

The End of Life Choice referendum will be held concurrent to the upcoming general election. In this referendum voters are asked to vote whether or not the End of Life Choice Act that passed through Parliament in 2019 should be brought into force. This issue is complex and emotional, and people of all ages, ethnicities, and religious backgrounds have different opinions about it, partly dependent on their personal beliefs, values, and experiences. The New Zealand College of Clinical Psychologists (NZCCP)¹ offers this psychological perspective about the End of Life Choice Referendum. Our aim is to encourage and support New Zealanders to address the issue and make an informed decision rather than to promote a particular viewpoint.

What are End of Life Choices

End of Life Choices are a deliberate act to end a person's life when they have a terminal illness, as thought about, discussed, and decided by that person. If end of life choices were to be made legal, the person needs to be assured/understand that their interests will be protected by safeguards. For this reason, clear processes and legal safeguards are required. The End of Life Choice Act is a carefully considered framework to establish these processes and safeguards. Overseas research indicates that people who make an end of life choice shorten their life by an estimated average of ten days.²

Who Is Eligible to make a choice to end their life?

To be eligible to make an End of Life decision, a person must meet all of seven criteria (conditions) including that they are over eighteen, have a terminal illness that is likely to end their life within 6 months, their physical capability is deteriorating, and they experience unbearable suffering. The law is specific that suffering due to a mental health condition alone is not sufficient for someone to be eligible to make this choice.

As part of this process, people must be assessed by health professionals to ensure that they have capacity to make an informed decision and that they are not feeling pressured or forced into the decision. If either of these criteria is not met then the patient will not be eligible to make this decision. The attending health professionals must ensure that no form of coercion or outside pressure interferes with the ultimate decision. Pressure could come from family or other associates, the health care system (e.g., no longer treating older people because of restricted budgets or resources), or from society (e.g., de-prioritising care for the elderly, age discrimination, handicap discrimination, etc.). The dying patient is free to withdraw their request at any time. This assessment is necessary but should not act like a tribunal in which the person has to prove the legitimacy of their request.

Considerable burden is put on health professionals in assessing the above criteria. Assessment of how long people with a terminal illness will live is often uncertain. Assessment of capability to make informed decisions can also be difficult. The Act allows for health professionals to decline involvement in the End of Life process if it is against their personal beliefs or they do not feel competent to undertake the functions required.

How Many People Make this Choice?

Overseas evidence gives some indication about how many people are likely to make an end of life choice. Our End of Life Act is relatively similar to the Death with Dignity Law in the state of Oregon in the USA, which has been in place since 1997. Statistics from Oregon³, which has a population slightly smaller than New Zealand, showed that in 2019 188 people died using medication obtained under their Death with Dignity Law. This equates to approximately one assisted death for each 200 natural deaths. Evidence from the Netherlands also indicates that relatively few eligible people make the choice to end their life⁴

The Psychological Impacts of End of Life Choices

Psychological Impacts and End of Life Choices for the Terminally Ill Person

Even in adversity, many people find meaning in living at the end of life. Suffering and pain is a private and subjective experience. Whilst some argue that modern treatment can manage the pain and suffering of terminally ill people adequately, the reported experience of many patients and family members is that this is not entirely the case. Beyond the deterioration and suffering, many terminally ill people describe the process as intolerably physically, emotionally, and spiritually exhausting. This is more subjective than the disease process or pain, but is often a reason why people may choose to end their life.

