Frequently asked questions about the End of Life Choice Act

What question will voters be asked in the referendum?

Key points:

- You will be asked the question "Do you support the End of Life Choice Act 2019 coming into force?"
- The referendum question is not about whether New Zealand should have some form of assisted dying.
- Electors are being asked to vote on a very specific assisted dying regime as laid out in the End of Life Choice Act 2019.

- The New Zealand End of Life Choice Act 2019 differs from other assisted dying regimes around the world in significant ways; it is both broader in its scope and has fewer and less robust safeguards than assisted dying laws in some other jurisdictions.
- There are New Zealanders who broadly support some form of assisted dying but who are opposed to the End of Life Choice Act 2019 because of its many flaws and lack of safeguards.

What does 'assisted dying' mean in the context of the End of Life Choice Act 2019?

'Assisted dying' is a generic term that can refer to assisted suicide or to euthanasia, or to both practices together. The End of Life Choice Act 2019 would allow both assisted suicide and euthanasia.

Assisted suicide occurs when lethal drugs are prescribed or supplied by to a person at their request and self-administered by the patient with the aim of ending his or her life.

Euthanasia occurs when a third party, usually a medical professional, intentionally and directly ends the life of a person by way of a lethal injection or the administering of a lethal drug.

The term 'assisted dying' is imprecise because it fails to distinguish between acts of 'assisted suicide' and acts of 'euthanasia'. The difference is important because the numbers of deaths in jurisdictions which allow only assisted suicide, such as Victoria (Australia), Oregon and Washington States (USA) are up to ten times lower than countries which allow euthanasia (Canada and the Netherlands).

Do most voters understand what they voting on?

No. Research by UMR in July shows only 33% knew there was even a referendum coming up. Fewer know what it's about and only a fraction of us have read the Act that will become law if it receives a majority vote.

We believe that Kiwis are confused about what the End of Life Choice Act aims to legalise. In November 2019 a nationwide Curia Market Research found that 74% of New Zealanders think the Act would make it legal for people to choose to have machines turned off that are keeping them alive. This is already legal. Similarly, 70% of respondents thought the Act would make it legal for people to choose to not be resuscitated. Again, people can already ask for such a request to be added to their medical file.

What's the problem with the eligibility criteria?

Key points:

- The eligibility criteria do not require that a person be receiving appropriate treatment or care for their illness or that they first try palliative care.

- There is also no corresponding right for New Zealanders to have access to quality palliative care or support for their terminal illness as a pre-condition for establishing eligibility.

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- Because palliative care is not uniformly available throughout New Zealand and not fully funded, this means that some people may choose assisted dying when they don't really want it, because of a lack of other choices. This is happening overseas.

Read more:
Under the End of Life Choice Act 2019, a person may be assisted to prematurely end their life if they meet all the following criteria. The person must be:

- a New Zealand citizen or permanent resident; and
- be aged 18 or over; and
- be suffering 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 acceptable; and
- be competent to make an informed decision about assisted dying.

Many supporters of euthanasia, including the Act's sponsor, believe that the law being proposed is too restrictive because it only covers terminal illness of six months or less. Proponents and opponents generally agree however that, if the End of Life Choice Act 2019 comes into force, the eligibility criteria will be extended in New Zealand, as has happened in all overseas jurisdictions that allow euthanasia (notably Belgium, the Netherlands, and Canada which is removing prognosis as a requirement).

Can a person receive assistance to die if they are suffering from mental health illness or have a disability of any kind – or simply very old?

Key points:

- Terminal illness, age and disability are not mutually exclusive.
- People with mental illness or disabilities will be eligible for a premature death if they also have a life-limiting illness that a doctor believes could end their life within six months.

- What the Act states is that persons with any form of mental illness, disability or advanced age will not be eligible for any of those reasons alone.

Read more:
Almost without exception, disability advocacy organisations world-wide oppose assisted dying because of the lack of choices available to many disabled people as well as the negative attitudes they encounter within society, including health providers – 'Better off dead than disabled'. Because of this, it is not unreasonable to suggest that persons with a disability or with severe mental illness, who fit the criteria (because they also have a terminal illness) will be more likely to choose assisted suicide or euthanasia than other persons in a similar position.

In the Netherlands and in Belgium, it was not originally envisaged that disabled people or mentally ill people would be eligible. However, that has changed. In Quebec, the legal phrase, "a reasonably foreseeable natural death", originally touted as an important safeguard, has also been removed because it was seen as discriminatory. There is also considerable pressure in Canada at the present time to include unbearable suffering from mental illness as a criterion for assisted dying.

If the End of Life Choice Act 2019 becomes law, we should expect that it will only be a matter of time before unbearable suffering will be extended to include disability or mental illness, as has happened overseas.

