

8 March 2024

Via email: [AgedCareLegislativeReform@Health.gov.au](mailto:AgedCareLegislativeReform@Health.gov.au)

Dear Sir/Madam

**RE: Consultation – Exposure Draft of the new Aged Care Bill**

[Go Gentle Australia](#) is a national charity established by Andrew Denton in 2016 to promote choice at the end of life. We have played a critical role in passing voluntary assisted dying (VAD) laws in all six states. Our focus is on developing high-quality VAD practice and systems to best serve the needs of dying people, their families and health professionals.

We are grateful for the opportunity to contribute to this consultation and congratulate the Department for its hard work. However, we are concerned and surprised that VAD is not included in the Exposure Draft (**the new Act**). We raised this as an issue [in response to Consultation No. 1](#) and do so again now.

VAD laws are operational in all six states, and legislation is being considered, or prepared, in both Territories. This means that VAD is now a legal end-of-life option for 90% of eligible Australians, and forms part of the provision of high-quality, person-centred end-of-life care.

Almost two thirds of Australians who have accessed VAD are aged 70+<sup>1</sup>, with one-third aged 80+<sup>2</sup>. VAD is an aged care issue. It is both important and appropriate that this new health care option is recognised in the New Act.

[REDACTED] health service, Go Gentle has been working with a range of health stakeholders to help them ensure that guidelines and training materials make appropriate mention and acknowledgment of VAD. We will ensure these references are accurate and up-to-date. Equally, it is critical to ensure all health teams are aware of all end-of-life choices.

The Australian Commission on Safety and Quality in Healthcare recently updated their [National Consensus Statement: Essential elements for safe and high-quality end-of-life care](#). The introduction confirms that VAD is within the scope of high-quality end-of-life care: 'People opting for voluntary assisted dying should continue to receive the safe and high-quality end-of-life care described in this document'<sup>3</sup>. We urge that the exposure draft is similarly updated.

VAD is now an accepted component of aged care, so its exclusion from the new Act risks this legislation being out of step with contemporary end of life care. To address this, we recommended the following changes/additions to the new Act:

**Recommendation: Include VAD in the State of Rights**

Proposed wording for a new provision to be inserted after Section 20(2)(b)

Section 20(2)(c): *voluntary assisted dying, when chosen, in accordance with the relevant jurisdiction's legislation.*

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<sup>1</sup> [Victorian Voluntary Assisted Dying Review Board Annual Report](#) July 2022 - June 2023 p3 - 64% (reflective of all states' data)

<sup>2</sup> *ibid* p3.

<sup>3</sup> [National Consensus Statement: Essential elements for safe and high-quality end-of-life care](#) p1.

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## Rationale:

### Inclusion of VAD in the new Act will reflect the current end-of-life landscape in Australia

- The Australian Charter of Healthcare Rights says a person's culture, identity, beliefs and choices should be **recognised and respected**<sup>4</sup>. This includes the choice of VAD.
- Inclusion of VAD in the new Act will ensure the legislation is fit for purpose now and in the future, achieving the intent of a 'forward-looking aged care system' (as defined in the **Objects**).
- VAD is legal healthcare. Yet the new Act neglects to consider or acknowledge the rights of people seeking VAD:
  - The **Statement of Rights** guarantees equitable access to 'palliative care and end-of-life care when required'. However, VAD is not mentioned.
  - The proposed new Act also excludes VAD from the **definition of high quality care** and the **Statement of Principles** (both of which recognise rights contained in the Statement of Rights).
  - It is therefore critical that VAD be included - either explicitly and in its own right, or as part of end-of-life care as defined in the Act.
- If Commonwealth law fails to recognise state VAD legislation, there is a risk, in the event of a conflict between jurisdictions, that federal law will take precedence. This may frustrate, or even obstruct, the states' legislated **provision** of VAD.

### are delivered in aged care settings

- VAD applicants are in receipt of aged care. In the first six months of 2023, 7.6 percent of Queensland applicants were living in a residential aged care facility and 6.6 percent resided in retirement villages<sup>5</sup>. In Western Australia, 8.9% of VAD deaths took place in residential aged care<sup>6</sup>.
- Average figures from five states<sup>7</sup> show 80.5 percent of people who apply for VAD are in receipt of palliative care - a significant proportion of which is likely to take place in an aged care setting.
- People seeking VAD are vulnerable; they are terminally ill and nearing the end of life. Extra care must be taken. Particularly vulnerable are aged care residents who can face acute challenges in accessing VAD as many Australian aged care providers are faith-based, and choose not to participate in VAD.

