

25 September 2024

End of Life Choice Review  
Te Whatu Ora | Ministry of Health

By email: [EOLCreview@health.govt.nz](mailto:EOLCreview@health.govt.nz)

Tēnā koe

### Review of End of Life Choice Act 2019

1. The New Zealand Law Society Te Kahui Ture o Aotearoa (the **Law Society**) welcomes the opportunity to contribute to the first review (**the Review**) of the End of Life Choice Act 2019 (**the Act**).
2. This feedback has been prepared with the assistance of the Law Society's Health and Disability Law Committee. It addresses several provisions of the Act that would benefit from further consideration. It does not convey a view on policy decisions regarding the settings for eligibility.
3. The suggestions and comments set out below are intended to be neutral, with a view to identifying areas that warrant further consideration. In light of the subject-matter of the Bill and the range of views on that subject-matter within the legal profession, it is important that the Law Society's feedback is not interpreted as endorsing a particular outcome.

### Eligibility requirements for a person to receive assisted dying

4. The Law Society expresses no view on the appropriate age for eligibility to receive assisted dying. However, we recommend that the age restriction is reviewed, taking into consideration the current settings for consent to medical procedures, and whether the restriction is a justifiable limit on the right to freedom from discrimination.

#### *Section 5(a) - 'aged 18 years or over'*

5. A person must be 18 years or older before they can elect to receive assisted dying. While the legal age of majority in New Zealand is 20 years old,<sup>1</sup> there are significant freedoms and responsibilities afforded to individuals younger than aged 20.
6. We note in particular, that:
  - a) Right 7(1) of the Code of Health and Disability Services Consumers Rights provides that every consumer (regardless of age) must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent;
  - b) New Zealand courts have previously adopted the Gillick competence test, which provides that a child and/or young person under 16 years will be considered competent and able to consent to treatment if they have a sufficient understanding

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<sup>1</sup> Age of Majority Act 1970, section 4.

and intelligence to enable them to understand fully what is proposed. Having “sufficient understanding and intelligence” is “a quality which does not depend on chronological age or the physical appearance of maturity”;

- c) section 36 of the Care of Children Act 2014 enables those over the age of 16 to consent to or refuse certain medical procedures;
- d) section 19 of the New Zealand Bill of Rights Act 1990 (Bill of Rights) provides that everyone has the right to freedom from discrimination on the grounds set out in the Human Rights Act 1993, including age;
- e) section 21(1)(i) of the Human Rights Act 1993 defines ‘age’ as encompassing differential treatment based on any age from 16 years; and
- f) at the time of the Act’s passage, the Attorney-General concluded that the age criterion is an unjustifiable limitation on right to freedom from discrimination.<sup>2</sup> The Attorney-General’s report under section 7 of the Bill of Rights noted:<sup>3</sup>

*I am not aware of any evidence that the age of 18 is a suitable proxy for maturity and competency to consent to assisted dying. Indeed, it seems unnecessary to use age (or anything else) as a proxy given the Bill’s other safeguards to ensure that the person is in fact competent to make the decision.*

...

*The Bill could be made compliant with s 19 by reducing the age of eligibility to 16, or by removing the age criterion altogether and relying on the other criteria and safeguards to ensure competence.*

- 7. Not long after the Act came into force, a series of proceedings commenced which challenged the voting age of 18 on the basis that it is unjustified age-based discrimination infringing section 19 of the Bill of Rights. This culminated in the Supreme Court’s judgment in *Make it 16 Incorporated v Attorney-General*, in which the Court made a declaration that the legislative provisions setting a minimum voting age of 18 were inconsistent with the right to freedom from discrimination and had not been justified.<sup>4</sup>

*Section 5(c) - ‘a terminal illness that is likely to end their life within six months’*

- 8. The Act does not define the term ‘terminal illness’. The Member responsible for the Bill considered at the time that the provision was self-explanatory, because of the requirement that an illness must be likely to cause death within six months.<sup>5</sup>
- 9. Snelling has highlighted that the ordinary meaning of ‘terminal’ is a condition leading ultimately to death and that it may also be defined more narrowly as ‘a disease that cannot be cured and will cause death.’<sup>6</sup>
- 10. The lack of clarity in respect of whether a terminal illness must be incurable creates some ambiguity for section 5(c) of the Act. For example, it is unclear whether an individual, whose

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<sup>2</sup> Hon Christopher Finlayson, Report of the Attorney-General under the New Zealand Bill of Rights Act 1990 on the End of Life Choice Bill (August 2017).

<sup>3</sup> Paragraphs 30 and 35.

<sup>4</sup> [2022] NZSC 134.

<sup>5</sup> (31 July 2019) Vol 739 NZPD 12790.

<sup>6</sup> Jeanne Snelling “Critiquing the End of Life Choice Act 2019” (2022) 30 NZULR 1 at 14.

condition is curable with treatment, but which without treatment is likely to end their life within 6 months, has a ‘terminal illness.’

