areas, with the following questions:

- The submitter's demographic information.
- Access to assisted dying:
  - Do you think changes are needed to the eligibility requirements for a person to receive assisted dying?
  - Do you think that changes to areas other than eligibility are needed to support access to assisted dying?
- Safeguards in the Act:
  - Do you think the Act provides sufficient safeguards to ensure that people only receive assisted dying if:
    - they are eligible
    - they actively seek and consent to it
    - they are competent to consent to it, and
    - this consent is provided without pressure from others?
  - Do you think any changes are needed to safeguards provided through the Act?
- The process to receive assisted dying:
  - Do you think any changes are needed to the process to apply for and receive assisted dying?
- Practitioners providing assisted dying:
  - Do you think changes should be made to the requirements for medical practitioners and nurse practitioners to provide parts of the assisted dying process?
- Oversight of assisted dying.
  - Do you think changes are required to the roles and responsibilities of the entities established under the Act to oversee assisted dying (the SCENZ Group (clause 25), the End of Life Review Committee (clause 26), and the Registrar (assisted dying) (clause 27))?
- Alignment with the wider health system.
  - Do you think the assisted dying process aligns with other parts of the health system?
  - Is there anything that could be improved?

- Any other feedback.

Submitters were able to submit free-form answers into text boxes. There was no word limit on these text boxes.

Structure of the submissions

The length of submissions varied. Most submissions were brief, containing a single word, sentence, or a short paragraph stating the submitter's opinion. Some submissions were longer and went into more detail. A small number of organisations made substantial submissions.

The structure and content of submissions was also varied:

- Many submissions expressing views supporting or opposing the Act were repeated, with identical phrases.
- Many submissions contained personal stories, and some submitters outlined their personal preference for care at the end of their life.
- Many submissions did not address the questions directly, preferring to make a statement and then repeat it in response to all questions. Other submissions offered experiences and thoughts unrelated to the Act.
- Others wrote nothing in some areas, or said they were unsure or uncertain. Some submitted, "you know what my views are."

71 submissions were received from organisations. Some of these submissions did not identify an organisation or present an organisational view – these have been treated as individual submissions. Some organisations made multiple submissions.

Questions 1 – 5: Demographic information of submitters

The demographics of submitters, based on submitters' answers to the questions in the portal, are set out in Table 1 below.

Table 1: Responses to demographic questions through the online process for the review

(N = 2759)		**Total count**	**% of responses**
I am or represent:	a medical or nurse practitioner who provides assisted dying services	17	0.62%
	a medical or nurse practitioner who does not provide assisted dying services	83	3.01%
	someone from the wider health workforce	186	6.74%

(N = 2759)		Total count	% of responses
	someone who has sought assisted dying, or the family member of someone who has sought or received an assisted death	121	4.39%
	a member of the public	2121	76.88%
	other (please specify below)	185	6.71%
	not answered	46	1.67%
Is this submission on behalf of an organisation?	Yes	71	2.57%
	No	2676	97.03%
	Not Answered	12	0.44%
Do you live in New Zealand?	Yes	2719	98.55%
	No (please specify)	30	1.09%
	Not Answered	10	0.36%

The Official Information Act 1982 (or OIA) enables anyone in New Zealand to make a request for official information held by government agencies. As OIA requests may be made about submissions to the online portal, the Ministry included a question about whether the submitter consented to have their personal details included in responses to those requests.

The responses were relatively evenly split about whether submitters consented to have their personal details included in OIA requests.

Table 2: Whether personal information can be included in Official Information Act responses

(N = 2759)	Total count	% of responses
Include my personal details in response to Official Information Act requests	1274	46.18%
Remove my personal details from responses to Official Information Act requests	1485	53.82%

Structure of this report

The online portal was designed to gather qualitative data only. It was not intended to provide (and should not be read as) a representative sample of views on assisted dying in New Zealand.

Rather, the portal provided an avenue for people to share points of view, or arguments in support of their points, recognising that these will vary. For example, on the question “Do you think changes are needed to the eligibility requirements for a person to receive assisted dying", two people might state 'yes' but for different reasons. For instance:

- *"Yes, an eligibility criteria for those in an advanced/irreversible state of mental decline,"* or
- *"Yes. The present act should be repealed."*

Each section of this report summarises the most common themes expressed by submitters. Where a subject has been canvassed in another section, it is not repeated, unless it introduces different information.

The report is organised into the following sections:

- Access to assisted dying.
- Safeguards in the Act.
- The process to receive assisted dying.
- Practitioners providing assisted dying.
- Oversight of assisted dying.
- Alignment with the wider health system.
- Other feedback.

Many submitters opposed the legislation and repeated this position throughout their response. Their views have been noted in the section on 'Access to Assisted Dying' but have not been repeated in the other sections.

Quotes from submitters have been inserted in the form they were entered and may contain spelling and grammatical errors.

Summary of online submissions

Access to assisted dying

The first section of the online portal addressed whether changes are needed to support access to assisted dying. The first question focused on changes to the eligibility criteria under the Act, and the second question asked about more general changes that would support access.

Question 6: Do you think changes are needed to the eligibility requirements for a person to receive assisted dying?

This question focused on eligibility settings in the Act. Currently, a person is eligible for assisted dying In New Zealand if they:

- are aged 18 years or over; and
- have New Zealand citizenship or are a permanent resident; and
- suffer from a terminal illness that is likely to end the person's life within six months; and
- are in an advanced state of irreversible decline in physical capability; and
- experience unbearable suffering that cannot be relieved in a manner that the person considers tolerable; and
- are competent to make an informed decision about assisted dying.

This section sets out a summary of submissions received on each of the above criteria.

A person must be aged 18 years or over

The age requirement was not an issue raised by many submitters. A few believed it should be raised to 25 – 30 years of age, and a very small number thought it should be removed in its entirety.

A small number of submitters believed that people of a certain age (for example, those over 90 years) should be able to access assisted dying regardless of their health status.

The New Zealand Association of Rationalists and Humanists (a not-for-profit advocacy organisation for the interests of non-religious people) submitted on lowering the age criteria to be eligible for an assisted death, commenting that it is discriminatory to deny a person the freedom to choose an assisted death based on an arbitrary age limit:

- *"…the likelihood of children seeking out an assisted death is very low, but the age restriction of 18 removes a young person's autonomy…"*
- *"…the exclusion of children from the End of Life Choice Act is based on a combination of developmental, legal, ethical, and societal factors. This approach aims to ensure that only those who can fully understand and consent to the implications of assisted dying are allowed to make such a choice. However, it is possible for the legislation to protect the well-being and rights of minors while enabling them to make informed choices about their care and treatment."*

The Law Society (the national regulator and representative body of the legal profession in New Zealand) submitted that, while they had no view on the appropriate age for eligibility to receive assisted dying, the age restriction should be reviewed, *"taking into consideration the current settings for consent to medical procedures, and whether the restriction is a justifiable limit on the right to freedom from discrimination."*

A person must have New Zealand citizenship or be a permanent resident

A small number of submitters believed that assisted dying should be extended to people who have lived in New Zealand for an extended period, but do not hold the status of permanent residence or citizen. Submitters noted that this exclusion varies from the provision of healthcare in general, and that a patient-centred service would allow applications from those with the right to live in New Zealand, but who are not citizens or permanent residents (for example, a person on a five-year work visa).

Others commented that New Zealand passport holders who have not lived in New Zealand for many years should not be permitted to return to New Zealand for the sole purpose of accessing assisted dying services, given the cost and possible impact on health sector resources.

"There are many Australians who live in New Zealand who do not hold a residence visa or citizenship. Many have lived here for the majority of their lives and have children and grandchildren in New Zealand. They assume assisted dying services will be provided as other medical and work related benefits are shared between our two great countries. Assisted dying is available across Australia and to New Zealanders living in Australia. Please can the requirement to have New Zealand citizenship and permanent residents being extended to include Australians living in New Zealand?"

A person must:

- suffer from a terminal illness that is likely to end the person's life within six months; and
- be in an advanced state of irreversible decline in physical capability; and
- experience unbearable suffering that cannot be relieved in a manner that the person considers tolerable

The above three criteria received the most responses to the overarching question, and were interlinked throughout submissions.

Section 5(1)(c) – the requirement for the person to suffer from a terminal illness that is likely to end their life within six months – was viewed as problematic by many submitters. All demographics questioned whether this requirement was reasonable, given the difficulty of timing a terminal diagnosis and the suffering a person could experience before they met all the criteria.

It was noted by a medical practitioner that *"the six month prognosis is hard to manage from a clinical point of view, as prognostication can be very difficult, even when the illness is clearly progressive, incurable and life limiting."*

The same submitter also noted that "*there are situations where people may be in temporary remission, but know they wish for assisted dying when they relapse. The relapse is unpredictable and may be so rapid that they do not have time for a new application."*

> *"Medicine is very poor generally at accurately prognosticating on an individual's likely period of survival. Generalisations can be made across groups of people with diseases in common, but this is not the same nor as accurate for an individual. "Likely to end a person's life in 6 months" is a pretty broad statement with no parameters of certainty and yet it is being used to argue for certain death in this instance."*

Some submitters believed that the current prognostic period should be lengthened. Voluntary Assisted Dying Australia and New Zealand (VADANZ) (an advocacy group representing health practitioners providing assisted dying services in Australia and New Zealand) made the following submission on this point:

- *"Terminal illness is not defined in the literature or the legislation (rightly as often definitions may change over time) and thus the AMP, IMP and Registrar may - and do – disagree. The current framework lacks a defined process of appeal when the practitioner and the registrar disagree regarding terminal illness.*

  An example of this is severe and end stage frailty with no possibility of reversal which may be recognised in NZ as a terminal illness, needing better palliative care, and is permitted as a cause of death in NZ – and yet it is not accepted for the purposes of *assisted dying applications, and the legal, clinical and ethical rationale is not clear. This has been a recurrent issue without transparent definition, appeal or evolution.*

The 6 months timeframe restricts patient access, and some patients die in process who would like to access Assisted Dying. Patients fall broadly into 2 groups: the planners and the late applicants. The former would benefit from the reassurance of being able to commence the process earlier especially those with neurological disease, even if the Assisted Dying could not be delivered until 6months."

VADANZ stated that they would like to see the eligibility timeframe extended to 12 months, even if this was restricted to the administration of an assisted death requiring a prognosis of less than six months.

The organisation Equinox Health (a primary health organisation that provides care specifically for people living in residential aged care facilities) commented:

- *"The 6-month terminal illness clause is unrealistic. In truth, clinicians cannot predict when death will occur. We had a particular clinical case whereby our patient with lung cancer requested assisted dying and was assessed by a SCENZ medical provider. Unfortunately, the SCENZ medical provider determined that he had longer than 6 months to live and, therefore, was ineligible. This sent our patient into a severe downward mental deterioration, and he subsequently actively tried to commit suicide by cutting himself. He received Mental Health Services care for this suicide attempt. He did, in fact, die from his lung cancer 5 months after his first SCENZ medical provider assessment."*

Another submitter commented that *"the six-month line in the sand is arbitrary and an extension to twelve months, or even removing a time limit for patients with a terminal illness associated with unbearable suffering should be considered."*

The End-of-Life Choice Society (an advocacy organisation that supports assisted dying) submitted that they would like to see the eligibility criteria changed to have no prognosis requirement specified, stating that *"prognostication is often extremely difficult and is openly acknowledged by doctors to be so."*

"I believe more flexibility is required - it's too restrictive. For example, the six-month period for a terminal illness should be more like a year, not just end stage because many people do not want to experience the pain nor put their families through it. They should be able to choose. Diseases don't think in months."

