



Submission on the review of the End of Life Choice Act 2019 (the Act)

About you

Your name	Catherine Hall
Who you represent	Alzheimers NZ
Are you part of an organisation?	Yes
Do you live in New Zealand?	Yes
Do you want your personal details removed from your submission in Official Information Act requests?	No

Access to assisted dying

Do you think changes are needed to the eligibility requirements for a person to receive assisted dying?

1. Alzheimers NZ believes every person, including those with dementia, has the same rights, privileges, and obligations as everyone else. This includes the right to participate in a society that recognises and provides for their needs. The Alzheimers NZ's Lived Experience Advisory Group developed the [Dementia Declaration](#) that sets out what they need to live well.
2. While every person should have the opportunity to exercise their fundamental rights, this needs to be balanced with sufficient protections for people when they need it. As a result, the existing legislation imposes restrictions that limit access for people whose decision making ability may be compromised. These restrictions include the six-month timeframe to death requirement, the requirement for informed consent in relation to administering medication, and the inability to create advanced directives for end-of-life care.
3. We believe that any review should continue to consider the balance needed between maintaining individual rights and autonomy, and appropriate protection and safety. Balancing individual rights with the need for protection is a complex and critical aspect surrounding assisted dying options. While we need to respect the autonomy and human rights of those with terminal conditions, we must ensure that they are protected against potential exploitation or coercion. Achieving this balance requires careful legislation that includes strong protections to prevent abuse and respecting personal choice and ethical responsibility to protect those at risk.

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4. Assisted dying should never serve as a substitute for adequate health care and support. The priority for the health system should be to provide comprehensive and compassionate care and support for people throughout their illness and including at end of life.
5. The protective measures in the legislation warrant review. However, we do not believe that now is the right time for such changes because:
 - a. the legislation is still relatively new;
 - b. we understand the End-of-Life Review Committee has been unable to fulfil its role due to insufficient membership, and there has been no independent review of assisted deaths for the past 12 months; and
 - c. research to evaluate the impact of this legislation in our population is still underway.
6. Alzheimers NZ recommends that:
 - a. the review to modify the legislation should take place during the next scheduled review in five years. It is important to approach this process cautiously to prevent the excessive use of legislation, as has been seen in [Canada](#); and
 - b. the focus must be on improving access to quality health care and support, so that people with dementia get the help and support they need throughout their journey including at end of life. This approach will help create an environment where assisted dying remains a choice rather than a requirement.

Do you think that changes to areas other than eligibility are needed to support access to assisted dying?

Safeguards

Do you think the Act provides sufficient safeguards to ensure that people only receive assisted dying if:

- they are eligible (referenced in clauses 5, 13, 14, 15, 16, and 17 of the Act)
- they actively seek and consent to it (referenced in clauses 11, 12, 18, 23, 33, and 34 of the Act)
- they are competent to consent to it (referenced in clauses 5, 6, and 15 of the Act)
- this consent is provided without pressure from others (referenced in clauses 11 and 24 of the Act).

Do you think any changes are needed to safeguards provided through the Act?

Process to receive assisted dying

- Do you think any changes are needed to the process to apply for and receive assisted dying?

Practitioners providing assisted dying

Do you think changes should be made to the requirements for medical practitioners and nurse practitioners to provide parts of the assisted dying process?

Oversight of assisted dying

- Do you think changes are required to the roles and responsibilities of the entities established under the Act to oversee assisted dying (the SCENZ Group (clause 25), the End of Life
- Review Committee (clause 26), and the Registrar (assisted dying) (clause 27))?

Alignment with the wider health system

- Do you think the assisted dying process aligns with other parts of the health system?
- Is there anything that could be improved?

Other feedback

- Do you have any other feedback related to the Act?