Submission to the University of Tasmania

from the End-of-Life Choice Society of New Zealand

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About us

The End-of-Life Choice Society of New Zealand has been in existence for 43 years and has the same objectives as those of Dying with Dignity Tasmania. www.eolc.org.nz

About the End of Life Choice Act 2019

You will be aware that the New Zealand parliament passed the End of Life Choice Act 2019 in November last year. Its coming into force was, however, made subject to a binding referendum conducted simultaneously with our recent general election. The final count of votes showed 65.1% support for the legislation as passed by parliament. The law will come into effect on 7 November 2021.

About the New Zealand parliament

New Zealand's parliament consists of a House of Representatives only, comprising 120 lawmakers; we have no Upper House. The debate on the End of Life Choice bill took 2.5 years to conclude and included a twice-extended period of public and stakeholder consultation through the Justice Select Committee.

COMPARISON BETWEEN THE END OF LIFE CHOICE ACT 2019 (NZ ACT) AND THE END-OF-LIFE CHOICES (VOLUNTARY ASSISTED DYING) BILL 2020 (VAD BILL)

Opening comment

As per the terms of reference, we have highlighted the clauses in both pieces of legislation which we consider offer comparatively greater protection for the vulnerable. In certain instances, we find that the VAD Bill offers greater protection and in this case, we recommend no change to the draft legislation. In other instances, we find that the NZ Act offers greater protection. "The vulnerable" are generally considered to be minorities, the socio-economically disadvantaged, the disabled, the elderly. We have these groups in mind when we make our comments. In addition, we consider persons dying in great suffering and with no hope of relief other than by an earlier death to be equally vulnerable, particularly when they encounter obstacles to that relief at law. We have therefore included this group in our comments also.

Eligibility criteria

- VAD Bill is for terminal illness, disease, medical condition or injury with prognosis of death within 6 months and also for terminally ill by way of neurodegenerative disease with prognosis of death within 12 months. (Part 2, Section 6 (1)). In addition, it would seem that the eligibility criteria can be varied by way of an application to the Commission for exemption. (Part 2, Section 6 (3) and (4).)
- NZ Act is for terminal illness or disease with prognosis of death within 6 months. There is no possibility of application for exemption. (Part 1, Section 5, (1) (c.)
- ***Our comment:*** The eligibility criteria of the VAD Bill are more generous than those of the NZ Act. We prefer the VAD Bill in this regard, as the NZ Act is likely to rule out an extremely vulnerable group, namely those with neurodegenerative diseases. This is because accurate prognosis of death is extremely difficult for these diseases so that they are generally considered "non-terminal'. Suffering can nevertheless be greater and even more prolonged for this group. We recommend retaining the clause that permits those with neurodegenerative diseases to make their request when their prognosis is within 12 months. We also recommend retaining the clause that permits the Commission to consider an application for an exemption.

Intolerable suffering

- VAD Bill provides an extensive definition including suffering by anticipation. (Part 3, Section 14).
- NZ Act provides no definition for this.
- ***Our comment:*** The inclusion of suffering by anticipation as part of the definition is a benefit. Overseas experience teaches us that the peace of mind for a person who is suffering by anticipation when they are permitted access to a VAD death is in itself palliative, even if the person never has reason to use the option. The inclusion of this descriptor protects all groups of vulnerable people from medical practitioners who might otherwise take only present-day, physical suffering into account in assessing eligibility. We recommend retaining the inclusion of "suffering by anticipation".

Who may be called in to determine decision making capacity if PMP, CMP or AHP unsure?

- VAD Bill permits another medical practitioner, psychiatrist or psychologist. (Part 3, Section 12 (4).)
- NZ Act permits a psychiatrist only. (Part 2, Section 15.)
- ***Our comment:*** We prefer the VAD Bill in this regard. The inclusion of another medical practitioner is an additional protection for the vulnerable, especially for the disabled and the very elderly in whom decision-making capacity can be misread or misunderstood. A medical practitioner with experience in caring for these groups may be more valuable to the determination of decision-making capacity than a psychiatrist or psychologist without similar experience. We recommend retaining

the options of another medical practitioner, psychiatrist or psychologist in the legislation if a third opinion is needed for decision making capacity.

Who must witness person make request in writing?

- VAD Bill requires two independent witnesses to the signature of the request by the person, or alternatively that the completion of the form and signing of the request be witnessed by a commissioner of oaths. (Part 6, Section 31, (3) (b).)
- NZ Act requires only the medical practitioner to be in attendance. No other witnesses are required. (Part 2, Section 12, (3) and (5).
- ***Our comment:*** We prefer the NZ Act in this regard. In New Zealand, death-hastening occurs legally when a person requests life support to be switched off, or refuses or discontinues life-sustaining treatment or refuses nutrition and/or hydration. Response to such requests and decision to cooperate or not is not mandated by law but is subject to medical best practice and clinical judgment. The person is not required to formalize the request in writing in these instances nor are witnesses required. We do not feel that independent witnesses add any protection for the vulnerable, as there is no evidence that the vulnerable are adversely affected by the absence of witnesses to other death-hastening requests. We recommend that the requirement for witnesses other than the medical practitioner be waived.