A small number of submitters thought the prognostic timeframe should be shortened to three months or less. The Maxim Institute (an independent think tank), commented:

- *"Even medical professionals cannot predict with high levels of accuracy if someone has fewer than 6 months to live. In fact, predictions of "weeks" or "months" to live are accurate only about 32% of the time according to PMC Palliative Care. The accuracy rate never climbs higher than 74%, and that is when the timeframe is two weeks or less. If we were to take the criteria of terminal diagnosis seriously, we wouldn't consider allowing anyone who is predicted to live longer than a few weeks to be eligible for assisted suicide."*

- *"…given the great lack of certainty for terminal diagnoses with time frames greater than two weeks, and the fact that approximately two-thirds of diagnoses are inaccurate when the time frame is 6 months, this criteria should have a cutoff of no more than a month."*

The New Zealand Catholic Bioethics Centre (an agency of the New Zealand Catholic Bishops' Conference) commented:

- *"An assisted death must remain a voluntary choice. There are those who seek to broaden the parameters of eligibility to include persons who will not be competent at the time of administration, for example those with dementia. This would represent a major shift and a challenge to public perceptions of the safety provisions of the current Act."*
- *"…some practitioners may not object in principle to assisted dying but may be concerned that the Act is unworkable (e.g. when it says they must give a definite prognosis or try to ensure the patient's request is not affected by pressure from others) and therefore may want to exercise their conscience right to opt out of involvement in assisted dying on professional grounds. Any expansion of the current eligibility criteria may also create new conscience issues for doctors who don't currently object."*

Submitters also noted that the criterion is problematic for people with progressive neurological conditions.[1] These conditions may satisfy the criteria that a person must be in an 'advanced state of irreversible decline in physical capability', and experiencing 'unbearable suffering that cannot be relieved in a manner they consider tolerable', but not the requirement related to the six-month prognosis.

On 'terminal illness', a common theme from submitters (with some wording variations) was that the six-month prognostic criteria for progressive diseases be removed and replaced with "*a progressive disease that will foreseeably result in the patient's death*" or a "*grievous and irremediable*" condition (the original wording in the End of Life Choice Bill).

The Law Society recommended that section 5(1)(c) be amended to define 'terminal illness':

- *"Any such definition should also consider the reasonable availability of any such treatments for the patient, noting that while some treatments may technically exist, there can be practical funding or other availability limitations, meaning that all treatments are not reasonably available to the patient."*

On the requirement that a person be experiencing unbearable suffering, a number of submitters considered the term 'unbearable suffering' to be subjective and difficult to quantify. One submitter noted: *"this is very difficult for 99% of patients as people are stoic in NZ and they don't like to think that anything is "unbearable" or admit to that even if it is the case."*

Other submitters commented that the criteria should be weighted, rather than being an 'all or nothing' approach. This would give people the option of assisted dying where they had a terminal condition and were in an advanced state of irreversible decline in physical capability, but no prognosis.

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[1] For example, motor neurone disease, Alzheimer's, dementia, and Parkinson's.

"Absolutely. Without drugs I would suffer unbearable pain. Any increase in drugs would turn me into a zombie. I'm a D-Day veteran coming up to my 99th birthday. I was declined because I didn't have a terminal illness. Compassion over faith or politics is needed to overcome this cruelty. Please please please. Use your privileged position to change things for the benefit of people with unbearable suffering without any relief."

A person must be competent to make an informed decision about assisted dying

Submitters expressed concern about the requirement that a person must be competent to make an informed decision about assisted dying. While acknowledging the importance of the criterion, some submitters felt that requiring the person to be competent at all stages of the process does not adequately take into consideration the deterioration of people's health and their changing competence to give informed consent.

One submitter commented that the process needed to *"ensure people who are unable to speak verbally are not assumed incompetent."*

Conversely, some submitters thought that a person should be competent at all stages of the process. One submitter commented that to require otherwise *"sets a dangerous precedent that is too reminiscent of a previous horror of mankind."*

Others commented that there should be no changes to the eligibility requirements related to a person's competence, as expanded criteria could lead to more assisted deaths, as has been the case in other overseas jurisdictions.

The impact of broadened criteria on vulnerable communities

Several submitters expressed concern that the current eligibility settings are too broad, and that any expansion of the criteria could impact negatively on vulnerable communities who may try and access assisted dying, especially if they felt they were a burden.

"I do not think any person should be eligible in NZ to Euthanasia as it puts vulnerable people at risk – the elderly, disabled, and sick. We also know that vulnerable people are more likely to feel a burden, be depressed, or worry they are not contributing any more to society."

The Christian Medical Fellowship (a network of Christian doctors and medical students) commented:

- *"We are concerned that the law is currently operating in a way that fails to protect the most vulnerable in our communities. Any broadening of eligibility will exacerbate the risks to people who feel that they are a burden. The law as it stands is not sufficient in* *protecting the vulnerable and risks enabling suicidal ideation among the disabled, depressed, misdiagnosed, isolated, those with inadequate access to treatment and those without access to adequate palliative care."*

Another submitter commented:

- *"…If people are going to be offered the 'right to die with dignity' they also need to be offered an equally available to all option of palliative care and wraparound support. There is a premise underlying the law that some lives are worth less than others; an ableist, functionalist view - the idea that being dependent is worse than death. The truth is we all have intrinsic dignity."*

The Disabled Persons Assembly New Zealand (DPA) (a not-for-profit pan-impairment advocacy group for disabled people) opposed *"any expansion in the current eligibility criterion beyond terminal illness of less than six months duration"*, stating that "*[t]he risks of expanding eligibility for disabled people are manifold."* The DPA further commented that they are:

- *"deeply concerned that any extension to EOLC may well see disabled people opting to end their lives through assisted dying simply because they cannot access the support they need to be included in their community. We are hearing that some disabled people may feel that they must end their lives this way due to implicit societal messaging that we are a 'burden' both to the state and our communities."*

Some also commented that removing the requirement that death be within six months and replacing it with "*an undefinable, ambiguous clause*" such as "*grievous and irremediable suffering*" would lead to an exponential expansion in the number of New Zealanders who 'on paper' would become eligible for an assisted death. One submitter noted that:

- *"…an unintended but real consequence of such a move is that it would reinforce the dangerous idea for tens of thousands of sick, disabled and dying people that their lives are 'objectively' no longer worth living, paving the way for many more people to choose an assisted death for ableist reasons related to existential suffering and, ultimately, mental illness."*

Opposition to the End of Life Choice Act 2019

In response to the question asked about eligibility criteria, many submitters expressed their overall opposition to assisted dying, simply stating that the Act should be 'repealed', 'scrapped', or 'abolished' and offering no further comment. Where this occurred in the first section, most submitters repeated it in the following sections.

Others noted that, while they would prefer the Act to be repealed, if it remained in place the criteria should be tighter and not expanded.

Some submitters expanded on their opposition to the Act – reasons given are canvassed below.

Faith-based reasons

Some submitters put forward religious or faith-based points of view, supported by biblical quotes. Others stated that only God, not the State, has the right to take a life.

"Yes please get rid of assisted dying all together. It goes against God our Heavenly Father and it goes against his word (the Bible). I guess if people want to do it they will have to stand before God on judgement day and be held accountable for their actions/decisions. Thou shall not murder is one of God's 10 commandments they we need to follow and obey. Euthanasia is just as bad as killing innocent unborn children in the womb. It's not right and should never be allowed ever in today and future society."

Sacredness of life

Some submitters commented on the inherent sacredness and sanctity of life, and the need to protect it. These submitters considered that people should be supported to live their lives, rather than end them: *"All life is sacred and no one has the right to end the life of another person…"*

"[1] Human Life is Sacred to God (The Sanctity of Human Life)

Genesis 1:27 So God created man in his own image, in the image of God he created him; male and female he created them. Also Genesis 5:1-2

[2] God FORBIDS the Taking of Human Life

Exodus 20:13 You shall not murder."

"There should be no further encouragement to end someone's life. We as a people must instead encourage and nurture life. We must under no circumstances encourage anyone to end their life."

A slippery slope

Some submitters commented that to make changes to the criteria was a "slippery slope", giving the example of the Netherlands, Belgium, and Canada where expanded criteria have led to an increase in the number of assisted deaths over time. They considered that expanding eligibility criteria for assisted dying in New Zealand would lead to the same outcome and open it to misuse.

Some further commented that New Zealand's tolerance for assisted dying will increase over time and were concerned that noncompliance with safeguards would increase. Submitters cited the Contraception, Sterilisation and Abortion Act 1977, stating that the restrictions in that Act were not complied with after it came into force.

Likening assisted dying to suicide or murder

Other submitters stated they believe assisted dying to be state-sanctioned suicide or murder.

Financial considerations

A small number of submitters who considered that the Act should be repealed stated they did not believe their tax money should be used to fund assisted dying. Others suggested that assisted dying was about saving money in the health system.

> *"Experience from other countries tell us that once you open the door to legislation like this, it becomes easier for people, including the medical profession, to participate in ending life prematurely. I understand that there may be financial compensation to Doctors who participate. As a taxpayer, I would object very strongly to any use of taxpayer money that encourages medical professionals to take this course of action."*

Other views on the eligibility criteria for access to assisted dying

Other views expressed on the eligibility criteria are as follows:

- A small number of submitters commented that they were happy with the criteria, that the criteria were appropriate, and that there is no need for the criteria to be extended.
- Some supported broadening of the criteria, but believed this should be done with caution.
- Several submitters noted that the current Act was voted in via a referendum, and that no significant changes should be made without another referendum. One noted: *"The referendum agreed to pass Euthanasia into law. It was voted on with clear rules. Would it have been voted for if it was more lax, I am not sure. But we do know it was easier to have approval by being clear and restrictive. Please do not water it down away from what our Nation agreed to…"*
- A small number of submitters believed people should be offered natural therapies.
- Some submitters stated they believe a person should not be able to progress with assisted dying without their family being informed and consulted.
- One submitter proposed there should be provision in the Act for "extraordinary cases" to be approved.

Question 7: Do you think that changes to areas other than eligibility are needed to support access to assisted dying?

A number of other areas were suggested where changes could be made to support access to assisted dying. These are summarised below.

Advanced consent documents and arrangements

Under section 33(1) of the Act,[2] a person is not able to use advanced consent documents and arrangements for assisted dying, such as advance care directives, living wills, and guardianship arrangements.

An issue of concern to several submitters (also noted in the previous section) was the requirement for people to consent to receiving the assisted dying medication on their chosen date, and that this requirement does not take into consideration a person's deterioration at the end of life, and their competence to give informed consent.

These submitters believed that if the attending medical practitioner is assured that the patient's intention is clear, evidenced by a consent document or arrangement, then assisted dying should be allowed to continue if the person loses competence to consent on the day. One submitter noted:

- *"If someone has a comprehensive advance decision to refuse treatment, stating the criteria under which they would like an assisted death, and they have an EPA, then they should be able to appoint a VAD advocate, so that they can be represented if they lose capacity."*

> *"…better education and support from the medical fraternity about accessibility, and encouragement for the general public to proactively address these topics in their life planning, as part of health care, end of life care, living wills, will preparation, so that family members are aware of their wishes, and how to support them."*

Another submitter noted:

- *"Competence/capacity can be impaired by the disease process, drugs, infection, dehydration etc. Again, if the person has met the criteria, is accepted for assisted death and has an advanced directive/request/consent, this should be adequate and accepted for assisted death to proceed if subsequently competence is impaired by the processes previously described."*

Conversely, as noted earlier, some submitters thought competence at the time of administration was key and that consent documents or arrangements should not apply to the end of life.

One submitter, a lawyer "with over 40 years' experience of preparing and administering wills and estates and end of life issues", commented:

- *"The Enduring Power of Attorney has over the years become a major trauma and worry for the elderly, who know that decisions could be made for them that they would not want. It is the same sort of pressure that Assisted Dying has introduced to the equation."*

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[2] Section 33(1): A person who wishes to request to exercise the option of receiving assisted dying under this Act must sign and date the approved form referred to in section 12(3) (the request form), and to the extent that any provision expressing such a wish is included by the person in an advance written or oral directive, will, contract, or other document that provision is invalid.

Many submitters mentioned the ‘Waiver of Final Consent’ which is able to be given in Canada. Under Canadian legislation, where the requestor is at risk of losing their competence to give final consent to receive medical assistance, the requestor completes a ‘Waiver of Final Consent’ which removes the requirement for a person to give their express consent before they receive assisted dying. These submitters believed New Zealand should adopt a similar system.

Enabling health practitioners to raise assisted dying with a person

Another area that received a high volume of comments was the direction under Section 10(1)[3] of the Act that a health practitioner must not initiate a discussion about assisted dying with a person. Many submitters across demographics believed that this should be changed to enable a health practitioner to raise assisted dying with a person as one of the care options available to them.

> *The 'gag' clause for Doctors is against the Hippocratic oath. In order for doctors to 'do no harm', they should provide their patients with ALL legal options available to them. they still have the right to simply refer the patient to SCENZ and not engage in conversation if they don't wish to, but they should at least be bound to tell the patient what their options are, including AD. After all, there is still all the eligibility requirements to safeguard the patient. That's not up to the Doctor."*

Submitters commented that the inability for practitioners to initiate a discussion with a person about assisted dying is a discriminatory barrier for those who do not have internet access, people with limited health literacy, people "*too intimidated by their doctor to raise the topic*", or people without "*the correct vocabulary ("assisted dying") to make themselves understood*".