11. For example, Victoria’s *Voluntary Assisted Dying Act 2017* provides that, to be eligible, a person must have a disease, illness or medical condition that is ‘incurable’, and that illness must also be ‘advanced, progressive and will cause death’, and is expected to cause death within six months.<sup>7</sup> The Explanatory Memorandum to that Act states that whether or not a disease is ‘incurable’ depends upon whether there is a ‘clinically indicated treatment that will cure the disease.’<sup>8</sup>
12. Without expressing a preference for the limits of any definition, the Law Society recommends that section 5(1)(c) is amended to define ‘terminal illness.’ Any such definition should also consider the reasonable availability of any such treatments for the patient, noting that while some treatments may technically exist, there can be practical funding or other availability limitations, meaning that all treatments are not reasonably available to the patient.

*Section 5(d) - ‘in an advanced state of irreversible decline in physical capability’*

13. Section 5(1)(d) of the Act is ambiguous in respect of the definition of ‘irreversible decline’. For example, some treatments may reverse symptoms of physical decline, however, in some instances a patient may not wish to receive such treatment, or such treatment may not be reasonably available to that patient in New Zealand. It is unclear whether a person who refuses or cannot reasonably access treatment that would improve or reverse an advanced state of decline would be considered to be experiencing ‘irreversible’ decline for the purposes of the Act.<sup>9</sup>
14. Broadly, there are two alternatives:
  - a) Section 5(1)(b) could be clarified to specify that the advanced state of irreversible decline in physical capability must be unlikely to improve as a result of reasonably available treatment. This would constitute a narrower approach and would not apply to those who refuse to take treatment which may temporarily alleviate their symptoms of advanced physical decline.
  - b) Alternatively, the wording in the *Assisted Dying for Terminally Ill Adults Bill* (UK) could be considered. This adopts a broader definition and provides that ‘*treatment of an inevitably progressive condition that only relieves symptoms temporarily is not to be regarded as treatment that can reverse that condition.*’<sup>10</sup> Under this definition, a person who decides not to receive treatment may still be eligible under the proposed United Kingdom assisted dying regime.

15. Without expressing a preference for the limits of any definition, the Law Society recommends that section 5(1)(d) is amended to define ‘irreversible decline’.

*Section 5(f) - ‘competent to make informed decisions’*

16. Section 5(f) provides that a person who is eligible for assisted dying or an eligible person must be competent to make an informed decision about assisted dying. Section 6 of the Act

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<sup>7</sup> Section 9.

<sup>8</sup> Explanatory Memorandum (2017), at Clause 9. Available via:

<https://www.legislation.vic.gov.au/bills/voluntary-assisted-dying-bill-2017>

<sup>9</sup> Snelling, above n 6, at 25.

<sup>10</sup> Clause 2(2).

provides that a person is competent to make an informed decision about assisted dying if the person is able to –

- a) understand information about the nature of assisted dying that is relevant to the decision; and
- b) retain that information to the extent necessary to make the decision; and
- c) use or weigh that information as part of the process of making the decision; and
- d) communicate the decision in some way.

17. A person must be competent throughout the assisted dying process in order to be eligible for assisted dying, including at the time of administration of medication.<sup>11</sup> An advance directive<sup>12</sup> may not provide for assisted dying.<sup>13</sup>

18. We note that the effect of the need to be competent at the time of administration of medication is potentially that an eligible person chooses to die earlier than they may otherwise have wished, in order to ensure their ongoing eligibility. Alternatively, a person who becomes increasingly unwell after having their request for assisted dying confirmed, but before administration of medication, may become ineligible, despite their illness and suffering becoming worse.

19. We therefore consider it appropriate to review the current prohibition on the use of an advance directive providing for assisted dying and the requirement for a person to be competent at the time of the administration of the medication. We note that advance directives are used in all other aspects of healthcare, including end of life treatment decisions. If advance directives were to be permitted, they would need to comply with the process outlined in the Act.

20. Finally, we note that the use of the word “competent” is now considered to be an outdated term, with the terminology “decision-making capacity” preferred.<sup>14</sup> The Ministry may wish to consider updating the terminology used in this regard.

## Safeguards

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<sup>11</sup> Section 20.

<sup>12</sup> Right 7(5) of the Code of Health and Disability Consumers’ Rights provides that “Every consumer may use an advance directive in accordance with the common law”. Clause 4 of the Code of Health and Disability Consumers’ Rights defines an advance directive as meaning a written or oral directive—

(a) by which a consumer makes a choice about a possible future health care procedure; and

(b) that is intended to be effective only when he or she is not competent.

“Health care procedure” is defined in s 2(1) of the Health and Disability Commissioner Act 1994 as meaning “any health treatment, health examination, health teaching, or health research administered to or carried out on or in respect of any person by any health care provider; and includes any provision of health services to any person by any health care provider”. “Health services” are defined as meaning services to promote health, services to protect health, services to prevent disease or ill health, treatment services, nursing services, rehabilitative services, diagnostic services, and services provided to a person who has requested assisted dying under the End of Life Choice Act 2019.

