dying with dignity victoria
respect for the right to choose

the overwhelming majority of australians believe in the right of the terminally ill to seek and obtain medical assistance to end their life with dignity

2nd February 2018

The Committee Secretary
Select Committee on End of Life Choices in the ACT
GPO Box 1020
CANBERRA ACT 2601

Dear Secretary,

Inquiry into End of Life Choices in the ACT

Dying With Dignity Victoria (DWDV) is pleased to provide this submission to the Select Committee on End of Life Choices in the ACT. DWDV was heavily involved in the lead up to and during a similar inquiry in Victoria, which commenced in 2015. This was the first stage of a multi-stage process which concluded with the passing of the first voluntary assisted dying law in Australia since the Rights of the Terminally Ill Act of the Northern Territory 1995, which was subsequently repealed by the federal government in 1997.

DWDV is of the view that consulting widely with the community, as was done in Victoria and as the ACT is doing with this inquiry, is a vital part of the process to determine the future direction of end of life services.

Our contribution to the Victorian inquiry can be downloaded at:
https://www.parliament.vic.gov.au/images/stories/committees/lsic/Submissions/Submission_625_-_Dying_with_Dignity_Victoria.pdf

We commend our Victorian submission to you. Apart from some statistics that relate specifically to Victoria (eg, data on the level of support for voluntary assisted dying in the various Victorian electorates in Appendix A), most of the material is equally relevant to all Australian jurisdictions. Much of the content of the submission directly addresses your terms of reference, as outlined below.

1. **Current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care.**

   Chapters 3 and 4 of our above submission deal with this.

2. **ACT community views on the desirability of voluntary assisted dying being legislated in the ACT.**

   The material presented in our Section 7.4 is based on national surveys. We would expect these to be largely representative of the views in the ACT. While the earlier parts of Chapter 7 relate specifically to a Victorian survey, again we would expect similar results in the ACT.

3. **Risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed.**

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We address this in our Chapter 9, *Countering opponents' claim.*

4. The applicability of voluntary assisted dying schemes operating in other jurisdictions to the ACT, particularly the Victorian scheme.

We conducted a comprehensive review of voluntary assisted dying regimes in other jurisdictions in Chapter 5 of our submission.

6. Any other relevant matter.

In general, DWDV is very pleased with the voluntary assisted dying legislation enacted in Victoria in late 2017. It provides adults with capacity to make health care decisions, who meet a set of criteria near the end of life, with the ability to request medical assistance to help them die. However, there are several ways in which the provisions of the Victorian legislation could be improved. These are discussed below.

DWDV's views on the Victorian voluntary assisted dying legislation

1 Eligibility to access voluntary assisted dying in Victoria after July 2019

- be an adult, 18 years and over; and
- be ordinarily resident in Victoria and an Australian citizen or permanent resident; and
- have decision-making capacity in relation to voluntary assisted dying; and
- be diagnosed with an incurable disease, illness or medical condition, that:
  - is advanced, progressive and will cause death; and
  - is expected to cause death within weeks or months, but not longer than 6 months, except in the case of a neurodegenerative disorder, such as motor neuron disease, where it is expected to cause death within 12 months; and
  - is causing suffering that cannot be relieved in a manner the person deems tolerable.

DWDV is of the opinion that the requirement that the disease, illness or medical condition is expected to cause death within 6 or 12 months should not be a requirement. That is, a condition with the characteristics of being *advanced, progressive and eventually resulting in death that is causing unbearable, irremediable suffering* should be sufficient as the medical criteria.

There are several reasons why we hold this view. One is the difficulty of predicting the trajectory to death for many illnesses. Another is that the key issue is the relief of suffering available from voluntary assisted dying when that suffering cannot be relieved by other means acceptable to the person.

2 Cumbersome process

The patient under the Victorian legislation will need to enter into a multi-step process to access voluntary assisted dying, some of which will involve actions DWDV considers are unnecessarily burdensome. These include:

- It is appropriate that two medical practitioners are required to assess a person as eligible for voluntary assisted dying. However, the Act states that both must be fellows of a recognised medical college. In addition, one of the practitioners needs to be a specialist in the disease of the person. These requirements will be difficult to meet for people in rural and remote areas; allowance for tele-consultation should be included. The Victorian provision may

exclude the patient's long term medical practitioner from being involved in the assessment process (if she/he were not a fellow of a recognised college). It is appropriate that the two assessing doctors have completed special training for this task.

- The medical practitioner prescribing the voluntary assisted dying medication will need to seek approval from the Department of Health and Human Services after completing the required prior steps. This approval requirement adds delay to the process and hence to the suffering.

3 Refusal by some institutions to participate

While DWDV accepts that no medical practitioner should be obliged to provide a voluntary assisted dying service if they have a conscientious objection to it, publicly funded private institutions, such as hospitals operated by religious orders, should be required to provide a voluntary assisted dying service.

4 Locked box to safeguard voluntary assisted dying medication

The Victorian legislation requires that the pharmacist supplying the voluntary assisted dying medication provide it in a locked box for safekeeping until it is required for use. A contact person is required to be nominated to return any unused medication after the patient has died, either from voluntary assisted dying or other causes.

This seems a clumsy approach. A better alternative would be to delegate to, or set up, a suitable organisation to safely hold the issued medication. In Switzerland, EXIT Deutsche-Schweiz performs this role for its members; alternatively, this role could be provided by a government-sponsored independent organisation.

5 Choice of voluntary assisted dying medication

Nembutal is the most widely used voluntary assisted dying medication in the world. There is wide, long-term experience that has refined the dosage required and the mode of administration, such as the need to take an anti-emetic prior to ingestion. This experience has confirmed its reliability and efficacy.

However, Nembutal is not approved by the Therapeutic Goods Administration (TGA) and as such

- it is an illegal import
- it is not mentioned in the Victorian legislation.

Unless the TGA approves Nembutal as a prescribable drug, Victoria will have to develop new, experimental voluntary assisted dying medications. Clearly, these will not be backed by the depth of experience behind Nembutal.

Yours sincerely,

Lesley Vick
President,
Dying With Dignity Victoria Inc

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