<sup>4</sup> [Australian Charter of Healthcare Rights](#) Australian Commission on Safety and Quality in Healthcare.

<sup>5</sup> [Queensland Voluntary Assisted Dying Review Board Annual Report 2022–2023](#) p18.

<sup>6</sup> This does not include self administration. [Voluntary Assisted Dying Board Western Australia Annual Report 2022-23](#) p37.

<sup>7</sup> Drawn from each states' independent VAD Review Board reports, excluding New South Wales who are yet to release a report.

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### Clarity is important to prevent patient harm

- Unfortunately, there have been multiple instances where an aged care provider's non-participation in VAD has prevented or significantly delayed a person from being able to access VAD. The experience of Colin M is indicative of the suffering inflicted on terminally ill Australians by such obstruction:

#### Colin M, a 79-year-old Melbourne man dying of metastatic bowel cancer

Despite having been assessed by two doctors and found eligible for VAD in 2020, the Catholic aged care institution in which Colin lived refused to let the VAD Statewide Pharmacy Service into the facility to deliver the VAD substance.

To make matters worse, they left Colin – whose every day was filled with fear that he would die painfully of a bowel obstruction before the substance arrived – waiting for nine days before informing him of their refusal.

*'He would have had severe pain. He wouldn't have been able to pass any bowel motions. He would have eventually started vomiting because everything in his bowel couldn't get out except by vomiting it up.'*

GP and VAD assessor, Dr John Stanton

*'A man at the end of his life, experiencing very difficult symptoms. I think he certainly felt abandoned.'*

Associate Professor, Peter Lange, head of acute medical unit, Royal Melbourne Hospital, where Colin was eventually admitted for VAD

*'They were forcing him down the pathway of a painful terminal phase.'*

Rheumatologist and VAD assessor, Dr Andrea Bendrups.

Having been instructed that he couldn't talk to anyone at the home in which he lived about his VAD choice, Colin was forced to leave his friends there without saying goodbye and be transferred to Royal Melbourne where he knew no-one. Once there, it was arranged for the Statewide Pharmacy Service to visit within 24 hours, and Colin took the VAD substance two hours after receiving it.

*'I don't understand how people can think that that's a good or an ethical thing to do to someone. Physically and emotionally, to put people through that suffering. They'd seen his decline, and were intimately aware of how difficult it was for him, and the impact that it had had on his mental health. I couldn't understand why it is better for someone to suffer and have a horrible death. It just seemed to make no sense to me at all.'*

Deb M, Colin's sister

- This level of obstruction is not limited to a single institution, or state. Under the NSW Act, for example, institutions can choose not to participate but they should not interfere with someone's choice. However, in a 2023 report presented to its Synod, Anglican Community Services said it would adopt a strategy of minimum compliance, but that they would *'seek to dissuade residents from accessing VAD by 'deed and word''*. This

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stated ambition - to actively try and dissuade residents from their legal (and deeply personal) end-of-life choice - does not promote person-centred care, which sits at the heart of the Australian Charter of Healthcare Rights, nor is it consistent with the 'forward-looking aged care system' the new Aged Care framework seeks to achieve.

- Palliative Care Australia's 'Guiding Principles on VAD'<sup>8</sup> embrace as a core principle that 'people living with a life-limiting illness are supported and respected as they explore their options and make end-of-life care decisions' and that 'people exploring VAD are not abandoned'. If VAD is excluded from the new Aged Care framework, the act of abandonment by non-participating institutions will be further encouraged.
- It is therefore of paramount importance that the new Act protects and acknowledges eligible people's right to access VAD.

For these reasons, it is critical that VAD is included in the new Aged Care framework.

Thank you for the opportunity to contribute.

Please do not hesitate to contact us at [policy@gogentleaustralia.org.au](mailto:policy@gogentleaustralia.org.au) if we can be of any further assistance.

Yours faithfully



Dr Linda Swan  
CEO, Go Gentle Australia

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<sup>8</sup> [Guiding principles for those providing care to people living with a life-limiting illness](#) Palliative Care Australia 2022.