<sup>13</sup> Section 33.

<sup>14</sup> See the *Health and Disability Commissioner’s Review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers’ Rights consultation document* (Health and Disability Commissioner, 2024); and *He Arotake i te Ture mō ngā Huarahi Whakatau a ngā Pakeke | Review of Adult Decision-Making Capacity Law: Second Issues Paper* (NZLC IP52, 2024).

### *Section 10 and the provision of information by practitioners*

21. Section 10 of the Act is a legislative safeguard, which is intended to ensure that individuals are not influenced by medical practitioners in making a decision to seek assisted dying. This so-called 'gag' clause may conflict with the common law, which has endorsed a right to be adequately informed to enable informed choice.<sup>15</sup>
22. It may also conflict with the Code of Health and Disability Services Consumers' Rights (**Code of Rights**), which includes the right to be fully informed and to receive an explanation of the options available.<sup>16</sup> Currently, part 2 of the Schedule to the Act explicitly provides that section 10 overrides the rights contained in clauses 6(1)(b), 6(1)(c) and 6(2) of the Code of Rights.
23. Section 10 of the Act therefore restricts the availability of information for those who are aware of, and feel able to initiate a discussion about assisted dying as an option, which may disadvantage those who are less 'health literate' or for other reasons are less confident navigating the health sector.<sup>17</sup> For these reasons, there is a risk that section 10 of the Act is operating as an unnecessary barrier and potentially creating inequities in access to assisted dying or, at a minimum, as an unnecessary barrier to informed decision making by patients.
24. We recommend consideration is given to repeal or amendment of section 10, bearing in mind the other safeguards that are already contained within the wider processes of the Act.

### **Complaints**

25. Section 27(4) of the Act specifies where the Registrar (assisted dying) must refer complaints received about the conduct of a health practitioner. The Te Whatu Ora website refers to an Assisted Dying Service Feedback and Complaints process, as well as the ability to make a complaint to the Health and Disability Commissioner (HDC). The health.govt.nz website then sets out information about the complaints process, again referring to both complaints processes.
26. It is not sufficiently clear to service users and their families or support people, where complaints should be made and whether it is intended that certain complaints are made to HDC and others to the Assisted Dying Service Feedback and Complaints process. We suggest that consideration is given to clarifying the public facing guidance and ensuring it is accessible and can be readily located.

### **Oversight of assisted dying**

27. Section 21 sets out the information that must be set out in a report of the attending medical practitioner or the attending nurse practitioner who provided or administered medication under section 20. This information must be sent to the Registrar within 14 days of the date of the assisted death.
28. The Registrar must send the report to the Review Committee, for the Review Committee to then report back to the Registrar as to whether it considers that the information contained in an assisted death report shows satisfactory compliance with the requirements of the Act. The Review Committee is then required to direct the Registrar to follow up on any

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<sup>15</sup> *Rogers v Whitaker* (1992) 175 CLR 479, 490 (HCA); *B v Medical Council* HC Auckland 11/96, 8 July 1996; and *Montgomery v Lanarkshire Health Board* [2015] UKSC 11.

<sup>16</sup> Right 6.

<sup>17</sup> Snelling, above n 6, at 13.

information contained in an assisted death report that the Review Committee considers does not show satisfactory compliance with the requirements of this Act.<sup>18</sup>

29. In order for the Review Committee to provide proper oversight, it must have access to sufficient levels of detail to undertake its role, which may be broader than the requirements set out in section 21(2) and/or the current approved form.
30. An additional point for consideration ought to be whether the section 21(2) requirements are sufficient to give the sorts of information that are considered important for the purposes of research. Research is necessary to allow for the evaluation of how the law is working in practice, for transparency and to guide improvements in practice. In particular, data is required to properly assess whether access is equitable, who is choosing to make use of the law, whether providers are well informed and whether the safeguards are working as intended. Such data is necessary to properly inform the ongoing implementation of the Act, allow for continuous evaluation, and provide for improved health service delivery of assisted dying services.<sup>19</sup>
31. The Law Society recommends further consideration is made as to the oversight settings and data recorded to ensure accurate reporting, compliance with the Act, and review of how the Act is operating in practice.

### **Te Tiriti provision**

32. The Act makes no reference to Te Tiriti o Waitangi, or tikanga Māori. There is no provision, for example, for members of the Review Committee to include individuals with suitable knowledge and experience of Te ao Māori and tikanga. Nor is it clear whether there remain concerns about how the Act has impacted Māori. The Law Society recommends this is included in the Ministry's review, informed by wide and meaningful engagement with the community.

Naku noa nā,



Taryn Gudmanz  
**Vice President**

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<sup>18</sup> Section 26.

<sup>19</sup> Jessica Young and others “The End of Life Choice Act: a proposed implementation and research agenda” (2021) 134 NZMJ 145.