The End-of-Life Choice Society submitted:

- *"There is no public education about assisted dying and none intended due to this "gag" clause. As shown by Heath NZ/Te Whatu Ora's own published data, applications from Māori (5.5%) and Pasifika (0.6%) applicants are small or negligible by comparison with their relative population importance in our multi-cultural landscape. Māori and Pasifika who may wish assisted dying are therefore disadvantaged. By comparison, Pākehā are over-represented in assisted dying application statistics (81%)."*

Conversely, some submitters believed that this restriction should be retained, as allowing practitioners to raise assisted dying as an option would lead to an increase in assisted deaths, and the way that practitioners raise assisted dying as an option is not able to be "*policed*".

Ethos Alliance (a Christian organisation that provides advice and advocacy on issues of conscience, religion, and belief) submitted:

- *"It is essential to maintain the prohibition on health practitioners initiating discussion about euthanasia or assisted suicide with a patient. This is necessary to protect people from suggestion at a time when they are very vulnerable, especially to suggestions coming from someone in a position of authority and expertise. Some argue that*

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[3] Section 10(1): A health practitioner who provides any health service to a person must not, in the course of providing that service to the person,—

a) initiate any discussion with the person that, in substance, is about assisted dying under this Act; or
b) make any suggestion to the person that, in substance, is a suggestion that the person exercise the option of receiving assisted dying under this Act.

> *patients have a right to full information about all their options in every other situation and therefore have a right to be told about the option of euthanasia and assisted suicide. However, this is not a procedure like any other. It involves the most serious possible consequences and it is right that practitioners should not be able to initiate it."*

Providing public education on options for end-of-life care

Some submitters thought that there should be more public education on the Act. These submitters noted that because there is a restriction on health practitioners raising assisted dying, people may not have easy access to information and may not know where to go to get information.

Some submitters commented that the contact details of the Assisted Dying Service should be widely available in general practices and in the community, along with brochures that advise on other health services and one submitter commented they would like to see information on assisted dying in advance care planning booklets.

The Cancer Society (a charitable organisation dedicated to reducing the impact of cancer) commented that there need to be improvements in communicating with the Assisted Dying Service, in particular "*the accessibility for people with impairments, the clarity of the call service and the usability and discoverability of the website."*

> *"Assisted dying needs much better public education than simply having information available on a website. A huge range of medical and care services make use of simple pamphlets made available in GP clinics. - for example, information about contraceptives, disease-specific support organisations, hospice, counselling services, suicide help lines etc. The same should happen for assisted dying. Having information available to those without much health literacy and without internet services is not "promoting" assisted dying. It is simply informing about assisted dying."*

Expanding the workforce to recognise shortages

Some submitters commented that the types of practitioners who can provide assisted dying could be expanded to recognise workforce shortages. This is explored later in this report.

Changing what is recorded on death certificates

A small number of submitters were concerned with the requirement for the death certificate to record the cause of death as assisted dying. These submitters commented that some people want to keep their choice for an assisted death private for philosophical, moral, cultural, religious, or ethical reasons. As a death certificate is often required to be provided as evidence of death to banks and insurance companies, people may not wish for this information to be shared.

Safeguards in the Act

This section of the online portal addressed the safeguards provided through the Act, including whether the safeguards are sufficient and whether changes are required. Safeguards are legal provisions, professional requirements, and other mechanisms intended to protect people, practitioners, and the public in the delivery of assisted dying.

Question 8: Do you think the Act provides sufficient safeguards to ensure that people only receive assisted dying if ...

This question asked whether submitters thought the Act provides sufficient safeguards to ensure that people only receive assisted dying if:

- they are eligible
- they actively seek and consent to it
- they are competent to consent to it
- this consent is provided without pressure from others (referenced in clauses 11 and 24 of the Act).

A summary of the responses to each of these are set out below.

In general:

- a number of submitters answered 'yes' without further comment
- of those that answered 'no', some provided further detail and some did not
- several submitters commented they were unsure, or did not provide a response
- many submitters repeated their comments from the previous section
- some noted they needed more specific references to enable them to answer the question.

...they are eligible

As noted above, many people repeated their comments and themes from the previous question about eligibility. However, some submitters spoke specifically to the safeguards around eligibility, for example noting *"...eligibility is not a safeguard. Diagnoses can be wrong. Feelings can change."*

Other submitters felt that the eligibility criteria included *"ambiguous or even non-definable phrases"* that can be difficult for the attending medical practitioner or independent medical practitioner to interpret, and therefore cannot be considered a safeguard.

One submitter commented:

- *"I don't believe the Act provides sufficient safeguards to ensure that people only receive assisted dying if they are eligible. While the Act outlines various eligibility*

> *criteria in all noted clauses, I have concerns about the potential for these safeguards to be misinterpreted or applied too loosely. Given my disagreement with the law itself, I believe that even with these safeguards in place, there remains a risk of people receiving assisted dying who may not fully meet the intended criteria or who might be vulnerable to external pressures".*

Others considered the current safeguards are too restrictive, and that the Act denies a care option for those suffering from non-terminal conditions.

> *"There is a balance between allowing meaningful personal autonomy and protecting the vulnerable. The problem with the current legislation is that the eligibility criteria is too narrow."*

…they actively seek and consent to it

Submissions to this question also mirrored themes from the previous section, with some submitters for and some against practitioners being able to raise the option of assisted dying with people, and the recognition of advanced consent documents and arrangements in situations where people may lose competence to give informed consent.

> *"It is difficult to watch someone who was previous to a sudden event, mentally capable, loss their right to consent to assisted dying, because they are now considered mentally incompetent. My family member was a strong and clear advocate for assisted dying. She set up a living will and planned to apply for assisted dying when necessary. She suffered a medical issue that rendered her mentally incompetent and died over 10 months of progressive deterioration, starvation and incontinence. If her wishes as written and legally notarised had been carried out, she would have been spared this terrible horror."*

…they are competent to consent to it, and consent is provided without pressure from others

Safeguards related to ensuring that a person is competent to give informed consent, and that this consent is provided free from pressure from others, were an area of concern for many submitters, particularly in relation to family involvement in the process, depression and other mental health issues and coercion.

Under Section 11(2) of the Act, the attending medical practitioner must:

- encourage the person to discuss their wish with others such as family, friends, and counsellors
- ensure that the person knows that they are not obliged to discuss their wish with anyone
- ensure that the person has had the opportunity to discuss their wish with those whom they choose

- do their best to ensure that the person expresses their wish free from pressure from any other person by:
  - conferring with other health practitioners who are in regular contact with the person
  - conferring with members of the person's family approved by the person.

Discussing with family, friends, and counsellors

As outlined above, the attending medical practitioner must 'encourage' a person to discuss their wishes with family and friends. However, this is not mandatory. Several submitters believed it should be mandatory for close family to be told of a person's interest and/or request for assisted dying, and that family being excluded from a consultation meant that the safeguards were less robust.

Others stated that the input of family and caregivers can help to detect pressure. One submitter commented:

- *"…The ability to exclude loved ones and those close to you is an unfortunate aspect of the Act. Patients make this decision alone and especially if whanau / family are not on the same page. Yet we have Section 7a of the Mental Health Act that requires whanau / family to be contacted when initiating the Mental Health Act. We infantilize and discriminate against adults with temporary mental illness when we compare it to the End of Life Care Act. WE must be consistent in New Zealand law the degree to which we respect the individual and also the family / whanau and even iwi rights to know and be involved. I understand the conflict of family / whanau recommending end of life care to access estate of the family member seeking end of life care and this remains a tension…"*

Conversely, others believed that autonomy and choice are key and it should be the decision of the person requesting assisted dying as to whether they discuss and involve others in the process.

Detecting pressure

Several submitters outlined concerns around people feeling pressure to access assisted dying, and on the other hand, pressure to live. One submitter noted: *"I think it's more likely that loved ones could coerce someone to not choose assisted dying, because of their own feelings, rather than the suffering of the person concerned."*

Submitters commented that people may feel pressure from family to have an assisted death for financial reasons, or to make beds and treatment available for other people, particularly if they are elderly.

> *"The lack of palliative care means that people are being made to feel as if they are a burden on society and that they are taking up valuable resources that should be used for life saving medical procedures. Family members and medical staff will play the guilt card."*

Other submitters cautioned that supporting their family members’ decision should not be seen as coercion or pressure, even though some have felt it was perceived as such during assessments of a person’s eligibility.

"Coercion is not appropriate but there needs to be mindfulness that there will always be people who will want and seek the support and guidance and advice of family and friends that may come across to an observer as coercion even though the person does not feel that pressure."

Voice for Life (a pro-life organisation) commented:

- *"In Section 11 [h],[4] the use of the phrase for doctors to "do their best" when assessing whether a patient is being coerced, is woefully inadequate and inappropriate legal language in an Act that deals with such grave legal questions as the right to intentionally assist or end the life of a patient with a lethal dosage. We call on the New Zealand Parliament to rectify this, improving the language so that medical practitioners who are assessing these patients under the EOLC Act, have structured and appropriate guidelines to ensure patient safety first and foremost. We believe that it is of the utmost importance for this section of the EOLC Act to be immediately improved to provide a clear and unambiguous definition of what practical steps must be taken during the assessment process in order to ensure coercion is not at play."*

Some submitters commented that although blatant pressure is easier to identify, there are forms of subconscious or unintended pressure which can be applied to a person in a vulnerable state that can be difficult to detect or measure.

One submitter noted: *"Pressure can be very subtle. Kōrero around dying in pain, sitting in a home with old people with nothing to do and costing the tax payer money, whittling away the inheritance money on residential care etc etc"*.

In expressing these concerns, submitters questioned whether it is possible or reasonable for a medical practitioner to determine whether pressure is being applied. These submitters did not believe the Act provided sufficient guidance in this area, other than the medical practitioner being required to 'do their best to ensure that the person expresses their wish free from pressure from any other person'.

"I witness regular 'pressure' from families for elderly people to go into rest home care, despite the individual's reluctance. Again, I have little doubt this will happen with assisted dying. Despite the good intent of AMP's this will happen. The system is unable to detect this but should not assume it is absent."

One submitter thought there should be a clearly defined legal process to ensure that no pressure or coercion was present, stating:

- *"There needs to be clear safeguards and guidelines that enable all consultations between an independent person (I suggest an independently appoint Barrister) whose job it is to discuss with the person (1) that they understand their request for assisted dying and that they (2) are not in the presence of any family members or friends who may influence their decision at the time of the consultation and (3) they believe they*

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[4] Section 11(h) outlines the steps that a practitioner must take to do their best to ensure that the person expresses their wish free from pressure from any other person.

> *are of sound mind and (4) they have been advised by at least two doctors that they can avail themselves of these provisions.*
>
> *This consultation should be video recorded live (much like a Police Interview) to show who is present and how the consultation is handled.*
>
> *It should be followed up with a printed copy of the transcript which is then signed and witnessed by both parties."*

> *"I don't believe the Act provides enough protection against external pressure. The current system relies too heavily on individual doctors to detect any coercion. If the so-called 'gag clause' is removed, it could lead to increased pressure on vulnerable individuals, as those at the end of life are particularly susceptible to influence."*

Two other submitters noted that there are benefits to recording assessments, as it is not always easy to assess a person's competence, and practitioners' decisions can be subjective.

- *"Currently providers are allowed to do assessments by Zoom and I have heard these can be as short as 30 minutes. This does not allow for uncovering more subtle capacity issues." and/or the variability (and potential errors) of brief one-time assessments of capacity." and "video recording of capacity assessment and informed consent may help with maintaining consistency between providers and allowing families who dispute informed consent after the fact could have an opportunity for impartial review."*

Depression and mental health issues

Some submitters noted that depression or other mental health issues can follow a terminal diagnosis, and questioned whether this could compromise the person's competence to make an informed decision and give informed consent to assisted dying.