How does a doctor know if a person will not live beyond 6 months?

Key points:

- Prognosis is an educated guess rather than a science. Doctors have great difficulty in predicting a person's time of death.
- There can be no guarantees that a person will die within six months and many people given a prognosis of less than six months to live go on to live full and normal lives for many years.

Read more:
Some submissions to the Justice Select Committee were from people living way beyond their original

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diagnosis. Bede - diagnosed terminal in 2013. Georgina - diagnosed terminal in 2000. Peter's Dad - diagnosed terminal in 2008.

A British Medical Journal study of doctors' prognoses (the medical prediction of the course of a disease over time) for terminally Ill patients found that only 20% of predictions were accurate – that is, within 33% of actual survival time. And another peer-reviewed British Medical Journal article shows that medical diagnosis (the process of correctly identifying a disease) is wrong 10-15% of the time.

Is it true that other countries allow assisted suicide and euthanasia for young people and children?

Key points:

- Yes. Belgium and Netherlands allow assisted suicide and euthanasia of children. Belgium, which introduced euthanasia for those at least 18 years of age in 2002 extended the practice to children in 2014 – children of any age are eligible.

Read more:
Euthanasia became legal in the Netherlands in 2002 and allows euthanasia for those aged at least 12 years of age. Children aged from 12 – 15 years require parental consent. Since that time, some Dutch doctors are urging lawmakers to extend the euthanasia law to include children aged 1 to 12.

Can a person change their mind after requesting assisted suicide or euthanasia?

Key points:

- The short answer is yes. However, there is no required stand-down period within the End of Life Choice Act 2019, as there is in other countries.
- A person could in practice get the lethal drug within 72 hours after diagnosis and first requesting it.
- By contrast, in Oregon, the mandatory stand-down period is 15 days, with a very limited exception. In Victoria and Canada, the stand-down periods are 9 and 10 days.

Read more:
The only timeframe specified in the End of Life Choice Bill 2019 is a minimum of 48 hours between the writing of the prescription and the chosen time of death. Persons who have just received a diagnosis of a life-limiting illness are extremely vulnerable and will likely go through a whole range of emotions from day to day. If they're caught in a moment of weakness and are not given the reassurance they need by people around them, compounded by undetected depression, they could be dead within 72 hours.

Moreover, once a person has made a request for assisted dying which is approved, this sets in train a process that will make it difficult for many to change their mind. This will be especially so in situations where there is undetected coercion or pressure from significant others, including the subtle coercion that arises when a person thinks that they are a burden to others and/or costing too much.

See https://www.bmj.com/content/320/7233/469
See https://qualitysafety.bmj.com/content/qhc/early/2013/08/07/bmjqs-2012-001615.full.pdf
See http://www.stuff.co.nz/taranaki-daily-news/news/9029192/Euthanasia-bill-close-to-MPs-heart

Does a person need to discuss their decision with their whanau/family?

Key points:

- No. The End of Life Choice Act states that the attending medical practitioner must "encourage the person to discuss their wishes with others", but then it also states that they are not obliged to do so.

Read more:
A person could easily choose assisted dying under a misguided sense of duty based on an inaccurate impression that they are a burden to their families. Some families may only find out about their relative's choice after they have died.

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What will happen if a whanau/family member pressures a person into assisted dying?

Key points:

- The End of Life Choice Act is notable for the fact that there is no requirement for an independent person to be appointed to oversee the assisted suicide process as it occurs.
  By way of comparison, in Oregon, Canada and Victoria (Australia), two independent witnesses are required. The bill also has no provisions that would ensure patients are provided with culturally appropriate care and no provisions that address broader kaupapa Māori considerations.

Read more:
Elder abuse is quite common in New Zealand and on the increase. It is estimated that 10% of our elders are abused. It will be extremely difficult to know if family members or others subtly coerce or pressure a person into requesting assisted suicide or euthanasia. If whanau/family members tell a terminally ill person that he or she is being selfish by staying alive – that they are a burden on the family – a competent person may request assisted dying even when it is not their deepest desire

Perhaps the worst form of societal coercion will occur when people choose assisted dying because there is inadequate access to quality palliative care, as has happened in Canada and other places overseas. It is a well-known fact that the standards of access to palliative care around New Zealand vary greatly.

What does the Act require so that decisions are freely made? How can this be validated?

Key points:

- The End of Life Choice Act 2019 only requires doctors to "do their best" to ensure the person is not being coerced into accepting assisted suicide euthanasia.
- While sign-off is required from two doctors, only one doctor – the first doctor to whom the request is made – is required to "do his or her best" to ensure that the person requesting assisted dying has expressed their wish free from the pressure of another person.
- The phrase "do his or her best" is a highly subjective term that constitutes a meaningless test should a case ever come to court.