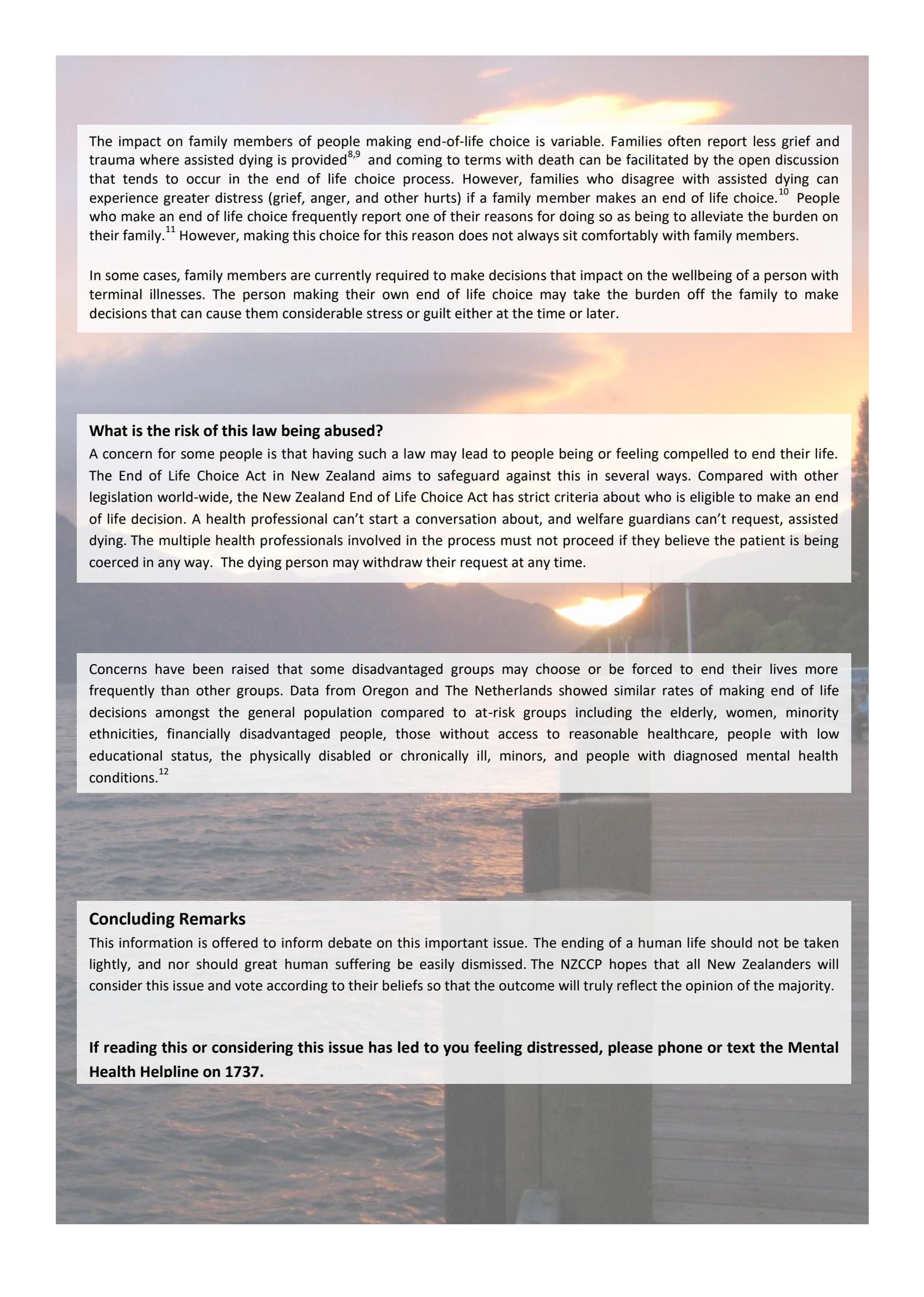
Depression and hopelessness are very common for people with a terminal illness. This may impact on people's capacity to consent, but overseas evidence suggests that people who make a decision to end their life are not primarily doing this due to depression.

In the current situation, some people choose to foreshorten their life using techniques such as stopping treatment, use of life-shortening palliative treatments, or "Do Not Resuscitate" orders. Overseas research shows that many people with a terminal illness find having the possibility of the choice to end life empowering even if they do not take it up. Fear of pain, suffering, and loss of dignity with disease progression is frequent in people with terminal illnesses, and knowing they could make an end-of-life choice if it becomes unbearable gives people a sense of reassurance and control. Data from Oregon consistently shows that over the years approximately one third of people who get the right to end their life do not follow through on doing so.⁵ The absence of opportunities for assisted dying may lead some people to end their life sooner than they need to so they maintain the ability of self-determination.⁶

Psychological Impacts and End of Life Choices for the Family of the Terminally Ill Person

End of life decision making does not just affect the individual - it affects the whole family and beyond. The death of a family member is an important transition for entire family, and having "a good death" is important for the individual and others around them. Psychologists can help with supporting both the person who is making an end of life choice and other family members in the presence or absence of an end of life choice.

