

End of Life Choice (EOLC) Act FAQs – know before you vote.

InterChurch Bioethics Council July 2020

1) What is euthanasia/assisted suicide/assisted dying and what is already legal in NZ?

Assisted dying in the EOLC Act is where a medical practitioner either administers (ie euthanasia), or gives to a patient to take themselves (ie assisted suicide), a drug to be injected or taken orally that causes death due to the drug's toxicity.

Already legal and supported by medical staff in NZ are: removal of life support; advance care directive for non-resuscitation; refusal of treatment, medicines, food and water by a patient; and palliative sedation as part of pain relief that doesn't cause death itself but might hasten death by the terminal illness.

2) What is the problem that assisted dying is thought to solve?

The most common reasons for requests for assisted dying reported in other countries stem from mental suffering and fear of loss of enjoyment of life, lack of support, loss of dignity, being a burden on family, as well as the physical process and potential pain of dying. A perception that most people die in terrible physical pain is incorrect. Depression is also a common response when coming to terms with terminal illness, affecting a person's view of living. The practice of palliative care has methods for alleviating the mental suffering as well as treating the physical symptoms experienced during the end of life. Reversal of requests has been reported when more support has been given to patients and families, including education of what happens during dying.

3) How good is palliative care in NZ?

Palliative care 'intends neither to hasten or postpone death' (WHO) and aims holistically to help those with life-limiting illness to live as fully as possible up until their death. Pain relief is only one part of palliative care - there is always something a palliative care practitioner can do to relieve pain and suffering. NZ palliative care is highly regarded internationally. However, the NZ government funds only some of the cost of palliative care, the rest must be raised by communities, and there is uneven access to best practice palliative care in homes, community clinics, hospitals, and hospices of different regions. Additionally, medical training for palliative care is much less than for beginning of life medicine, and NZ public education and discussion does not happen enough for death to be approached without fear. The NZ Palliative Council, NZ Medical Association, Hospice NZ, NZ Palliative Care Nurses and Australian/NZ Society of Palliative Medicine each do not support legalisation of euthanasia or assisted suicide.

4) The End of Life Choice Act – how does it work?

An eligible person must be over 18 years, have a terminal illness that will likely end their life within 6 months, and is experiencing unbearable suffering that can't be relieved in a manner they consider tolerable. A person must first ask their doctor to assist them to die. If the doctor agrees to participate, they make a prognosis, check the person knows what euthanasia means and entails, checks there is no pressure by others, and encourages the patient to speak to family or friends if they wish to do so. The doctor signs a

registration form to be sent to the SCENZ (Support and Consultation for End of Life in NZ) group which has a second independent doctor review the application. If the initial doctor conscientiously objects to assisted dying, they must refer the patient to SCENZ to arrange two doctors. A psychiatrist may be asked to check the patient's files for competency to request euthanasia. Application forms signed by the doctors are sent to the assisted dying Registrar, who lets the patient know of the outcome. The patient decides with their doctor the timing and place of dying, and the doctor informs the Registrar at least 48 hours before that time. After the patient has been euthanised, the doctor informs the Registrar, and files a death certificate noting causes of death (original illness and assisted dying) with Birth, Death, Marriages and Relationships. An End of Life Review Committee will assess death reports, oversee any follow up actions, and evaluate the EOLC Act after 3 years.

- 5) What are the safety concerns about the EOLC process?** The main concern is the lack of detail about safeguards in this Act. (A similar law for assisted suicide in Victoria, Australia, written in consultation with many professionals, is four times as long to include enough detail.) The lack of safeguards in the EOLC Act includes: a participating initial doctor has to 'do their best' to determine competency and lack of coercion, both very difficult to do without a longstanding relationship with the patient; only patient competency is considered, but not physical and mental states such as depression that might affect a patient's judgement; there is no review of family over- or under- involvement; the same doctor decides eligibility, carries out the euthanasia, is the witness and the reporter, therefore not safeguarding the patient or the doctor; it is possible for euthanasia to be carried out 3-4 days from request, other countries give much longer for a cooling down period/change of mind; there is no review process to assess standards of practice throughout the country, as happens for other Acts such as the Mental Health Act; regulations for recording assisted dying are lacking – there is no data recorded about the reason of request, ethnicity, other available options, socioeconomic aspects, and with no right to question doctors involved, the 3-year review has little information to assess.
- 6) Which countries have assisted dying legislation, and which have rejected it?** Countries with legal assisted dying include the Netherlands, Belgium, Luxembourg, Canada, 9 states in the USA, and 2 states in Australia (Western Australia and Victoria). More than 30 countries have rejected legalisation of assisted dying including the United Kingdom, 26 USA states, and New South Wales, Australia.
- 7) Has the expansion of eligibility 'slippery slope' really happened in other countries?** There are several examples of other countries that have started off with similar legislation to the EOLC Act, then have proceeded to widen eligibility. The **Netherlands** has allowed euthanasia since 2002 for competent patients over 18 years old who were suffering, and now allows euthanasia for those not competent to decide, advanced care directives for patients who are not competent, children 16-18 years with parents notified, 12-16 years with parental permission, mental illnesses