Read more:
Other countries such as the UK have rejected any form of assisted dying law because coercion is so difficult to detect and prove, even in a law court.

The End of Life Choice Act 2019 fails to describe any process for doctors to follow in detecting coercion. Given the likelihood that a high number of doctors will not want to be directly involved in prematurely ending the life of one of their patients, there is a high chance that the attending doctor won't know the patient or their family and may only meet them on a couple of occasions.

Isn't it compassionate to allow a person in terrible pain to end it all?

Key points:

- It is understandable that people in terrible pain may want to end their life.
- No one should have to live with unbearable pain if they have access to quality palliative care.
- Even the worst pain can be managed, if necessary, through the use of palliative sedation.
- No person needs to die in pain. We do not need have to have assisted suicide euthanasia to effectively relieve physical pain.

Read more:
In other countries where some form of assisted dying is available, requests for a premature death are made primarily and overwhelmingly for reasons related to fear of being a burden, fear of institutionalisation and/or fear of disability – not because of pain or even fear of pain. A compassionate response to pain is to kill the pain, not the patient. Compassion also means whanau/families caring for their loved ones.

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Suicide is a big problem in New Zealand. What will be the impact of the End of Life Choice Act on the numbers of non-assisted suicides in New Zealand?

Key points:

- This is a critically important question for New Zealand because we have some of the highest suicide rates in the world, particularly for rangatahi Māori, and our rates continue to rise.
- While the evidence of a direct or indirect link is not conclusive, because no-one has yet done the research, there is some statistical evidence which indicates that, over time, as the rates of assisted dying increase, there is a corresponding increase in suicide rates.

Read more:

In November 2019, 21 experts with an interest in mental health and associated fields wrote an open letter* to MPs in which they highlighted that there is a risk of assisted dying leading to further increases in New Zealand's already high suicide rates. Drawing on a comprehensive peer-reviewed study, the experts specifically rebutted the claim made by MP David Seymour and others that implementing assisted dying would lead to a reduction in suicide rates. The experts then concluded: "Until it can be shown beyond reasonable doubt, based on robust evidence, that there is no causal link, and while suicides remain at epidemic levels in New Zealand, in particular for Māori, we maintain that it is too risky to legislate for euthanasia and/or assisted suicide in New Zealand."

What do doctors and nurses think about this?

Key points

- Euthanasia and assisted suicide are not medical treatment.
- The New Zealand Medical Association Position Statement on Euthanasia states: "Euthanasia, that is the act of deliberately ending the life of a patient, even at the patient's request or at the request of close relatives, is unethical.
- Doctor-assisted suicide, like euthanasia, is unethical …This position is not dependent on euthanasia and doctor-assisted suicide remaining unlawful. Even if they were to become legal, or decriminalised, the NZMA would continue to regard them as unethical."
- Their statement reflects the World Medical Association Resolution on Euthanasia which "strongly encourages all National Medical Associations and physicians to refrain from participating in euthanasia, even if national law allows it or decriminalizes it under certain conditions". All of the major providers of end of life palliative care in New Zealand – Palliative Care Nurses New Zealand (PCNNZ), Hospice New Zealand and the Australia and New Zealand Society of Palliative Medicine (ANZSPM) oppose the End of Life Choice Act 2019.

Read more:

The philosophy upon which the Hospice movement is founded is that euthanasia is not part of palliative care. The ANZSPM Position Statement on Euthanasia (2017) states: "In accordance with best practice guidelines internationally, the discipline of Palliative Medicine does not include the practices of euthanasia or physician assisted suicide." The 2015 Scotland Report on Assisted Suicide states that both supporters and opponents of the Assisted Suicide Bill acknowledge that "the involvement of healthcare professionals in assisted suicide, even if it were legal, would not amount to 'medical treatment'" (n. 207). One of the most common arguments for assisted suicide or euthanasia – "that patients have a right to control when and how they die – in fact points to the involvement not of doctors but of legal agencies as decision makers, plus technicians as agents. A letter signed by more than 1500 New Zealand doctors makes the same point: "Doctors are not necessary in the regulation or practice of assisted suicide. They are included only to provide a cloak of medical legitimacy. Leave doctors to focus on saving lives and providing real care to the dying." The End of Life Choice Act 2019 makes doctors complicit in a practice that does not belong in medicine and could be set up outside of healthcare.

* https://carealliance.org.nz/clone_suicide-risks/

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What are the key arguments against the Act?

The weight of Justice Select Committee evidence was overwhelmingly against the Bill

- 38,707 written submissions, with 34,932 (90.2%) against the Bill. There was no distinct platform of support for the Bill, while numerous groups and sub-groups were against it.
- For example, 93% of 600+ doctors, 800+ nurses and 500+ other health care professionals were opposed.