One submitter commented: *"Depression limits ability to consent. Treatment for depression increases competency and reduces the perceived need to see euthanasia as a desirable option."*

> *"I think the Bill's wording is too vague and lacks protection for those suffering depression and mental illness. There's currently room for people who "feel a burden" to be pressured to give consent from carers and family members. The reluctance of hospice nurses and Doctors speaks volumes about the intent of this Bill which goes against the protection of life previously affirmed by medical ethics."*

Some submitters commented that, because of possible depression or other mental health issues following a terminal diagnosis, people requesting assisted dying should be required to undergo a psychiatric evaluation and be cared for and supported before undertaking further service assessments. Other submitters considered that anyone who seeks out assisted dying must have a mental illness, and they should be excluded from the process.

Some submitters felt the safeguards around a person's competence to provide informed consent were sufficient, and achieved a balance between personal autonomy and the inclusion of family in decisions around competence and consent. One submitter noted: "*at the end of the day, it is the person's decision how much they wish to share power with significant others.*"

One practitioner who provides assisted dying services commented that *"the current legislation is very safety orientated. As a practitioner I feel protected by it and I feel patients are very safe. I feel the criteria could be relaxed without impacting on the safety of the Act."*

Impacts on vulnerable communities

DPA expressed a concern that the "*limited safeguards that currently exist in the EOLC Act against abuse can be eroded,*" and about "*the implications of the clause preventing disabled people with permanent, non-terminal impairments and health conditions from opting for euthanasia being removed from the legislation. For these reasons, DPA wants to see at all existing safeguards within the legislation retained.*"

Appeal process

A small number of submitters suggested a tribunal be required to hear appeals when a person has been denied assisted dying. VADANZ noted:

- *"The Registrar currently holds the final decision-making control but there is no process to appeal or understand the decisions made. This contravenes natural justice and usual clinical care which is transparent. We would like all decisions which differ to the AMP+IMP to be explained and an appeals process for patients and whanau, and practitioners to be implemented."*

Question 9: Do you think any changes are needed to safeguards provided through the Act?

Suggested changes in this area included that:

- independent witnesses should be involved and present throughout the process (including at the time of assisted dying) to ensure that the person is making their decision free from pressure
- regular reviews should be conducted to ensure compliance with the legislation
- processes should be put in place to prove that safeguards are followed and correctly documented
- practitioners providing assisted dying services should be required to be trained and certified in an accreditation programme before they are able to provide assisted dying services.

The process to receive assisted dying

This section of the online portal focused on whether submitters considered changes are needed to the process to apply for and receive assisted dying. Under the Act, the process to apply for and receive assisted dying includes:

- making a request and confirming a request
- a first assessment by the attending medical practitioner
- a second assessment by the independent medical practitioner
- if required, a third opinion on the person's competence provided by a psychiatrist
- a determination that that the person is eligible or ineligible for assisted dying
- if eligible, choosing the date and time and making provisional arrangements for the administration of the medication
- the administration of medication for the assisted death
- the death being reported.

Question 10: Do you think any changes are needed to the process to apply for and receive assisted dying?

Overall process

Some submitters thought that the process works well, with step-by-step requirements allowing plenty of time for discussion between the person, the attending medical practitioner, and family.

> *"The process is careful and thorough and the length of time it requires is an important part of the safeguards. Assisted dying is a planned care service, not an urgent care service. Better public education and the removal of the "gag clause" should enable more timely planning."*

One submitter commented that, because a person is reminded on several occasions that they can change the date or change their mind at any time, this leaves sufficient time for "deep reflection" for the person.

Others had concerns about the process being "*long winded*", and that unintended delays could mean people die before receiving authorisation for assisted dying. This was particularly seen as a problem for people seeking assisted dying who live outside of a metropolitan area.

"the process has a lot of bureaucratic hurdles and delays for terminal patients to overcome, that make it impossible to achieve in many cases. The current process is quite obstructionist towards dying patients who are suffering unbearably."

"I think the access is working well from a legal point of view, though some clinicians and palliative care providers still struggle with the concept - this needs a societal change and education, not a law change. The delay between the patient and medical practitioners deciding that assisted dying is appropriate and the bureaucratic processes of approval and ordering the medication can be a problem. I think the Registrar needs more resources to be able to offer a 7 day a week service with a quicker turnaround. Sometimes people deteriorate too rapidly for the planned death."

One submitter commented that *"approval should be streamlined, getting an appointment with a psychiatrist could take well over a year in some places, just as an example"*.

Another noted that variability in timeframes for assessment, and availability of local doctors in different areas, can make the process *"a bit of a post code lottery."*

Others commented that if the person requesting assisted dying has communication difficulties, this could impact the process overall and put support people in a vulnerable situation if they are asked to assist in expressing the person's wishes.

A small number of people believed that the whole process should take several years, suggesting: "*The request should be punctuated over a very long period of time - years at least. There needs to be an independent report re the possibility of elder abuse for every scenario."*

Making a request and confirming a request for assisted dying

Only a few submitters commented on making and confirming a request.

One submitter commented that the general practitioner took a long time to work out what needed to happen in the process, and that finding two doctors willing to make assessments would not be easy in all areas of New Zealand. The submitter considered there needs to be more promotion of information about assisted dying, and education, to encourage health practitioners to participate.

Some commented that only the person seeking assisted dying should be able to make the request, rather than their next of kin or an Enduring Power of Attorney.

Another commented that as there is no defined timeframe between making a request and an eligibility decision, this can cause issues for applicants in family discussions and arrangements.

One person noted that people who have a disability affecting their speech have a disadvantage in communicating their needs and having an accurate assessment, and that this needs to be considered within the system.

As outlined in the previous section, a common theme through submissions was that any person requesting assisted dying should be referred for a psychiatric evaluation as the first step, or be required to attend counselling before progressing further.

> "*There should be a compulsory counselling session between making the request and confirming the request. This session should focus on exploring the person's motivation for the request, and thoroughly investigating options other than euthanasia ie life-affirming options."*

Another common theme was allowing medical practitioners to raise assisted dying as an option with people and the recognition of consent documents and arrangements. These are outlined in more detail in the earlier section on 'Access to Assisted Dying'.

Assessments

Some submitters commented that assessments take too long and should be more patient-focused, with the number of appointments and assessments reduced.

> *"The only criticism I have read is that there have been cases when the initial assessments have taken too long. That is why people need to apply as soon as they can. And more doctors can be involved with the assessments. From all reports I have read the process is otherwise working well."*

Several submitters believed that at least one of the assessments should be done by a practitioner who knows the family. Others thought one of the assessments should be performed by a palliative care physician.

A nurse practitioner outlined a situation faced by nursing home residents:

- *"I am a Nurse Practitioner working solely in residential aged care. My patients are enrolled in my practice and do not have a designated GP. I am their sole primary healthcare provider. Therefore, I have the closest relationship with these patients. I provide all primary care services and am in constant communication with patients and their families as per the NP scope of practice. It is appropriate that I do the initial assisted dying consultation and assessment rather than call in a separate medical practitioner who does not know my patients at all. Nurse Practitioners should be added to have the ability to do the initial consultation and assessment for assisted dying services."*

Provisional arrangements for administration of medication

Choosing a date

Several submitters believed that people accessing assisted dying should not need to nominate a date for the administration of medication, as they may feel they cannot change it.

> *"The requirement to choose a date and time for administration at the time of approval for AD creates a social contract that is a type of mild coercion. This is the "wedding effect". Getting married in Aotearoa is an act of free will, but when the wedding is planned, the invitations sent out and the celebrant, family and guests have expectations, it is VERY difficult to back out. Assisted Dying need not suffer the "wedding social expectation" as it is not necessary to require the person to set a date."*

One submitter with a family member who received assisted dying commented:

- *"My family member chose a date for her assisted death at her first meeting with the AMP. However, she did not decline as rapidly as she had expected and if she had not had to set this date at the first meeting, I feel she would have waited and been able to have a longer life of good quality than she had first thought. Once this date was set, she felt locked into it as it was inevitable that family members etc made plans to be in attendance on the day (at her request). I would like to see a change so that the person does not have to nominate a day and time as part of the application process. I feel this would enable people to choose when they are ready at an appropriate time."*

Others thought that people seeking assisted dying may need more guidance around choosing a date or time for the assisted death. Because people may not necessarily have full awareness of the progression of their disease, they may need to go through the process of changing the date.

Other submitters believed the person should be able to have a prescription that they can fill to use when they are ready.

> *"…There is no need for the government to control the exact timing. Having the script and then having the medication would bring more sense of control to the dying person, they may decide never to use it, but it has provided comfort. It would be extremely stressful to pick a perfect time to die and have to tell everyone."*

Changing the date of the assisted death

Some submitters expressed concern that changing the date of the assisted death took at least 48 hours. They noted that if people are extending the date out this is generally not an issue, but this causes distress and suffering for people bringing the date forward (possibly due to deterioration in the person's condition).

One medical practitioner noted:

- *"I've been involved with a number of cases now some 40 + cases where I've carried out either an AMP or an IMP assessment. One of the safeguards, which I think is too strong, is the 48 hour rule for change of date. It is my opinion that once the patient has been given eligibility by the registrar of Assisted Dying that it is then between the AMP and the patient, when to choose the date without the need for reapplying for permission for a change of date. I have had a number of cases now where the patient has deteriorated quickly and has not been able to have their assisted death, because* *there was insufficient time to successfully get the date brought forward in time to help the patient pass. So the patient in the end died in the manner which they were so strenuously trying to avoid with the assisted dying process clearly failing."*

> *"My experience recently with my dying husband, who had completed the process and had been declared eligible was that the dying process accelerated rapidly in the last days and his request to bring the date forward again was not able to be granted. It was Friday and the paperwork couldn't be dealt with over a weekend so he had to wait until the following Wednesday for the process. Those last days were terrible for him. He died before the process could happen. There needs to be a rapid response capability for a situation like his so that paperwork can be dealt with swiftly and drugs made available swiftly. This change would be very good to make."*

Administration of medication

Few submitters mentioned the administration of medication. One noted the importance of planning:

- *"There must be precise planning for access to the medication; ie a situation I know of where, because of a public holiday, (long weekend), the administrating person was unable to access the medication, as planned, leaving the patient to die badly instead of his being assisted."*

Ethos commented on the requirement for a person to be competent to consent at the time of medication administration:

- *"Section 20 says that an AMP or an attending nurse practitioner (ANP) must check if the patient chooses to receive the medication at the appointed time, or to delay or rescind their request. It does not say that they have to ensure the patient is competent to make that choice. Section 20 does refer to the patient as "the eligible person," which is defined in section 5 as a person who (among other things) is "competent to make an informed decision about assisted dying." This may mean that the patient has to remain eligible (including competent) throughout the assisted dying process. This would be consistent with other professional obligations—for example, the Medical Council says, "In most situations, treatment should only go ahead if you are sure that your patient understands that information and the consequences of their decision." (Medical Council of New Zealand (2021), 5, 8). But given the high stakes and irreversible consequence of administration, the EOLCA should be amended to be explicit that AMPs and ANPs must check that a patient remains eligible, including that they are competent, before asking them whether they wish to proceed."*

Some submitters stated there should be mandatory reporting of the time between administration of the medication and time of death, noting that "*transparency is essential*" and that people receiving assisted dying should have full awareness of the process. One submitter commented that "*people have an unrealistic view of what to expect.*"

Another submitter noted that the Act makes "*no allowance for ineffective administration of the medication*", and that "*the application of capital sentences in the*

USA (and presumably elsewhere) shows that administration of drugs may not be simple much of the time."

Reporting of the assisted death

Few comments were made on the reporting of assisted deaths.

One submitter noted that *"notification of family could be too easily overlooked as there is no requirement to discuss disposal of the resultant body if the person has not made a will or instruction."*

Another commented: *"The notification of death seems at odds with BDM Act clause 48 1, which also only relates to after disposal, reducing potential for family calls for coroner intervention. It's all just too loose and ripe for corrupt actions."*

Other views on the process to receive assisted dying

- Some submitters believed New Zealand should adopt a 'cooling off' period. This is provided for in Australian states (generally between 5 – 9, days with some allowing this period to be shortened or waived if the person is likely to die or lose competence sooner), and Belgium and Canada. The DPA recommended in their submission that a cooling off period of seven days be added once approval has been given before proceeding with the assisted death: "This would bring NZ more in line with other comparable countries. A cooling off period would apply to everyone who successfully applies for assisted dying in that they would not be able to proceed with it until after a minimum of seven days have elapsed from time of approval."
- Several submitters stated that a practitioner should be required to stay with the person until death is recorded. This is already provided for under Section 20 of the Act.
- A few submitters commented that there should be independent witnesses during the process to ensure compliance with the legislation.
- Several submitters believed that reporting overall should be more open, and that most of the details required by clause 21 of the Act (Death to be reported) should be publicly reported on with identifying information removed.
- Some submitters raised the issue of rural and regional servicing for those wishing to access assisted dying, particularly regarding the availability of practitioners providing the assessment services.