Certain persons not to initiate discussions about assisted dying

- The VAD Bill does not permit a registered health practitioner to initiate or suggest voluntary assisted dying to a person in their care, although they are permitted to respond with the relevant information to a direct request for assisted dying. (Part 4, Section 17, (1) and (2).
- The NZ Act does the same and we regret this. (Part 2, Section 10, (1) and (2).
- ***Our comment:*** We feel that this insistence in both jurisdictions is misguided and will give less protection to the vulnerable rather than more. Disadvantaged persons may not be aware of the possibility of voluntary assisted dying or may feel too intimidated to initiate the conversation themselves, thereby cheating themselves of the option of a peaceful death even when eminently eligible. We have been advised by two Victorian AHPs (Dr Nick Carr and Dr Cameron McLaren) that this is a handicap for medical practitioners seeking to do the right thing by persons in their care. Quoting Dr Nick Carr: “Our law forbids doctors to tell patients of the option of VAD. No problem for the informed, articulate English speakers who know that they have to ask, but a significant potential barrier for the more marginalised. How can my patients give informed consent if I cannot tell them about all the choices? It’s like being told that I can tell someone with heart disease about pills, but not about stents or surgery.” We recommend that a person’s medical practitioner be permitted to initiate a discussion pertaining to the option of a VAD death as one option among others.

Second request

- VAD Bill requires person to make second request to the same PMP no sooner than 48 hours after being after making the first request, unless death is foreseen within 7 days or there is fear that the person may lose decision-making capacity. (Part 6, Section 30, (1) and (2).)
- NZ Act does not require a second request to be made to the same PMP with a minimum 48-hour interval between the two. (Part 2, Sections 12 and 13.)
- ***Our comment:*** We prefer the NZ Act in this regard. Presumably, the purpose of the first and second requests to the same PMP is designed to assess constancy of intent on the part of the person and as a "cooling off" period. Instead, the NZ Act specifies that the PMP must hold relevant information discussions with the person "at intervals determined by the progress of the person's terminal illness". The first of these conversations much be recorded and the relevant form sent to the Commissioner (Registrar). (Part 2, Section 11, (b).) We see the requirement to demonstrate constancy of intent by being made to wait 48 hours before making a second request to the same PMP as being excessively onerous to the person. The waiver by way of Part 6, Section 30 (2) further proves that this "protection" is dispensable. We recommend that the requirement to wait for a minimum period of 48-hours between first and second requests be waived.

Referral to medical practitioner for second opinion

- VAD Bill requires the PMP to refer an eligible person to another medical practitioner (potentially the CMP) for a second opinion. The potential CMP is chosen by the PMP subject to certain restrictions. However, the potential CMP may refuse to accept the referral including for reasons of conscientious objection. (Part 7, Section 37 (1), (2) and (3).)
- NZ Act requires the PMP to apply to the SCENZ group for a second opinion. The SCENZ group (Support and Consultation for End of Life Choice in New Zealand) will be a new group set up by the Director-General of Health and will comprise medical professionals willing to be involved in VAD. (Part 3, Section 25, (1) – (4). The SCENZ group will supply the name and contact details of a willing practitioner in two circumstances: as a replacement for the first opinion if the person's medical practitioner refuses to accept the request on grounds of conscientious objection and always for the second opinion to ensure professional independence between PMP and CMP. Their choice is subject to restrictions identical to those of the VAD Bill.
- ***Our comment:*** We prefer the NZ Act in this regard. Both a replacement first opinion medical practitioner and a second opinion medical practitioner are guaranteed not to have a conscientious objection to VAD. We consider this a better protection for those dying in great suffering in that they are not unduly subject to a "trial and error" search for a medical practitioner willing to discuss VAD as an option and to proceed where necessary. We recommend the inclusion of some mechanism in the legislation that imitates the NZ Act legislation so that the vulnerable from all groups

do not have a VAD death withheld from them by means of an extended search for a medical professional without conscientious objection to it.

