



End of Life Choice Act. High Court Judgment & ongoing concerns.

This September, New Zealanders will have a life changing decision when they vote in the referendum on the End of Life Choice Act at the general election.

When we reviewed the End of Life Choice Act, we were concerned with the lack of clarity and detail when it came to the potential application of the Act.

We knew the Act would not be revisited as the Parliamentary process is complete. Following legal advice, we found it necessary to ask for a Declaratory Judgment from the High Court.

We sought clarity for these four questions:

- Whether an organisation such as a hospice can conscientiously object to Assisted Dying and operate a 'euthanasia-free' service.
- Whether a DHB or other funding agency can decline to fund or contract with an organisation if it does not agree to provide Assisted Dying services.
- Whether the Act's mandatory obligations on a health practitioner override the ethical, clinical or professional judgments of that practitioner and their obligations under the Code of Health and Disability Consumers' Rights.
- Whether a health practitioner may exercise a right of conscientious objection on the basis that they hold as a core value that they must not act in a way that is contrary to their ethical, clinical or professional judgment and obligations.

The Attorney General requested that all medical organisations who had made a submission to the Justice Select Committee be served to offer them the opportunity to apply for intervener status. The rationale for this was they would have an interest and perspective on the request and would be impacted by any declaration that was made. Of the seven served – two applied and were given intervener status – Palliative Care Nurses New Zealand and the Australian and New Zealand Society of Palliative Medicine. The New Zealand Medical Association declined to be interveners but provided a statement to support our request for the Declaratory Judgment.

The Attorney-General was represented by Dale La Hood and provided submissions and representation.

The Judgment in summary

Organisations such as hospice have a right to hold conscientious objection – and the Crown should not be able to override that through funding decisions.

The Court ruled that organisations such as hospice can have an entrenched moral ethos that qualifies for protection under the right to freedom of conscience in the New Zealand Bill of Rights Act 1990. This means that organisations like hospice services, aged care facilities or GP practices for example, can object to assisted dying as set out in the End of Life Choice Act happening on their premises by their staff.

Justice Mallon appreciated the ethos of palliative care and how placing the option of assisted dying on the table could undermine palliative care delivery. This is important recognition of why an organisation such as hospice should be able to "opt out" of providing the services described in the EOLC Act.

It is important to note that this option is also available to other health care provider organisations following the judgement. There are a range of health care providers who may wish to create a safe space for staff, volunteers, patients and family members who do not wish to be exposed to the practice of euthanasia while receiving care, in their place of work or, in the case of aged residential care residents, their home.

The Attorney General conceded that the Ministry cannot compel any service provider to provide assisted dying services, with Justice Mallon reiterating that funding decisions must be made lawfully, considering that organisations are legally allowed to offer euthanasia-free services.

The mandatory provisions in the Act do not override the Code of Health and Disability Consumer's Rights.

Judge Mallon made it clear that the mandatory obligations in the Act do not override the standard ways in which a health care practitioner determines competency and informed consent without coercion. There is concern that the Act sets a much lower standard for both as part of the assessment process. However, Doctors and Nurse Practitioners will be required to comply with all their usual duties and obligations, for example the standards for informed consent by the Medical Council and the Ministry of Health guidelines for responding to elder abuse and neglect. A practitioner must decline to follow a direction in the Act if they are not satisfied under existing professional standards.

The attending medical practitioner must have appropriate qualifications and experience to undertake assisted dying services

Judge Mallon clarified the definition of attending medical practitioner – despite being defined in the broadest possible terms in the Act. The judgement outlines that an attending medical practitioner in the case of this Act, must be practicing within a scope of practice that includes care of the dying (yet to be developed for EOLC), and have been involved in the patient’s care. They must also have sufficient skill, expertise and knowledge of the patient to be able to properly undertake the assessments, provide the advice and reach the opinions required of them. Any doctor who does not meet these requirements would be expected to transfer on the patient’s care to someone appropriately qualified and experienced.

Hospice New Zealand view on euthanasia

- **Euthanasia has no place in palliative care** - it does not fit with the internationally agreed and defined philosophy of hospice that aims to neither hasten nor postpone death.
- **Hospice will continue to support people regardless of their desire for euthanasia.** We appreciate and acknowledge an individual’s right to choose and acknowledge the range of perspectives around euthanasia.
- **People living with a terminal illness should be supported to live in whatever way is important to them, their family and whānau.** People should have access to good palliative care support regardless of where they live. We need to address issues of access to care, social isolation, lack of support for family carers before we give people the means to choose death.

Hospice New Zealand key concerns – End of Life Choice Act

- **There is a lack of adequate safeguards in the Act** – there is no stand down period from the request to administration of the lethal drug. The only delay between request and death is the 48 hours required for the registrar to check the paperwork. In Oregon, the cooling off period is 15 days, 9 days in Victoria and 10 days in Canada. There are 68 safeguards in the legislation in Victoria, Australia – and within 3 months of the law being passed in 2018, people were pushing for changes.
- **Determining how long someone has to live is often inaccurate** - predicting a life expectancy of 6 months is difficult and often people live longer than expected. A study of doctors’ prognoses¹ (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, 80% of the time medical prognoses are inaccurate.

- **The process does not allow nor encourage discussion with family and whānau.** For Māori and Pasifika, collective group decision making is expected. Under this Act, a person’s loved ones may not be aware of a request for euthanasia. There is no opportunity to address the underlying factors which motivate the request – such as unresolved physical or emotional pain, fear of being a burden, depression or isolation.
- **Several long-term conditions that cause disability are also a terminal illnesses.** People living with a disability caused by multiple sclerosis and motor neurone disease, for example will meet the criteria, as these chronic conditions are incurable.
- **Detecting coercion and the real reason for a request.** Detecting what goes on behind closed doors is incredibly complex. There is no test to determine if someone is making a request of their own free will. Coercion or pressure can be very subtle and may not even be intended, e.g. when patients see the stress on family members who are trying very hard to care for them, this often leads to the feeling of being a burden. A 2018 analysis into the reasons/end of life concerns that prompted people to request and undertake physician assisted dying in Oregon tells us that, of the 168 people who died, 95% were concerned with a loss in autonomy and the loss of being able to engage in activities that made life enjoyable. 79.4% indicated concerns around loss of dignity, and 63% were concerned about being a burden. Only 31% were concerned with inadequate pain control.
- **There is no such thing as a slippery slope, it is a natural progression that occurs to many laws, the expansion of criteria over time.** Belgium initiated euthanasia law for a small group of people in 2002 – now, euthanasia deaths increase in Belgium by 27% every year. The largest increase in euthanasia cases is among people that are not expected to die in the near future. When the law was first enacted, euthanasia was only available for people 18 or older. In 2014, Belgium extended euthanasia to children as well. Based on the experience of overseas jurisdictions, there is real concern that the criteria in the EOLC Act could very quickly be challenged at a Human Rights level. How long will it take before someone with a disability or dementia or someone under 18 feels discriminated against and takes a case to the Human Rights Court to allow them to access euthanasia?

For a full copy of the Judgement and other EOLC Act information please visit <https://www.hospice.org.nz/resources/end-of-life-choice-act-our-concerns/>

¹ Nicholas A Christakis and Elizabeth B Lamont, “Extent and determinants of error in doctors’ prognoses in terminally ill patients: prospective cohort study,” *BMJ* 320 (2000): 469, <http://www.bmj.com/content/320/7233/469>.