"We need more people in rural areas to be the first and second assessors. As time is of the essence the assessments should be considered very urgent. Perhaps to cover this off the assessments can be completed virtually so they can be recorded and not require the patient to travel up and down the country while in pain or other suffering in other ways."

Practitioners providing assisted dying

This section of the online portal addressed whether changes should be made for the requirements for medical and nurse practitioners to provide parts of the assisted dying process. The following practitioners currently have a role in the assisted dying process:

- The attending medical practitioner is central to the assisted dying process as the practitioner that the person primarily interacts with throughout the process. An attending medical practitioner can be any medical practitioner who is registered with the Medical Council of New Zealand as a practitioner of the profession of medicine and holds a current practising certificate.
- The independent medical practitioner performs the second assessment to determine whether the person is eligible for an assisted death. An independent medical practitioner is required to meet the same requirements as an attending medical practitioner, but must have held their practising certificate, or the equivalent certification, for at least five consecutive years.
- An attending nurse practitioner can arrange for and administer the medication for a person receiving an assisted death at the end of the process. Under the Act, an attending nurse practitioner is a nurse practitioner who is registered with the Nursing Council of New Zealand, whose scope of practice permits the performance of nurse practitioner functions and holds a current practising certificate. Under the Act they are also required to act under the instruction of the attending medical practitioner.
- A psychiatrist may perform a third assessment of the person's competence to make an informed decision if needed. Under the Act, a psychiatrist means a medical practitioner whose scope of practice includes psychiatry.

Question 11: Do you think changes should be made to the requirements for medical practitioners and nurse practitioners to provide parts of the assisted dying process?

Most submitters did not respond to the question about requirements for practitioners to provide the service, but rather submitted on whether it was appropriate to ask practitioners who had sworn the Hippocratic Oath to perform this service.

Some expressed concern about the psychological impact on those providing assisted dying services, and thought that these practitioners should be required to undergo regular psychological assessments or have access to regular debriefing and support. In addition, a few submitters stated that a practitioner should not need to perform the service alone.

"I do not think that clinicians should perform this service alone. They are medicolegally and at times physically vulnerable and there are no witnesses except the patient and their loved ones. One day there will be a disaster, and we can all say it could have been avoided. Do doctors or nurses do intimate examinations alone? At their peril! This ranks similarly!"

The Christian Medical Fellowship stated: "*we believe that doctors have the training and skill to promote and maintain a caring doctor-patient relationship. It is our view that skilful and effective pain management neither requires nor uses lethal doses of drugs. We believe neither assisted suicide nor euthanasia is a medical procedure. Doctors should play no role in the regulation, or practice, of euthanasia and assisted suicide*."

Some submitters commented that an increase in practitioners offering the service, and less judgement in the medical community about assisted dying providers, would mature the service and reduce pressure on practitioners and people enquiring about the service.

One submitter commented that *"medical practitioners and nurse practitioners should have personal knowledge of the patients' medical records. They should be required to work with the whānau to explore all options to assisted dying practices, including Māori preferred ways of healing and caring."*

Conscientious objection

Conscientious objection was mentioned by many submitters. Under the Act, a health practitioner is 'not under any obligation to assist any person who wishes to exercise the option of receiving assisted dying under this Act if the health practitioner has a conscientious objection to providing that assistance to the person.' However, the practitioner must tell the person of their conscientious objection, and of the person's right to ask the SCENZ Group for the name and contact details of a replacement medical practitioner.

Submitters stated that practitioners who conscientiously object must be able to maintain their position, and the provision to enable them to do so must remain in the Act.

However, some submitters noted that they had experienced resistance when enquiring about assisted dying, and thought there should be information available independently of medical practitioners.

The End-of-Life Choice Society commented:

- *"While the Society fully supports individual conscientious objection for all those working in the medical profession, it is unlawful to obstruct or frustrate the desire of a person within their care to access assisted dying. As the law currently stands, a conscientiously objecting medical professional or NP [nurse practitioner] is required only to let the person know they can get information from the SCENZ Group. It does not require them by law to provide the 0800 223 852 phone number of the SCENZ Group, nor the assisted.dying@health.govt.nz email address. Unless this important* *and simple access information is included, a person who is not internet-enabled is disempowered by the conscientious objector."*

One practitioner who provides assisted dying services commented:

- *I wonder about clinicians who are conscientious objectors - should they be on some sort of a confidential register? I have had an AD [assisted dying] nearly stalled due to the vexatious interference by a CO [conscientiously objecting] consultant!"*

Several submitters also commented that doctors should be able raise assisted dying as an option for those with a terminal diagnosis. This is outlined in more detail in the 'Access to Assisted Dying' section.

Issues that relate specifically to roles and responsibilities of practitioners providing assisted dying services are outlined below.

Role of nurse practitioners

Some submitters believed that with the health workforce constraints in New Zealand, the roles and responsibilities of nurse practitioners could be expanded to take the pressure off medical practitioners. While there is a provision in the Act for nurse practitioners to perform some roles, submitters believed this could be expanded further.

Some submitters commented that nurse practitioners should be allowed to perform assessments, noting that they provide some aspects of the service on a day-to-day basis.

> *"I believe nurse practitioners (NPs) should be permitted to participate in all aspects of assisted dying including consultation, assessments, prescription of the medication and delivery of the medication. There are multiple advantages to this. They are more often at the bedside than doctors are, particularly in aged care settings where they are increasingly replacing doctors. Their participation would help cover rural and regional communities where there is no doctor. Their participation would increase the assisted dying workforce and reduce the likelihood of burn-out for participating medical practitioners. NPs have the education and the experience for participation at every level."*

Conversely, some submitters thought that only medical practitioners should be able to provide the service and roles should not be expanded, commenting that nurse practitioners do not have the competencies relating to end-of-life care in their training and they should not be able to provide aspects of the service.

Other submitters stated that given the nature of assisted dying, only those with a high level of expertise in assessment, competence, eligibility assessments and prognostication should be able to deliver the service, and believed this was well beyond the skills of junior medical personnel and nurse practitioners.

Registration of medical practitioners and practising levels

A small number of submitters stated that they thought medical practitioners should be registered and licensed to provide the service with training which included psychological assessment and post procedural care.

One submitter noted that *"the IMP should not have to be continuously registered with the medical council for five years as this discriminates against clinicians who take time out for pregnancy / parental leave or are sick."*

VADANZ noted:

- *"The Act allows a postgraduate year three doctor to provide assisted dying services. This is highly unusual and markedly different from other countries where service provision is restricted to doctors with vocational registration (i.e., who have completed specialist training) and/or 10 years experience. There is no requirement for continuing professional development (CPD) and/or education or reflection on practice, and there is no monitoring of the performance of practitioners involved in providing the service. This needs to be more robust to ensure practitioners remain current and up to date with legislation/requirements, and a quality patient centred service continues to develop…the service needs to design and implement a framework around practitioner knowledge, skills and professional standing."*

DPA recommended that *"all persons and bodies involved in the EOLC system mandatorily undertake disability responsiveness and awareness training as part of their work."*

Wotton + Kearney, representing the Medical Protection Society (a mutual protection organisation for medical, dental and healthcare professionals that protects and supports members' professional interests), submitted:

- *"An AMP must be a 'medical practitioner' — i.e. any registered doctor with an annual practising certificate. A junior doctor who has achieved full general registration (e.g. a PGY3) could be an AMP and assess the person's eligibility and competence and administer the lethal dose of medication to assist the person's death. The clinical knowledge and assessments required combined with advanced communication skills and the medico-legal aspects of work under the Act are complex and challenging. It is submitted the Act should require that an AMP must be vocationally registered or be PGY10+ (i.e. they would have had at least around 10 years of experience)."*

Ethos provided the following comment:

- *"The EOLCA currently allows euthanasia and assisted suicide to be assessed and provided by a "medical practitioner", which just means a doctor with a current practising certificate. But in many areas of medicine, junior doctors are not allowed to practice unsupervised and must obtain oversight and sign-off on decisions from senior doctors with appropriate qualifications. To quote one senior doctor, "This reflects that decisions about what treatments are and are not appropriate are nuanced clinical judgements that often involve advanced communications skills as well." Because the EOLCA does not explicitly reserve the role of AMP to those with sufficient experience, there is a risk that a doctor with insufficient knowledge or training could assess a patient as eligible for euthanasia and carry out the associated procedures. It is true that the High Court has said that where an AMP "does not have the knowledge and* *experience to provide the advice required under s 11 or to make the eligibility assessment under s 13," he or she "may need to consult with, or refer or transfer the patient's care, to a practitioner who has the relevant knowledge or experience." (Hospice New Zealand v Attorney-General, [161]) But this should be made explicit in the legislation itself. The definition of "medical practitioner" should be amended to restrict this role to those with the appropriate clinical experience, perhaps by linking the term to vocational registration or something similar."*

Oversight of assisted dying

This section of the online portal addressed whether changes should be made to the roles and responsibilities of the following groups established under the Act to oversee assisted dying:

- **Registrar (assisted dying)** is responsible for: establishing and maintaining a register of approved forms for the assisted dying process; reviewing the assisted dying forms completed by practitioners to ensure compliance with the Act; receiving and managing complaints (including referring them to other appropriate authorities); reporting annually to the Minister of Health about the number of deaths occurring through assisted dying; and taking any action as directed by the End of Life Review Committee.
- **Support and Consultation for End of Life in New Zealand (SCENZ) Group** is a statutory body under the Act responsible for maintaining the list of medical practitioners and psychiatrists involved in providing assisted dying services, and providing contact details for replacement or independent medical practitioners and psychiatrists as part of the Assisted Dying Service. The SCENZ Group also has oversight of the standards of care for the medicines used in assisted dying.
- **End of Life Review Committee** is a statutory body appointed by the Minister of Health responsible for considering reports about assisted deaths after they have taken place and whether they show compliance with the requirements of the Act. The Review Committee may direct the Registrar to follow up on any information contained in an assisted death report that the Review Committee considers does not show satisfactory compliance with the requirements of the Act.

Question 12: Do you think changes are required to the roles and responsibilities of the entities established under the Act to oversee assisted dying?

Few submitters commented on this area, many replying 'yes', 'no', or 'unsure/uncertain', without further clarification.

VADANZ commented on the oversight groups in general:

- *"The role of the SCENZ group is ill defined and not particularly pragmatic at present especially after the formation of Health NZ and the delegation of many duties to the operating service inc. practitioner lists. It is unclear if there is a role for SCENZ at present or if this should be amalgamated into a robust clinical service with much strengthened clinical leadership and governance. The oversight roles should be* *combined with the review committee into a single robust group, independent of the Registrar and Health NZ."*

Wotton + Kearney, representing the Medical Protection Society, submitted:

- *"The Act does not provide for any in-depth independent review of assisted deaths. Such a review could contribute to timely patient safety, practitioners' education and training, and better outcomes for patients and their whanāu. Neither the SCENZ Group nor the Registrar have a review function. While the Review Committee's name suggests it will fulfil this role, its functions are limited to considering assisted death reports and it has no power to request further information. This raises a real question whether the administrative bodies established under Part 3 are providing meaningful oversight and accountability of the regime overall. The role and responsibilities of the Registrar should also be clarified, particularly in relation to information sharing with the Review Committee and the Health NZ / Te Whatu Ora operational services; the Registrar's procedure to refer complaints; and the Registrar's mandate to issue guidance."*

Some further areas of feedback raised are detailed below.

Data collection and reporting

Some submitters commented that there should be more detailed, transparent data collected, along with independent analysis.

In addition, a submitter commented that annual reporting means data is delayed and "*thus reviews such as the current one may not reflect the pattern of applications. Bi annual would be more useful in capturing the uptake."*

> *"…The recording and reporting requirements are minimal, as is the information provided to the Review Committee, which does not allow for sufficient analysis or public understanding of this fundamental change to the health system of Aotearoa New Zealand."*

Membership of the statutory groups

Many submitters commented on End of Life Review Committee vacancies, stating:

- *"the End of Life Review Committee needs to be fully constituted. It never has been to date, with vacancies for roles. This is unacceptable for such a serious piece of law – literally life and death. The failure to have done so indicates significant process issues and calls into question what other processes are flawed."*

However, other submitters noted that this was not the only group to have issues with meeting minimum member requirements and that all the groups and committees should be required to be fully staffed with good representation "*from all sides of opinion and background."*

One submitter questioned whether representation of other cultures and values are provided for within the entities constituted under the Act, noting: *"I think there is overlap in that there is a clash of interest and the lack of care for particular ethnicities -*

Māori, Pasifika etc (vulnerable communities) they will need their own people to better represent them and offer palliative care and give informed advice to both, not favouring one over the other."