such as depression and anorexia, and euthanasia for newborns. A Completed Life Bill is currently being debated, allowing those over 70 years to request euthanasia regardless of health. Over 80% of Dutch people support current euthanasia laws. **Canada** legalised medical aid in dying (euthanasia and assisted suicide) in 2016 for competent people with terminal illness. Eligibility has widened quickly to include non-terminal illness, advance care directives to override a patient's final wishes, and some children's hospitals are currently preparing for legalisation of euthanasia for children. A quarter of the initial doctors volunteering to provide euthanasia have stopped doing so. Quebec has in July 2020 proceeded to remove foreseeable death as a criterion for eligibility, removed cooling off and wait periods, reduced number of witnesses required, and will now allow advance care directives for euthanasia. In **Belgium**, assisted dying was legalised in 2002, and since 2014 the law has extended to euthanasia regardless of age (in 2016-17 children aged 17, 11 and 9 were euthanised). The majority of requests have shifted from being made mostly at the last stages of life to now happening at the first oncologist consultation. One in twenty medical practitioners have reported trauma from delivering euthanasia. **Oregon, USA**, reported that 65% of assisted dying uptake in their state were by people on low incomes. Reasons for requesting were 90% life not enjoyable, 59% being a burden, 33% pain. Similarly, in Washington State in 2018, 51% of those requesting assisted suicide gave the reason of not being a burden on friends and family compared to 38% pain. Recent reports have been made of an Oregon health insurance company refusing cancer treatment costs but offering euthanasia costs. **Seen together**, evidence from these countries show a trend emerging of eligibility for euthanasia expanding, and moving from being socially accepted, to becoming normalised, with the danger of becoming expected.

- 8) What does the disabled community in NZ say about the EOLC Act?** The disability sector in NZ is strongly opposed to the EOLC Act. A quarter of New Zealanders have a disability, including 60% of those aged over 65 years. Life choices for disabled people are more limited than for those without disability, underlining the need for more support for disabled people to live well. Overseas, the main reasons for requests for euthanasia by disabled people are loss of independence, lack of participation in the community, loss of control and being a burden on others – each of these reasons can be relieved by more support. Allowing assisted dying without improving disability funding will offer a very limited choice to disabled New Zealanders. A choice that shows itself to be ableist and ageist does not sit well in a compassionate society.
- 9) What do NZ medical practitioners think of the EOLC Act?** The New Zealand Medical Association (5000 doctors) does not support euthanasia or doctor-assisted suicide, regarding euthanasia as unethical and harmful to vulnerable people and society, and changing the trust of the doctor-patient relationship. They regard the EOLC Act as unsafe and flawed. Medical diagnoses are sometimes wrong, and prognoses estimating the likely time-course of illnesses can at best be an estimate – most doctors would not want someone to decide on euthanasia due to a prognosis of 6

months left to live. Unlike other euthanasia laws, full non-participation of a doctor is not an option in this Act, as the initial doctor still has to refer a patient to SCENZ.

10) How did this EOLC Act get to be a referendum vote? David Seymour's EOLC Bill was drawn as a ballot, with MPs voting 76 for, 44 against in the first reading in Dec 2017. The Bill then went to a Justice Select Committee which received almost 40,000 public submissions (92% against) from groups and individuals, including doctors, nurses, hospices, psychiatrists, disabled, Muslims, churches, euthanasia groups both for and against, and ethics groups. The Justice Select Committee reported back to Parliament in 2019, without deciding on many of the substantial issues, instead leaving Parliament to make changes to the Act for further readings. The second reading of the Bill passed 70 for, 50 against. Parliament then submitted amendments to be discussed; those amendments agreed upon limited the eligibility to people likely to have less than 6 months to live (a Green Party requirement), and for the Act to be enacted by a binding public referendum (a NZ First Party requirement). In 2019 the final reading passed (69 for, 51 against), the Bill became an Act requiring the 2020 public referendum. This Act is unusual in that amendments were drafted in Parliament rather than by lawyers, and is enacted by a public referendum to decide whether it becomes law without further discussion and amendment.

11) What then is most compassionate and caring? Some people with terminal illnesses have said that having euthanasia available would give peace to the few people needing it. However, other terminal illness survivors have been glad they hadn't been able to take the euthanasia option prematurely, having outlived their prognoses and been given more support. Groups of people who might become eligible such as those with disability and the elderly, have expressed vulnerability and feeling less valued because of potential eligibility for euthanasia. What is more compassionate; journeying with someone giving them support to live their last days well, or helping them end their life quickly? A blurry line exists between advocating against suicide in NZ, for which we are known to have a problem, and supporting someone to choose euthanasia. An EOLC process needs to have strong safeguards in place, with enough legal detail of support for people to choose not to have euthanasia as for people to choose euthanasia. People need to be given as much support to live well as the support given to die for a choice to be regarded as compassionate.

12) What happens if NZ votes yes?

The voter is being asked to vote on passing the End of Life Choice Act, not just voting on agreement with the concept of euthanasia. The EOLC Act is all ready to be enacted into law if the referendum vote is passed; no further discussion or amendments of the Act will be made. It is our choice then to decide if the potential benefit from the Act to a few outweighs the potential risks to many. Given the lack of safeguards in this Act, the experience of other countries, and how we aim to care for all people in our New Zealand communities, this vote also needs your care.