Right of Conscientious Objection

- VAD Bill covers this under Part 5, Sections 19, 20 and 21 (for first request). It is also covered under Part 7, Section 39, 40 and 41 (for second request). A medical practitioner who wishes to refuse a request for any reason, including for conscientious objection, must make a note on his/her file within 7 days to that effect. The VAD Bill is, however, silent on the topic of how and when the person must be communicated with.
- NZ Act covers conscientious objection under Part 2, Section 8 (1) – (5) and Section 9, (1) – (3). Under the NZ Act, a medical practitioner who has a conscientious objection must tell the person of their conscientious objection and must inform the person of his/her right to seek the name and contact details of a replacement medical practitioner from the SCENZ group.
- ***Our comment:*** We prefer the NZ Act in this regard. We deem it to be more open and honest toward the person who, whether disadvantaged or not, is seeking potentially legally available medical help. Vulnerable persons from all groups can only be more disadvantaged by a refusal of assistance without directing them to an alternative source. The SCENZ group will provide a replacement medical practitioner if the first medical practitioner is unwilling to become a PMP. It will always be the only source of CMP, both for purposes of ensuring professional independence from the PMP and for purposes of providing a CMP in a timely way. We recommend the inclusion of some mechanism in the legislation that imitates the NZ Act legislation so that the vulnerable from all groups do not have a VAD death withheld from them by means of an extended search for a medical professional without conscientious objection to it.

Acting voluntarily

- VAD Bill specifies this as one of the eligibility criteria (Part 3, Section 10 (d) and further provides a definition (Part 3, Section 13 (1) (d).) We can see no explicit recommendation, however, on how to determine that the person is acting voluntarily or what should be done if the PMP or CMP suspects the person is acting under duress.
- NZ Act similarly requires the person to be acting voluntarily. It goes further, however, by recommending ways whereby the PMP can be more safely assured of this, namely by conferring with other health practitioners in regular contact with the person (including bedside nurses) and by conferring with family members approved by the person. (Part 2, Section 11, (h) (i) and (h) (ii) and (i).) Furthermore, the NZ Act requires a medical practitioner who suspects the person is not acting voluntarily to halt the process, tell the person they are halting the process, and to report by means of the prescribed form to the Commission (Registrar) that they are halting the process. (Part 2, Section 4 (a) – (d).)

- ***Our comment:*** We prefer the NZ Act in this regard for two reasons. Firstly, the requirement to confer with others to be reassured of voluntary action is a clear additional protection for the vulnerable. Secondly, the requirement to report to the Commission (Registrar) that the PMP is taking no further action alerts the Commission (Registrar) to an instance of potential coercion/pressure in the case of that specific person. Should the person subsequently make a different attempt to access VAD, the Commission will have this previous incident on record and can make further enquiries of the new PMP. We recommend that the legislation be amended to more closely imitate the NZ Act, as this offers greater protection to the vulnerable who may be under pressure from family or others to seek a VAD death that they do not actually want.

Self-administration in private with certificate

- VAD Bill allows for the person to choose one of several options for administration of the VAD substance. One of these is self-administration in private with certificate, this being an option to take the VAD substance home and self-administer at a time of the person's choosing.
- NZ Act also allows for self-administration as one of several options, but this must be done under the supervision of the AHP. Persons are not allowed to take home the VAD substance for later administration in private. To counter this constraint, the NZ Act allows the person to defer the time/date of self-administering the VAD substance for up to 6 months, after which time the person becomes ineligible.
- ***Our comment:*** We prefer the NZ Act in this regard. We believe that self-administration under AHP supervision ensures the person is acting voluntarily right up to the last minute; this cannot be guaranteed when self-administration takes place out of sight. Accidental out of sight self-administration could also take place after the person has lost decision-making capacity. Furthermore, all USA/Oregon reports of VAD deaths being botched have been due to self-administration in private.

Approved VAD training course

- VAD Bill requires all authorised medical practitioners (AMPs) to voluntarily undergo VAD training within 5 years of accepting to act on the person's behalf. This applies equally to PMPs, CMPs and AHPs although the training will be different for each. (Part 17, Section 116.)
- NZ Act is silent on the issue of training. However, this may be requested by the SCENZ group during the 12-month preparation period under Part 3, Section 25 (g). It may also be recommended by the Colleges and/or by the NZ Medical Council whose feedback will be sought by the Minister for Health. Question 1 - Brooke van Velden to the Minister of Health on Vimeo

- ***Our comment:*** We prefer the VAD Bill in this regard. It is in the interests of all groups of vulnerable people and in the interests of the health practitioners involved that training be completed.

Report on initial operation of Act

- VAD Bill requires the Commission to make an initial report to the Minister 6 months after commencement.
- NZ Act requires the Registrar (Commissioner) to report to the Minister by 30 June each year for that year.
- ***Our comment:*** We do not have an opinion on the comparative merits of the two systems in terms of better protection of the vulnerable.

Closing comment

We thank the Governor of Tasmania and the University of Tasmania for the opportunity to make comment on the End-of-Life Choices (VAD) Bill 2020.

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