Review following an assisted death

A small number of submitters expressed concern that the End of Life Review Committee makes their assessment after the assisted dying procedure takes place. They considered there needs to be a review prior to the procedure to ensure eligibility and compliance with the process under the Act.

The Registrar

A small number of submitters commented that the Registrar appears to work well and is a valuable safeguard. A submitter noted: *"Registrar's role should include implementing and maintaining a registry of end-of-life directives as described (i.e. include the living). Forms and processes need to be kept as simple as possible - a process of continual simplification, informed by the real world."*

Complaints processes

The Law Society commented:

- *"Section 27(4) of the Act specifies where the Registrar (assisted dying) must refer complaints received about the conduct of a health practitioner. The Te Whatu Ora website refers to an Assisted Dying Service Feedback and Complaints process, as well as the ability to make a complaint to the Health and Disability Commissioner (HDC). The health.govt.nz website then sets out information about the complaints process, again referring to both complaints processes.*
- *It is not sufficiently clear to service users and their families or support people, where complaints should be made and whether it is intended that certain complaints are made to HDC and others to the Assisted Dying Service Feedback and Complaints process. We suggest that consideration is given to clarifying the public facing guidance and ensuring it is accessible and can be readily located."*

Alignment with the wider health system

This section of the online portal sought feedback from submitters on whether the assisted dying process aligns with other parts of the health system, and whether this alignment could be improved.

Questions 13 and 14: Do you think the assisted dying process aligns with other parts of the health system? Is there anything that could be improved?

Overwhelmingly, submitters across demographics stated that they did not believe assisted dying aligns with the wider health system. Submitters considered the fundamental purposes of the health system and the Hippocratic Oath sworn by medical practitioners are diametrically opposed to the provision of assisted dying.

A small number of submitters said they were 'unsure', and others said they did not have sufficient understanding of the health system as a whole to comment.

Others commented that there were similarities between the health system and assisted dying *"in the sense of removing pain and suffering. No, in the sense that a health system is about living, not dying*."

One submitter commented:

- *"Currently there is resistance to mentioning a 'good death' as part of what our health system and medical practitioners should provide, along with promoting good health, treating illnesses, alleviating suffering, and prolonging life. Greater acceptance is required that death is part of life…"*

A few submitters noted that funding suicide prevention while funding assisted dying was incongruous: "*You can't aim for Zero-suicide rates in the population on one hand and offer it freely on the other - it is a false idea."*

Another commented:

- *"Somewhat. It does align with the abortion strategy which is a permanent solution to a temporary situation. It does not align with the mental health strategy of keeping people alive. There is also no form of community involvement, counselling, visiting or family involvement like most other parts of healthcare. There is no connection to te whare tapa wha - in particular, taha whanau."*

Locations where people can receive assisted dying services

Between 7 November 2021 and 30 September 2024, 9.3% of assisted deaths took place at a hospital, 8.8% took place in an aged care facility, and 3% took place in a hospice facility. The remaining 78.9% took place in a private residence.

Several submitters commented on the lack of options for locations where people can receive assisted dying.

It was a concern for many submitters that more hospices do not allow assisted dying on their premises, as people may need to be moved to a place where the assisted death can be carried out at a time when they are in poor health.

> *"Assisted dying does not align well with hospice-based palliative care and faith-based care facilities that "transfer out" if a resident chooses to receive assisted dying. We support individual conscientious objection, but not organisational conscientious objection. It should be a minimum requirement that Health care and Aged Care organisations are legally obliged to refer people to an alternative provider who does offer assisted dying and arrange for transfer to that alternative. They should also be obliged to publicly list their position towards assisted dying on their websites and in their literature so that people are aware of this from the beginning."*

Submitters also noted this applies to aged care facilities where people are receiving hospital level care, with one submitter noting that *"persons living permanently onsite or as patients at these facilities who wish to access assisted dying, need the law to better protect them against obstruction, obfuscation or delay."*

One practitioner providing assisted dying services commented: *"Better access to residential care beds and hospice support for patients that can't/don't want to have their assisted death at their own home. Leaving hospital beds as the default "last resort" is not appropriate due to the pressure on the health system and the clinical environment for a patient at the end of their life."*

A small number of submitters believed that there should be dedicated clinics or facilities in New Zealand that provide assisted dying services, as happens overseas, noting that options were limited in terms of the location for the assisted death unless the person wishes to die at home .

Some submitting organisations commented on the issue of institutions objecting to providing a location for people to receive assisted dying.

VADANZ commented that:

- *"The Act allows for individual conscientious objection. This is likely to be a pragmatic and useful inclusion whilst this major social, cultural and clinical change occurs. This Act is silent on the concept of 'institutional objection' but has been interpreted to allow institutions to conscientiously object with significant impact on patient access to Assisted Dying care. This should be explicitly revised to ensure patients can access the legal service of Assisted Dying in their home environments inc residential care institutions and any govt-funded institutions including hospices."*

On the other hand, the NZ Catholic Bioethics Centre commented:

- *"The current ability for Institutions to exercise conscience must be protected. While the EOLC Act is silent on institutions, it has been ruled 'that organisations like hospice*

> *services, aged care facilities, or GP practices can object to assisted dying, as set out in the End of Life Choice Act, taking place on their premises or with the assistance of their staff', under the right to freedom of conscience under the New Zealand Bill of Rights Act 1990. Access to assisted death has been described 'working well'; there is no need to force institutions such as hospices or hospitals or rest homes to provide assisted death on their premises; such a change could bring about a significant impact on the atmosphere of these places and on the ability of the staff there to work in ways that support their approach to healthcare."*

The Cancer Society commented that New Zealand should *"establish rules within the Act, or in policy, regarding institutional objection. We broadly favour the approach to regulating institutional objection in the Queensland VAD Act."*

Palliative care

Aspects of palliative care were mentioned in many submissions, with people commenting that palliative care is an essential part of the journey for people who have received a terminal diagnosis. In some cases, submitters stated that exploring palliative care should be mandatory before people commence the assisted dying process.

Submitters often commented that assisted dying services are not necessary, as suffering can be alleviated by effective palliative care, and hospices already provide care and comfort for people at the end of their lives.

Some noted that 'assisted dying' already exists in other forms within the health system (such as withdrawing treatment or providing palliative sedation such as morphine). This was cited as another reason not to have a dedicated assisted dying service.

Submitters also commented on the funding issues experienced by hospices, noting it was incongruous that government funds assisted dying but not hospices.

> *"While the act allowed the people to choose Euthanasia, the government should not be making it the easier choice. Currently, while our dedicated Hospice organization struggles for funding, the option of euthanasia is fully funded. Just as the health system aims to help New Zealanders to live well, so the system should be supporting people to die well, and not be pushed into taking a short cut."*

Submitters noted that this is particularly an issue for people in regional and rural areas who do not have access to the same level of palliative care and service available in metropolitan areas.

Other views

Organ donation

A submission was received from Organ Donation New Zealand (ODNZ) (a 24 hour, national organ and tissue donation service which is part of New Zealand Blood Service) noting that some people who choose an assisted death could donate their organs and/or tissues after their death, and recommending the Act be amended so that

"…individuals who are eligible for assisted dying may also be eligible to donate organs and/or tissue after an assisted death (subject to compliance with other applicable legislation, such as the Human Tissue Act 2008); and require that the attending medical practitioner consider discussing organ and tissue donation with an individual who has been assessed as eligible for assisted dying, and where appropriate raise the possibility of donation with that individual."

ODNZ noted that it believes this aligns with the ODNZ guiding principles of equity, respect, good practice, and self-determination, as well as the Ministry's document *Increasing Deceased Organ Donation and Transplantation: A National Strategy*, and the health sector principles set out in the Pae Ora (Healthy Futures) Act 2022.

Alternative and spiritual health providers

A small number of submitters believed there was space for people to consider alternative health providers and Māori spiritual healers before accessing the assisted dying service or as part of the assisted dying journey.

> *"The process of finding a medical specialist to approve assisted dying should be easier (fewer gatekeepers); perhaps religious specialists or a Māori spiritual healer could take the place of one of the medical specialists since dying is a spiritual matter as much as a physical matter."*

Other feedback

The final section of the online portal asked submitters whether they had any other feedback on the Act.

Question 15: Do you have any other feedback related to the Act?

In this section, most submitters took the opportunity to share their personal stories, experiences and thoughts. Below is a selection of those submissions, identified by demographic and expressing a range of views.

Members of the public

“In my experience as a nurse and a person who cared for family through to their death I have found NZ services are already very very good, kind and helpful allowing a person to go through the process of dying with dignity.”

……

“Until such time as Holistic approaches to life are fully explored by all that are involved, we may well be defrauding the patient of a potential increase in quality and quantity of life. Any form of assisted mortality should only be explored once ALL avenues have been exhaustively explored in an unbiased manner without preconception.”

……

“I think that assisted dying should be regarded as a form of culpable homicide again. There is no way to draft such legislation as to eliminate abuse. As for ethical concerns, I believe taking an innocent life because of their medical condition will never reduce the suffering of the patient and the people around them. Even worse there will be always the implication to the patient of being unwanted and unvalued and being a burden to society, even when it is not the case and even if the patient is not eligible. this will place an undue mental burden on the patient on top of all the other problems they are facing, and overall greatly reduce the quality of life. Instead we should be redirecting the resources from Assisted Dying to palliative care without that option.”

……

“It is clear there has been measured and respectful use of the legislation since it was enacted. Please remove the underlying moral and social constraints to accessing assisted dying and encourage uptake. Bring New Zealand health services to a more mature and compassionate space so we can receive care in our last days not terrible struggle and potentially family assisted suicide."

……

“My daughter died recently in a hospice. She applied for assisted dying, and the response from the 2 doctors was smooth and timely - no difficulties there. However, it wasn't possible for the process to continue as there was nowhere manageable for her to go to have it administered, except in an ambulance from the Wellington hospital up to the Kenepuru hospital, or to a relative's house about the same distance away, neither being appropriate. She needed an oxygen tank and various lines delivering continuous pain relief. In either case, there would have been a further problem, she couldn't swallow apart from sips of water which she immediately vomited up, so pills wouldn't have been possible. She couldn't administer an injection herself. Assisted dying, though approved, was just not possible. It was a very upsetting, stressful and unsettling time for my daughter and our family, when it should have been a calm and peaceful way for her to end her life. If there had been a pleasant, accessible facility at a nearby site e.g. the main hospital, my daughter's wishes could have been met.”

……

“The law was written in a hurray and I are heard from medical friends and law makers, it was badly written. It did not take the usual time to get through law making processes as it was more of a political agenda than one that considered the human beings behind this. For a country to allow people to commit suicide and then worry about the metal health of their citizens on one breathe is not a country that has thought deeply enough about the whole of life and what they really want to stand for. My concern is that writing a law that allows for PAS is VERY trickily and the temptation to let standards slip is far too easy because of the complexity of the task. It is not as easy as saying I am in pain I want to die. There was already a medical pathway to allow for 99% of people to die without pain. What we now have is potentially a can of worms when someone is unwell and then subtle pressure can so easily be applied. It needs to be a VERY VERY high bar.”

……

“I repeat that assisted suicide should be user pays. This would greatly clarify the demand for it. The law is not needed. It is a gross distortion of medical practice. It implies that some lives are more valuable than others. The funding necessary for it would be more productively spent on improving life through the funding of palliative care. The review appears to be part of a predetermined liberalisation of the law, encouraging assisted suicide. It seems strange that assisted suicide was once a crime and is now being encouraged by the law makers. Ethics seem to have been turned upside down.”

