

The End of Life Choice Act: YES or NO?

Rev Dr Graham O'Brien

Ministry Education Coordinator, Nelson Anglican Diocese, Co-Chair InterChurch Bioethics Council.
15/7/2020.

On September 19th, the New Zealand public are going to vote in both a general Election and at the same time on two referenda: The End of Life Choice Act, and the Legalisation of Recreational Cannabis. Of these two highly important pieces of legislation, let's talk here about the End of Life Choice Act (EOLC).

The voting public will be asked:

"Do you support the End of Life Choice Act 2019 coming into force?"

The wording of the 2 options for which electors may vote in response to the question:

"Yes, I support the End of Life Choice Act 2019 coming into force,"

or "No, I do not support the End of Life Choice Act 2019 coming into force."

This is not a vote for or against assisted dying, this is a vote for a specific piece of law. The result is binding, if the simple majority say yes – this legislation, unchanged in its present form, will become law after 12 months.

What does the EOLC Act say?

The purpose of the EOLC Act is to give persons who have a terminal illness and who meet certain criteria the option of lawfully requesting (and receiving) medical assistance to end their lives; and to establish a lawful process for assisting eligible persons who exercise that option – ensuring, in other words, that those who help them cannot be prosecuted. In defining "terminal", the Act does not take into consideration treatment options that may prevent or delay a terminal diagnosis. The EOLC Act defines assisted dying as (Part 1, 4): (a) 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 (b) the self-administration by the person of medication to relieve their suffering by hastening death.

"Assisted dying" is a catch phrase for the two practices being covered by this legislation: (a) euthanasia and (b) assisted suicide. And here-in lies the first of many problems. The terminology of the Act is inaccurate and designed to soften what is actually happening: (i) these practices do not *hasten death*, they cause death; and (ii) what is prescribed is a lethal drug which is wrongly described as a medication. In these definitions the intent is key. For example: by switching off life support, the intent is to let the person die of their illness; to give a drug for the purpose of ending a person's life (even if done so to relieve suffering) – that is either euthanasia (a doctor delivers the drug) or assisted suicide (the person themselves administers the drug).

The language used is problematic because it confuses the public who often equate these practices with turning off life support, or stopping treatment etc, both of which are legal end-of-life choices.¹ Such confusion has also been evident in polling done

¹ Research that the InterChurch Bioethics helped commission prior to lockdown suggests that as a country we are poorly placed to make such decisions, with a low awareness of the issues involved, and almost one in five participants were not even aware that a referendum is to be held at the General Election.

by Curia Market Research in 2017 and 2019, where 70-74% of those polled thought the EOLC Act would legalise already legal end-of-life choices.²

An additional term to consider is the “suffering” that this legislation seeks to address. A subjective and multi-faceted phenomenon, suffering within the end of life discussion is most frequently associated with physical pain. However, research with those who request assisted dying reveals that it is not physical suffering due to inadequate pain control that people fear, but rather loss of autonomy, reduced enjoyment of life and becoming a burden on family and friends.³ These ‘top three’ are all forms of emotional and mental suffering that can be alleviated through our social relationships and practices. Palliative care provides a multi-disciplinary approach to the many facets of suffering (physical, emotional, psychological and spiritual) that a person may deal with as they deal with the reality of a life-limiting illness. No person needs to die in pain these days if they can access quality palliative care. So will this law relieve suffering? As Prof Rod McCleod states, “to say something like assisted dying will relieve suffering is an impossible and immeasurable goal”.⁴

Has it been a robust process?

It has been stated by many commentators that the EOLC Act must be a robust piece of law because of the time it took to get through parliament. However those who followed it closely would argue otherwise. The initial EOLC Bill written by MP David Seymour was a private members bills pulled from the ballot box. The Bill, having been then passed through to the Justice Select Committee, attracted 39,159 written submissions and 1,350 oral submissions – the largest process in New Zealand’s history. Of interest is that 91.8% of submissions opposed this Bill, including 93% of doctors who wrote submissions,⁵ as well as groups such as Hospice NZ and the NZ Medical Association. It is worth noting that of those who said no, only some 10% cited religious reasons therefore over 80% of submissions said no with no reference to religion. Yet the Bill still proceeded through Parliament with only 3 changes: a significant re-write to limit criteria to people with a terminal illness; and two changes allowing a binding referendum. The other 111 proposed changes designed to improve various aspects of the Bill were all rejected. For most of the final debate which happened over several days, the majority of MP’s were absent from the House and failed to hear the arguments for amendments.

Reasons For or Against the EOLC Act.

In her recent book *“The Final Choice: End of Life Suffering: is assisted dying the answer?”*,⁶ journalist Caralise Traves identifies a number of reasons for and against the End of Life Choice Act. Reasons for such a law include:

² Caralise Traves, *“The Final Choice: End of life suffering: Is assisted dying the answer?”*, (C&T Media, 2020), 39.

³ <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf> (2014). Losing autonomy (91.4%); less able to engage in activities making life enjoyable (86.7%); loss of dignity (71.4%); burden on family, friends/caregivers (40%); inadequate pain control or concerns about it (31.4%). Also see Traves, *“The Final Choice*, pg 82-3 and 186.

⁴ Traves, *The Final Choice*, pg 92. Also see page 123.

⁵ <https://carealliance.org.nz/wp-content/uploads/2019/04/Care-Alliance-Report-on-EOLC-Submissions-March-31-2019.pdf>. Traves, *“The Final Choice*, pg 37-38.