The Act will place vulnerable people at risk by making existing abuse even worse

- A person needs to be terminally ill with six months or less to live to be eligible. This includes all New Zealanders from age 18, and in practice will particularly apply to those over age 65.
- The June 2020 SuperSeniors letter from Seniors Minister Tracey Martin reads: "As many as one in ten older people in New Zealand will experience some kind of elder abuse. The majority of cases will go unreported. Abusers are often someone they depend on for support or care, someone close, someone they trust. This can make it especially hard to speak up. It can be difficult to identify abuse, there is no single 'type' of elder abuse. It can be psychological, financial, physical or sexual. More often than not, people experience more than one type of abuse."
- In the 2020 budget, the Government set aside $25 million to strengthening elder abuse response services.
- The Select Committee heard evidence that vulnerable people, including the terminally ill, feel a burden on others – concluding that an early death "might be best" even though they don't actually want to die. One geriatrician reported: "elder abuse is common, frequently unreported; and perpetrated by someone close."

Euthanasia disrupts the doctor-patient relationship of trust

- The Act licenses every Doctor in New Zealand to intentionally end the life of a terminally ill person with six months or less to live by administering lethal drugs. This contradicts why doctors enter medicine – which is to care not kill.
- It is totally against the stance of peak bodies: NZMA/ ANZSPM/Palliative Nurses/Hospice NZ, and imposes an unethical practice on medical practitioners who overwhelmingly don't want it.
- The AMA (217k members) in June 2019 reaffirmed its ethical position that: "Physician-assisted suicide and euthanasia is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks."
- Dr Peter Bennie of the BMA: "there is no way to guarantee that someone has not been coerced."
- Royal New Zealand College of GPs submission: "We have noted the numerous challenges euthanasia and physician-assisted suicide presents to general practice and believe that, in its current form, the Bill does not adequately address these challenges." "Coercion of patients will be impossible to discern in every request for assisted death. Doctors will not be 100% correct in their assessments of coercion. Wrongful deaths will be the result of this proposed new law."

Overseas experience is not reassuring

- The number of deaths keeps growing eg Netherlands 2000 to over 6000 per annum in 10 years. Canada reached a total of 13,000 during the first four years after legalising assisted dying, much ahead of initial expectations.
- Eligibility criteria inevitably broaden because once the principle of state-sanctioned ending of life is established, rights-based arguments for expanded eligibility become irresistible.
- Induced death normalised as the default: Netherlands over 32,000 terminal sedation deaths pa.
- Many people are choosing euthanasia primarily due to a lack of good care and societal support in adjusting to their chronic or terminal illness. They name relational, societal, and even financial reasons, rather than purely irremediable ones. Pain is rarely the main motivator.

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Double standard in relation to suicide

- This was among the greatest concerns expressed in Justice Select Committee & Health Select Committee submissions. … including from experts.
- South Auckland GP submission: "we are telling youth that suicide is not the answer and yet saying to our disabled and terminally ill that it is. Those youth that have talked to me about the issue have mentioned the double standard."
- It is argued that euthanasia will prevent people with terminal illnesses or other grievous and irremediable suffering from taking their own lives. But the evidence does not support that conclusion – if anything it points to the opposite. Jan Latten of the Dutch Bureau of Statistics (CBS), when presenting the 2017 suicide figures in the Netherlands, suggested that even speaking about assisted dying leads to more death wishes which in turn exacerbates the underlying suicide rate.

Palliative care

- Significant advances have been made in palliative care over the last decade and it works well for the vast majority of patients. While people have experienced hard deaths in the past, most would be much improved with today's knowledge.
- Doctor JSC submission: "if the public were educated about real palliative care and experience it to the highest standard then they will change their minds about wanting assisted suicide."
- David Richmond Professor Emeritus Geriatric Medicine, Auckland University – NZ Herald: "In more than 40 years of medical practice as a physician, geriatrician and terminal care manager … I have never seen a person dying with unmanageable suffering … We cannot judge the effectiveness of today's palliative care by comparing it with what was available even just 10 years ago."

Choice

- The EOLC Bill if passed will apply, not just to a few hard cases, but to everyone in differing contexts and circumstances – resulting in early deaths due to coercion in its various forms. Page 30 of the Justice Select Committee report is profoundly disturbing because it raises serious concerns without even a single rebuttal. Terminally ill people could in some instances choose assisted dying because of coercion and feeling a burden.
- Choices have consequences, and "my life my choice" has the consequence that someone else must be a party to your death. If Parliament creates a moral right for a person to have their life ended then that creates a moral duty and obligation for someone else to end that person's life. The burden of this moral duty falls on doctors and nurse practitioners.
- Choices and rights need to be balanced against the wider good of protecting each other, particularly those in vulnerable circumstances.

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