……

“There is widespread opposition to this law from those in the disability sector, senior citizens, human rights advocates, lawyer, doctors and others in the health sector. This Right to Life Choice Act only provides a 'right' to one choice - premature death. Of course from a financial point of view, Euthanasia is much cheaper that funding a good health system and palliative care to support people until the end of their days. Again as in Nazi Germany the vulnerable, the disabled and the weak are being preyed on. The mandate of government to protect the weak from injustice. Unfortunately the previous Labour government failed in its obligation by passing this Bill. I call on this government to repeal this Bill and care for the people of our nation whether they are old or young, sick or healthy, poor or wealthy. What legacy are we leaving for our children: one of a caring society or a place where there is no safety for the weak? Several submitters utilised the following statement in the Other Feedback section to express their views:”

……

“Euthanasia and physician assisted suicide are not needed in New Zealand. End of life care should be about caring for someone till natural death, using the extensive supports available via palliative care which addresses the physical, mental, social, and spiritual needs of people.”

……

“The current Act distorts medical practice; explicitly suggests that some lives are not worth living; and implicitly says to those in our disabled and ageing communities that their lives are not as valuable as younger or more abled people.”

……

“Now the law is in place, the continual push to expand the scope is happening as was predicted by proponents.”

……

“The functioning of this law remains clouded by a lack of transparency and a failure to follow the simplistic review structures already in place. This in itself should be raising concerns even before the ethical implications are considered.”

……

“The law should be repealed however, seeing this review process appears designed to enable expansion of the law, then it is critical that no changes in scope, eligibility, or conscience rights (for medical/health practitioners) should be made. Finally, this whole review process is highly questionable. The Ministry’s review of itself (in effect) is very narrow, including choosing who they will talk with. Secondly, that these public submission comments have no bearing on the review itself. While useful to have a collation of the public’s thoughts, it is concerning that these thoughts are explicitly to be ignored by the review.”

……

“My view is obvious. I am 83, have neuropathy and osteo basically from treatment of a rare Grade 4 cancer. Radiotherapy kept me alive. But, my ability to be independent is being compromised and I dread the future….to the extent that, while I can I will take my own life. This should not be……I should have choice.”

……

“My husband had a traumatic ending to his long life in 2018. The memory of his pain and my distress affects me still. There was no dignity in how he was bundled out of our home – crying.”

……

“I am concerned that of the 1000 applications received in 2023 for assisted dying that only 430 met all the criteria. The "Lost Competence " 53 and "Lost eligibility" 13 and "Died in the process" 307 means the Act is not yet functioning to best outcomes for the applicants.”

……

“The elephant in the room is the rising cases of dementia. We need a process whereby people can make an advance request for an Assisted death, when their illness progresses past a specified point. All existing clauses relating to actively seeking AD and consenting to it, free from pressure, must apply.”

……

“This is the slippery slide that was always expected. I do not want to be a part is a society that endorses the taking of life.”

……

“No. I am saddened, as a NZ born person, that we have sunk this low as to legalise assisted death. The contradiction is enormous! We claim to promote suicide prevention, then we legally assist suicide. What ever happened to "First, do no harm?"

……

“This Act was not a result of a comprehensive consultation with the public and does not reflect our voice. Scrap the Act altogether.”

……

“I think that the Act has a good balance. It is fair. If I selected to use this Act one day, I would be prepared as a member of the public to proceed with it. However, I would want a stand down period which I would self impose and I would want a period of counselling and discovery before embarking on this ending. I am also concerned that society is removing the value of eldership and the aging from society. we use phrases like dying with dignity. My whanau who have died with serious medical conditions and cancers, have indeed died with great dignity through family care and analgesia. they have had time to farewell life. They end well despite the pain. They even process the past and find meaning through suffering. Yes, this is a choice but we need to safeguard the message this Act provides. Once again a quick fix. assisted death at life end is no guarantee for dignity at the end. Rather the opposite dying in despair, no hop and possibly alone.........”

……

“My father used the assisted dying option to end his life. It was an amazing experience for our whole family. Of course it was very sad time for us but it made his death a painless experience. He got to say goodbye to all his children and grandchildren individually. He chose the time and place of his death.”

……

“My husband and I have now lost all our parents and Dads who was the only one who qualified for assisted dying was by far the best death experience for both us and him. In my opinion the other deaths in our family were horrific for both us and our loved ones. It is bad enough they are dying but to die in misery and pain is just awful.”

“In New Zealand the process of increasing pain relief through morphine has been used, this of course has also quickened death. I see no need for any other Act.”

……

“We have made a good start but we need to show the maturity to be able to broaden access and acceptance of the right for people to choose this option.”

……

“I firmly believe that the wealthy govt leaders are trying to save money by extending euthanasia laws, rather than caring for the sick and elderly like other countries do. They continually interfere with kiwis from birth to death by coming up with solutions to save money and this is another one.”

……

“Wanting something, especially a controlled death, doesn't make it right to have. Human life is precious, even when painful and untidy. Taking life is usurping a responsibility that belongs to our Creator. Most of the world's history and all world cultures have understood this until very recent times, when we have, ironically, the best end-of-life care and medication there has ever been. Improve hospice care instead."

……

"I think it is sad that this legislation was ever enacted when those in hospice work were giving people mental, spiritual and physical care, comfort and guidance that enabled them to have meaningful time with family and friends."

……

"Euthanasia and physician assisted suicide are not required in New Zealand or any country that has a properly functioning health care system. End of life care should be about caring for a human being until natural death, using the extensive supports available through palliative care which meets the physical, mental, social, and spiritual needs of people."

……

Practitioners who do not provide assisted dying

"The provision that assisted dying cannot be accessed by those suffering from 'old age' is ageist. There should be a provision for mentally competent older people to access assisted dying services in the case of severe frailty and multi-morbidity. This would also require the removal of the 6-month timeframe to death. "

……

"Assisted dying is a reasonable option in a health system that isn't meeting some basic needs of its consumers ie. adequate GP and ED access for individuals who are near the end of life, community and hospital palliative care access, access to adequate physical care supports like quality residential care as a person's physical capacity declines. If we care about improving the experience of dying people in NZ these need to be addressed also."

……

"I strongly disapprove of this act. It is not part of the Health system at all!"

……

"This act is already too broad with too few safeguards - more rigorous evaluation needs to be done for people seeking euthanasia."

……

"The data collection and reporting on AD under the Act is incomplete. The Aotearoa data collection standards do not match the international standards in Oregon, Canada or provinces of Australia."

……

"There is the perception by the public that this law is running well but that has not been my experience. Families have been left in conflict, workplaces in moral distress, and health professionals have had to practice in a way that is foreign to them. Some transparency and balance would help people with a life-limiting illness make better choices."

……

“End-of-life care should be about "caring" for someone. There should be no distinction on who to provide medical care. End-of-life care is about genuine compassion and support for every individual, regardless of their circumstances. All individuals deserve access to comprehensive medical care, including palliative care. Assisted dying should not be categorized as medical care, as it ultimately denies individuals the opportunity to receive proper medical support. The existing legislation distorts the practice of medicine and puts vulnerable individuals at a disadvantage.”

……

Practitioners who provide assisted dying

“I think it works well. I feel it is a privilege and an honour to carry out someone's last wish and the experience is truly humbling. I would definitely like to see the time (six months) removed as I see some people who are truly suffering (eg MND, Parkinson’s,) and easily fulfil all the criteria except the six month one. This is VERY distressing for them.”

……

“Yes, the current law was written by lawyers and politicians. It does not put the patient first.”

……

“It doesn't have any provision for emergency time frames. Many suffering patients cannot wait 2-3 weeks. It also treats assisted dying unlike any other life-changing medical decision, with too many hurdles, delays and hoops to jump through, for patients that are already dying. And suffering.”

……

“It needs to be streamlined into a 1-week process, at the most.”

……

“A person is a body, mind and soul. Death and palliative practice is often the end of the medical or physical but the spiritual closure a patient and their family find at the end of life is sacred. Without this time for the soul our society is robbing itself of peace. Statically over 70% of people have a 'supernatural' experience on their death beds and it has been a joy to bear witness to that peace which families and the person receive when death has been well managed through expert palliative medicine and care, as well as making space for the unseen.”

……

“This is a changing situation. I am involved with providing assisted dying services to patients in the public hospital setting in the last 12 to 18 months. I have seen a softening of attitudes by the medical and nursing staff in public hospitals to the benefit of the patient who is requesting an assisted death on site. Things are steadily getting better as medical and nursing staff fears of Assisted Dying reduces. However, the biggest opposition is hospices in NZ (bar one in Auckland) by not allowing patients to die on site with an Assisted death. I find this a great deal of stress and frustration for doctors, such as myself, families of patients, and most importantly, the patients themselves. I have had cases where this refusal to allow an assisted death on site has created major stress for the families of their dying loved ones, where the family is forced to remove the patient to the home setting where the family members feel quite uncomfortable about their loved one being forced to pass in their own homes Hospices can and should allow the person to pass on site. There is my firm belief that these hospice doctors and nurses have no place in forcing their beliefs on dying patients in the hospice system. I find this particularly difficult to except given that hospices receive public funding and therefore have an obligation to provide a public service that's clearly required. It is my firm hope that overtime this major barrier will be removed. It is my belief that government does have a part to play in directing hospices to allow practitioners, such as myself to go on site to provide an assisted death."

……

"As a practitioner at the coalface, I find it an absolute privilege, helping people pass at a time and place of their choosing with dignity and with their family, and loved ones around them. It is my firm wish that those people with neurological diseases have a much easier path to eligibility than is currently the case with an unrealistic six-month prognosis being required. I have currently two patients with severe Parkinson's that are suffering every day with no realistic prospect of a timely assisted death as a result of this legislation as it currently stands. Please consider these people and allow the necessary changes to be made."

……

People from the wider health system

"It would appear ELOC is working as it is, which, while I remain weary as to the risks, I am heartened we have people on the board who can make sound clinical decisions. The disability community is under extreme pressure with cuts, and attacks on our access to supports and services etc, if you were to extend this Act while disabled are under attack from cuts etc, you will essentially create an issue which could lead to abuse of this law on disabled. We are seen as burdens, as wasteful eaters by many still out there, we need protections, we do not need nondisabled who don't understand the complexity of impairment to be put at risk of having to make a fake choice because they are denied supports etc. do not extend it to non terminal cases please."

……

"Feedback from people who have been accepted is uniformly positive and the relief is clearly very significant. This is mirrored by the comments from people close to the applicant, who have been suffering watching their loved one suffer. They share a determination to make very good use of the short time left, secure in the knowledge that they have a planned, peaceful endpoint."

……

"Feedback from the providers is reassuring they speak of the sense of privilege, the differences between a planned assisted death and the traumatic ones, for patients, families and health staff. they find the training excellent and the system supportive and easy to navigate. The travel required is sometimes an issue."

……

"Other countries have found that once the gate was opened more and more opportunities were presented that allowed people to have this option. Please be careful when considering human life and how precious it is. Kia ora."

……

“Dying is very final. This is in reality assisted suicide. This decision should not be allowed to be easily and without the person receiving appropriate health care for their conditions. Please fix access and availability of good quality health and hospice care for all as a priority. Assisted Dying should not be available if good care has not first been provided.”

……

“Palliative care should be fully available to the dying wherever they live. It is a sad country that fully funds Euthanasia and has bake sales to fund Hospice. Ideally both should be equally available when one finds themselves in a potentially end of life situation.”

……

“The premise of the Act is that taking a human life under certain circumstances is right. But suicide is not. Murder and manslaughter are not. Even from a totally secular view, why should assisted dying/killing a patient be ok if the others are not? The Act should acknowledge that human life is intrinsically valuable. Many in our country with religious beliefs believe this. Christians believe people are made in the image of God, so human life is of great value. This Act does not consider the spiritual side of humans but treats us as no better than animals which can be "put down" when suffering or when inconvenient to the carers. These views are ignored by proponents of the bill. Killing is not the only way to put a person out of their misery. Love, kindness, friendship, caring medications, doing no harm are better alternatives.”

……

“The Act needs to be revised from an angle that is not fundamentally financial. It is a mistake to think that ending life will ultimately benefit New Zealand. The language of care towards death needs to be replaced with language of care towards life, including the life benefit of natural death processes to those who accompany them. The Act needs to be clear that funding priorities of the NZ government are for life care, suicide prevention and hospice development, and its language needs to reflect this.”

……

“This review is typical and expected - it was predicted that advocates for this law would want to extend it to include all sorts of conditions and situations that were not included in the original bill (mainly because no one would agree to it then … but they figured if they just gave it time and warmed people up to the idea, then maybe they’d agree … just like the proverbial frog in the pot of warm water). This is a slippery slope that we would do well to avoid at all costs.”