⁶ You can buy this book at bookshops (but it is selling out fast), or purchase hard copies or e-book online at www.thefinalchoice.nz. You can also join the Facebook conversation – www.fb.com/TheFinalChoiceBook.

- Individual autonomy/choice and being in control
- Self-reliance
- Maintaining dignity and distinctions between existing and living
- The comfort of having a choice
- Fear of dying badly.

Reasons against such a law include:

- Value of life
- Care for the vulnerable, including the disabled, those with mental health issues, and indigenous peoples.
- A lack of or inadequate safeguards especially against coercion, suggestion and mental health
- Changes to the doctor-patient relationship
- Normalisation and extension of criteria

Is this particular legislation safe?

The safety of this legislation is a key feature of many discussions. While the EOLC Act requires two doctors to approve euthanasia or assisted suicide, only one doctor – the first doctor to whom the request is made – is required to “do his or her best” (Part 2, s11(2)) to ensure that the person requesting assisted dying has expressed their wish free from the pressure of another person. There is no mandatory requirement for a psychological assessment – especially for depression, family consultation, or a “cool down” period between approval and undertaking (the minimum time between approval and action could be 4 days). Doctors alone (or nurse practitioners under their guidance) are left to assess coercion, mental capacity and eligibility. Of note, there is no requirement for the doctors to have a long-term relationship with the patient – in Oregon the average time of relationship is 10-14 week.⁷

If a doctor objects, they must refer to the SCENZ group, who will refer the patient to those willing to be involved. Reviews of the process happen via an End of Life Review Committee after the fact, using the reports filed by the doctors concerned. The lack of robust safeguards is a significant concern for many. It is also worth noting that in the State of Victoria, their assisted dying legislation (which essentially provides for assisted suicide only) is three-times longer than New Zealand’s and has 68 safeguard regulations.⁸

Overseas Evidence.

The first aspect to note in looking at overseas practices is that the majority of places that have investigated euthanasia or assisted suicide have rejected these practices. Since 2015, 13 countries or states have legalised assisted dying, while over 30 jurisdictions have rejected such legislation including the UK, 26 States in the US, and NSW. Of those 13, the majority practice assisted suicide only and not euthanasia.⁹ This is not a global tide sweeping the world.

Research from international jurisdictions where assisted dying is practiced (and in the few that also allow euthanasia), shows that there is a significant increase in numbers year-on-year, and clear extensions of the criteria beyond those with terminal conditions. Examples of criteria extensions include the availability to those

⁷ Trayes, *The Final Choice*, pg 82 and 186.

⁸ Trayes, *The Final Choice*, pg 180.

⁹ Trayes, *The Final Choice*, pg 46 and 181-192.

under 18; those with mental health conditions including depression; those with dementia; and those with disabilities. Moves to change laws to extend criteria or remove restrictions are currently underway in the Netherlands, Oregon and Canada.¹⁰ As the Royal Society of Canada states, there is “no principled basis for excluding people suffering greatly and permanently, but not imminently dying”.¹¹ Professor Theo Boer notes in the Netherlands, “the very existence of a euthanasia law turns assisted suicide from a last resort into a normal procedure”.¹²

There is also some evidence in overseas studies showing that allowing euthanasia or assisted suicide also increases rates of unassisted suicide. A recent report (Oct 18, 2019) on “The Danger of Assisted Suicide Laws” by the US National Council on Disability, identifies a 6% increase in total suicide rates across US states with assisted suicide laws.¹³ Given our already high rates of unassisted suicide is this a risk we can take?

So can we make a robust law in NZ that can withstand these pressures for change? The original EOLC Bill contained the phrase, “irremediable conditions” which extended the scope of assisted dying beyond terminal illness. This phrase was removed by David Seymour so that the Act would pass its 2nd and 3rd readings. Furthermore, the NZ Attorney General has also stated that based on our Bill of Rights, the age restriction of 18 years is discriminatory and had suggested either scrapping any age limit or changing it to 16 years old.¹⁴ There is therefore, a strong likelihood of extensions such as “irremediable conditions” and assisted dying clauses in advanced care directives being reintroduced over time, not to mention challenges to the age restrictions. In fact the EOLC Act already includes a review clause to “consider whether any amendments to this Act or any other enactment are necessary or desirable” (Part 3, s30).

To conclude:

I believe euthanasia and assisted suicide are not practices we want in NZ. We have other means to provide effective end-of-life care and compassion to those in need – especially through ensuring access to adequately funded quality palliative care and hospices and addressing the imbalance of accessibility to these services. For those sympathetic to some form of assisted dying for the hard cases, the End of Life Choice Act is an overly broad and weak piece of legislation with poor safeguards, and so I would encourage us all to vote NO.

¹⁰ For a good summary, see Trayes, *The Final Choice*, pg 181-213.

¹¹ *End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making, Chapter 5; 7.b part (iv) at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3265521/>*

¹² <http://www.dailymail.co.uk/news/article-2686711/Dont-make-mistake-As-assisted-suicide-bill-goes-Lords-Dutch-regulator-backed-euthanasia-warns-Britain-leads-mass-killing.html#ixzz475CQjW5M>

¹³ US National Council on Disability,

https://www.ncd.gov/sites/default/files/NCD_Assisted_Suicide_Report_508.pdf, pages 11-12 and 46.

Also see Aaron Kheriaty, “The dangerous contagious effect of assisted suicide laws”. Washington Post, 20 November 2015. <http://carealliance.org.nz/the-dangerously-contagious-effect-of-assisted-suicide-laws/>.

¹⁴ Trayes, *The Final Choice*, pg, 205.