It is often ideal as part of the dying process for there to be talks about death with trusted (close) family members and/or, if needed, a proxy. In the case of an end-of-life choice being requested, the choice is often not a surprise to the participants in such meetings. Some may already have an opinion about the situation and it is a good opportunity to share those opinions and feelings. It is important that the person who is considering ending their life gives their assessment of their situation and is able to talk about their needs. This can be part of the anticipatory grief process for all participants. Disagreement among the group can be attended to in these meetings. This can help family and friends to work through the loss of a loved one involved. There are many models for undertaking such consultations.⁷



The impact on family members of people making end-of-life choice is variable. Families often report less grief and trauma where assisted dying is provided^{8,9} and coming to terms with death can be facilitated by the open discussion that tends to occur in the end of life choice process. However, families who disagree with assisted dying can experience greater distress (grief, anger, and other hurts) if a family member makes an end of life choice.¹⁰ People who make an end of life choice frequently report one of their reasons for doing so as being to alleviate the burden on their family.¹¹ However, making this choice for this reason does not always sit comfortably with family members.

In some cases, family members are currently required to make decisions that impact on the wellbeing of a person with terminal illnesses. The person making their own end of life choice may take the burden off the family to make decisions that can cause them considerable stress or guilt either at the time or later.

What is the risk of this law being abused?

A concern for some people is that having such a law may lead to people being or feeling compelled to end their life. The End of Life Choice Act in New Zealand aims to safeguard against this in several ways. Compared with other legislation world-wide, the New Zealand End of Life Choice Act has strict criteria about who is eligible to make an end of life decision. A health professional can't start a conversation about, and welfare guardians can't request, assisted dying. The multiple health professionals involved in the process must not proceed if they believe the patient is being coerced in any way. The dying person may withdraw their request at any time.

Concerns have been raised that some disadvantaged groups may choose or be forced to end their lives more frequently than other groups. Data from Oregon and The Netherlands showed similar rates of making end of life decisions amongst the general population compared to at-risk groups including the elderly, women, minority ethnicities, financially disadvantaged people, those without access to reasonable healthcare, people with low educational status, the physically disabled or chronically ill, minors, and people with diagnosed mental health conditions.¹²

Concluding Remarks

This information is offered to inform debate on this important issue. The ending of a human life should not be taken lightly, and nor should great human suffering be easily dismissed. The NZCCP hopes that all New Zealanders will consider this issue and vote according to their beliefs so that the outcome will truly reflect the opinion of the majority.

If reading this or considering this issue has led to you feeling distressed, please phone or text the Mental Health Helpline on 1737.

References

1. The New Zealand College of Clinical Psychologists is an organisation of more than 1000 clinical psychologists and postgraduate clinical psychology students.
2. Emanuel, E.J., Onwuteaka-Philipsen, B.D., Urwin, J.W., & Cohen, J. (2016). Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. *Journal of the American Medical Association*, 316, 79-90.
3. Oregon Health Authority Public Health Division (2020). *Death with Dignity Act: 2019 Data Summary*. <https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx>
4. Rietjens, J. A. C., van de Maas, P. J., Onwuteaka-Philipsen, B. D., van Delden, J. J. M., & van der Heide, A. (2009) Two decades of research on euthanasia from the Netherlands. What have we learnt and what questions remain? *Bioethical Inquiry*, 6, 271-283.
5. Oregon Health Authority Public Health Division (2020). *Death with Dignity Act: 2019 Data Summary*. As above.
6. Weaver, J. C. (2014). *Sorrows of a century: Interpreting suicide in New Zealand 1900-2000*. Bridget Williams Books.
7. For example, the Boulder Conversation Project <http://theconversationprojectinboulder.org/>
8. Srinivasan EG. (2010) Bereavement experiences following a death under Oregon's Death with Dignity Act. *Dissertation Abstracts International: Section B: The Sciences and Engineering*. 70 (10-B):6098.
9. Swarte, N.B., Van Der Lee, M.L., van der Bom, J.G., Van Den Bout, J., & Heintz, A.P.M.(2003). Effects of euthanasia on the bereaved family and friends: A cross sectional study. *British Medical Journal*, 327(7408), 189.
10. Ganzini, L., Beer, T.M., and Matthew C. Brouns, M.C. (2006) Views on physician-assisted suicide among family members of Oregon cancer patients. *Journal of Pain and Symptom Management*, 32, 230-236
11. Emanuel, E.J., Onwuteaka-Philipsen, B.D., Urwin, J.W., & Cohen, J. (2016). Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. *Journal of the American Medical Association*, 316, 79-90.
12. Battin, P., van der Heide, A., Gazini, L., van der Wal, G., Onwuteaka-Philipsen, B. D. (2007). Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups. *Journal of Medical Ethics*, 33, 591-597