……

“Please for the sake of New Zealand’s health care future and practitioners reverse it. It's very confusing to send opposite messages to a professional that you should preserve and care for and heal lives but also destroy them. Health staffs’ mental health will decrease hugely because of incongruence and decompartmentalization.”

……

“It is very good that the AD process is available in NZ although it needs to have wider eligibility criteria to allow for use by people with degenerative diseases that typically lead to premature death.”

……

“This is an ethically loaded dilemma for health professionals and quite traumatic for some. Also traumatic for some family members so perhaps there should be consideration for ongoing therapy for those post traumatically stressed.”

……

“I have held the hand of my darling friend of 50 years at her request, whilst she was euthanized recently. She was 87, with inoperable bowel cancer. Despite Palliative Care service, visits and morphine, my dear friend was in constant pain. Once I had processed my friends request, I felt it to be an honour. The Doctor and R/N were so professional, kind, and sensitive to my friend and all present. It was all fully explained, options to be present or not, and we were all given however much time we wanted to speak with Marg. It was a peaceful gracious time. so delicately handled.”

……

“We need to see changes and I am interested in how many people who are declined an assisted death then go on to die by suicide or stop eating and drinking to hasten death and the impact this has on society as a whole.”

……

“I believe it has made a very positive difference for patients who have made the choice to have assisted dying. Prior to the act coming into effect, I nursed patients who had tried, unsuccessfully, to end their own lives and that was extremely painful for them because they still had to endure an end of life that they had tried desperately to avoid.”

……

“Integrity on the part of the medical practitioners needs looking at seriously. I am not confident the current Medical Council are sufficiently rigorous or ethical a group to oversee the persons/ practitioners involved in any process.”

……

“I've been a RN since 2008, I've been in health care since 2003. I've worked in elder hospitals and acute surgical wards. I have cared for many patients who have received a terminal diagnosis. I have cared for people in the final stages of dying. I've seen good deaths and I've seen bad ones. All of the bad ones came about because the patient fell through the gaps in the palliative care service.”

……

“Over the years, before EOLC Act passed, there were very few folks who were bold enough to ask me to give "a little extra morphine" to hurry things along. It was never pushed by a desire for a kind end for their loved one, rather inconvenience. One family member told me they expected the patient to die by Sunday as they had a flight booked for Monday. I have far too many stories of horrible people abusing their vulnerable relatives.”

……

“As a member of the Allied Team at Mercy Hospice, I oppose any changes to the current euthanasia law. I value the life of all New Zealanders. Extending the Act to people with longer prognosis, or to mental health problems could lead to more vulnerable people having access to an easy way out when they feel vulnerable. On the contrary, more funding should go into palliative care and hospice services so that ill patients can be cared for physically, emotionally, spiritually and socially. We do not need to extend the criteria of that law; we need to provide sick patients with more care."

……

People who have sought assisted dying, or supported someone to receive assisted dying

"We were so very grateful it exists, even in its restrictive form. My dying husband said this many times. It meant he was able to have a humane and dignified death at a time of his choosing. His take on it was that he would rather a drug went into his system and stopped his bodily functions in less than four minutes, than that it happened over four days as the intake of drugs was ramped up in the name of pain relief. The end was the same only quicker and more planned. Our mourning encompasses memories of a shared, gentle and kind death at home with family around."

……

"I would like the Act to address organisations (such as Hospice/Rest Homes) being able to deny the procedure happening on their premises. My Dad was in a care facility which was his home yet we had to move him somewhere else (when he was very sick) to have the actual procedure carried out."

……

"My personal experience of the Assisted Dying process was positive and I am eternally grateful that this was an option for my mother as the alternative for her living until a natural death would have been traumatic for all of us, but incredibly agonising and undignified for her."

……

"I do not fully agree with the assisted dying act, as people should be allowed to die naturally. However, I also respect that in some situations, it could be beneficial for patients to have assisted dying, depending on their situations."

……

"We are a multi-cultural, multi religion country with varying views on this Act. The Act should not be influenced by these cultures/religions. The Act should be purely concerned with the wishes of the individual and their quality of life and wishes."

……

"My brother who had inoperable pancreatic cancer was able to access Assisted Dying as he wanted and passed away peacefully. I am grateful that he had this choice provided by this Act and that he had control over his own destiny. I fully support this legislation. However, the actual process for him, his wife (his primary caregiver at home), his children, his two siblings and the doctor involved was painful. It was unnecessarily complicated. It was made worse because of his rapid illness and his location in Coastal NZ. Please consider the Canadian MAID laws and improve our Act. Particularly, the final consent process. At a minimum, please allow a waiver to the final consent process. I do not want other New Zealanders and their whanau to suffer like we did."

……

“My son, aged 54, with terminal cancer chose assisted dying. I am so glad he was able to do so. He may have lived another 3 or 4 weeks but he would have had to move to another place, he would have been cared for by people he didn’t know. He would have been unhappy. He died surrounded by family and friends, conscious and alert. The doctor was marvellous. It could not have been more graceful a process. I am so glad this is available in our society.”

……

“I am so, so glad that my partner Phil was able to use assisted dying in March this year. He was only 57 years old and was dying from prostate cancer than had moved into his bones 3 years ago. Over that time, he did a couple of different chemos, there was quite a bit of radiation, mostly on the tumours in his skull towards the end, & in the end a lot of morphine. His last couple of weeks he could barely walk, but with my help could make it to the toilet, which he only needed to do once a day. He was about to need full time hospital-level care, with more & more pain as the tumours took over more of his bones. I'm so glad he didn't have to go any further.

Phil had the most beautiful death, surrounded by people he loved, he was not afraid at all at the end, he knew it was time. He spent 2 weeks saying lots of goodbyes to special friends - it was tiring but it also perked him up, & it helped everyone else so much too, that they could say goodbye. He also had an excellent goodbye party last October with lots & lots of friends, timed for as soon as the worst of the chemo effects had worn off, as we knew it was only going to be downhill from there.

His second-to-last week I was worried the whole week that he had left the Assisted Dying too late, as you have to be judged competent on the day & he was starting to have some confusion at times. But his last week I could see he was going to make it. Make it to be able to have a beautiful peaceful death at home with family, a few close friends & his beloved dogs rather than having to have a long drawn-out more & more painful existence unable to enjoy food or anything & be in more & more pain, & quite probably having to leave home & go to an old people's home (as hospice here only have short-term beds).

Beforehand he thought he would know when it was time, when he could no longer do any of the things he loved - skiing, mountain biking, cooking, eating, taking the dogs for a walk on the beach, playing bass in his band - but then he just got caught up in keeping going even though there was none of that left. In the end it was a combination of his dad coming from Dunedin to say goodbye, & a friend talking to him about how Māori seafarers would navigate using love, light & frequency when they had no map, reading the signs. He realised it was okay to let go, it was time. He was ready, he wasn't scared, we were holding hands, it was beautiful. And after he had gone, I found that a lot of my grieving had been done ahead of time over the years of knowing what was coming, of having to let go of things bit by bit by bit, & mostly I felt relief that he didn't have to suffer any more. And I could remember the good times instead of living the hard ones.

Luckily for Phil he was in the category of people with a terminal illness with less than 6 months to live, but there are many people suffering hugely & with irreversibly declining physical health that do not fall into this category & are therefore unable to use assisted dying. I really hope the eligibility can be widened to allow people suffering unbearable with no hope of getting better to be able to stop, instead of forcing them to continue suffering."

……

Other

"Human rights protections on the right to life are needed in national law. New Zealand is a signatory to the Convention on the Rights of Persons with Disabilities, which includes Article 10 – affirming that disabled people have the right to life and Article 4.3 – requiring governments to actively engage with disabled people in relation to law and policy. [1] Further - ableism is the devaluing of bodies and minds that deviate from accepted norms and which leads to beliefs like disabled people inherently having lower quality of life and/or being less worthy of support. We're seeing the latter play out at scale from this Government, evidently targeting not only disabled but also Māori and all those living in poverty, stuck within the justice system, or at heightened risk of homelessness. Over the years, these concerns have been raised in many countries by disabled people including here in Aotearoa. [2] In such an environment, the idea of progressing rights to assisted death is terrifying for many of us disabled because even though we are not the intended target, it is far too easy for some in our community to become the unintended recipients."

[1] **https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf**.

[2] **https://ojs.victoria.ac.nz/pq/article/download/4542/4029/6098**.

……

"We need dedicated places for people to go to die by Assisted Dying. If they do not want to die in their homes, hospital is not a good alternative. Poroporoaki in the Marlborough sounds provides a beautiful place for people and their families to go to create final memories in the last days of life, and where a person can receive AD. We need many more places like this around the country. Not just for AD, but it is very important to have places where AD patients can go to die well, and with the dignity, peace and tranquillity they deserve in their last day of life."

……

Organisations

"The End of Life Choice is a blessing for many people. The problem is that there is so much misinformation and disinformation about this subject that has been written in the press or spread by people who do not agree with End of Life Choice. I suggest it would be a good idea to research the countries that are advanced in their thinking - let's join them. I THINK WE SHOULD ADVERTISE END OF LIFE CHOICE and see how many people may be interested in knowing more."

……

"I am very grateful that the Act has come into play, and it has given many a way to die well, before their quality of life is totally unbearable. as Doulas we provide non-judgemental holistic care of the dying, so we support those who choose to die naturally, or by AD. It's up to the person to make their own informed decision. But it's our job to ensure they have all the right information in order for that to happen. I do feel the changes I've suggested are very important for us to strengthen this Act in order to help our sickest and most vulnerable people. thank you."

……

"DPA recommends that this review investigate the Victorian assisted dying legislation as being a better model for New Zealand to follow given that it affords more robust safeguards to protect the interests of disabled people and people with health conditions. We also reiterate our earlier recommendation that disabled people and disability organisations, including disabled person's organisations, are involved in all facets of decision making around the assisted dying review.
Recommendation 6: that the Victorian assisted dying legislation is investigated as a better model for strengthening New Zealand's EOLC Act. Impacts on Tāngata Whaikaha Māori and ethnic communities. It is important to note that not all cultures follow an individualised approach to life, with some taking a multigenerational approach and this includes many Māori who would never think about euthanising a loved member of their whānau. This is reflected in the most recent New Zealand assisted dying statistics which show that lower percentages of Māori, Pacific and Asian peoples opt for this compared to Europeans who do so by a significant percentage. This means that voluntary euthanasia remains a largely European concept that remains largely foreign to people from other non-European nations. It is essential that the views of Māori, Pacific and other ethnic communities are accorded due weight in terms of this review."

……

"There is a fear that if assisted dying becomes being applied more widely that Tāngata Whaikaha disabled Māori will feel more pressure to go through assisted dying, something that will be concerning to many whānau throughout Aotearoa."

……

"The Act makes no reference to Te Tiriti o Waitangi, or tikanga Māori. There is no provision, for example, for members of the Review Committee to include individuals with suitable knowledge and experience of Te ao Māori and tikanga. Nor is it clear whether there remain concerns about how the Act has impacted Māori. The Law Society recommends this is this is included in the Ministry's review, informed by wide and meaningful engagement with the community."

……

"This is an exceptionally dangerous request, and one that needs to be absolutely and explicitly refused by the New Zealand Parliament.

Regarding the media, we have concerns that their pro-euthanasia campaigning lacks balance, rarely presents a thoughtful counter narrative and oftentimes includes misinformation.

As a result of this, we feel that the New Zealand public has been misled into the nature of the EOLC Act, [which is, quite frankly, not fit for purpose] and the consequences of voting for.

We believe that the members of the New Zealand Parliament need to sincerely engage with the issue, to do appropriate research, and to take the time to listen to views which challenge a pro euthanasia narrative.

Attempts to dismiss such views as religious extremism, or the imposition of faith-based dogmas on a secular society are, at best, unhelpful.

This issue touches all Kiwis, and as such, every person and group who is part of our diverse society has a right to be heard without prejudice and bigotry. The fact that we are also speaking specifically about the state-sanctioned legal right to deliberately end the life of a patient or assist them in their suicide means that concerns must be treated with utmost care and seriousness.

To ignore the opposing view because of some ignorant opinion that we are all religious extremists is a naive assumption that will harm vulnerable New Zealanders. Expansion of criteria cannot just be a ‘knee jerk’ reaction to essentially cherry picked, emotionally harrowing hard cases peddled within the media.”

……