

19 January 2023
Mr Chris Leahy
Acting CEO
Australian Commission on Safety and Quality in Healthcare
GPO Box 5480
Sydney NSW 2001

Via email: mail@safetyandquality.gov.au

Dear Mr Leahy,

RE: National Consensus Statement: Essential elements for safe and high-quality end-of-life care

Go Gentle Australia is grateful for the opportunity to contribute to the consultation draft of the [National Consensus Statement: Essential elements for safe and high-quality end-of-life care](#).

Go Gentle Australia is a national charity that promotes choice at the end of life. We were established in 2016 and have played a critical role in the introduction of voluntary assisted dying (VAD) laws across Australia. We empower people to choose the care that is right for them, including the option of VAD.

VAD laws have passed in every state and are now effective, following implementation periods, in Victoria, Western Australia, Tasmania and Queensland. South Australia's law will take effect on 31 Jan 2023, followed by New South Wales on 28 November 2023. We work to ensure that the new option of VAD is recognised as a valid, legal medical treatment for eligible people and that it is afforded equal respect as other important provisions such as hospice and palliative care.

We appreciate your time and effort in drafting the National Consensus Statement and hope you will consider our recommendations. We have addressed each section where we have suggestions below.

Scope

The final paragraph of this section states *'Specific requirements for VAD are not discussed in this document as each state has its own legislation that regulates access and should be referred to if a person is considering this option.'*

VAD is a compassionate, patient-focused treatment which is now part of end-of-life care in Australia. Although there are some differences between the laws in different

states, they all have core elements in common. We suggest a more comprehensive explanation would be helpful for this consensus statement and that VAD should be included in relevant sections throughout the document.

In the Scope section, for example, we suggest:

‘Voluntary assisted dying (VAD) laws have been passed in all Australian states. These laws ensure voluntary assisted dying is available alongside other end-of-life care services as a valid, legal medical treatment which can provide an additional choice for eligible, terminally ill adults who are suffering unbearably at the end of their lives. The elements that are essential for delivering safe and high-quality end-of-life care apply equally to patients choosing voluntary assisted dying.’

Guiding principles

We suggest a reference to VAD is included in the guiding principles. Since VAD laws have now been passed in every state, the services available in this area are evolving quickly. End-of life care is quickly adapting. If VAD is omitted, the document will be out of date at the time of publishing. We recommend adding an additional point under n11:

‘Adults with terminal illnesses have the right to request voluntary assisted dying, provided they meet their state’s eligibility criteria.’

Essential element 2: Person-centred communication and shared decision making

In the first paragraph of this section, we suggest adding wording so the final sentence reads:

*‘Significant events that may indicate that conversations about end-of-life care should occur are listed 1.3 as well as when a person is actively dying, expresses an interest in discussing end-of-life care or **asks about voluntary assisted dying**.’*

Under 2.10, we recommend an additional point specifically about VAD:

‘The rules around discussing voluntary assisted dying differ between states and health professionals should be clear about how the law applies in their jurisdiction. A person’s choice about their end of life care should be respected and, where possible, supported. All laws allow health professionals to conscientiously object to participating in the voluntary assisted dying process. In this case, the person must be informed and, wherever possible, the person must be referred to a participating health practitioner or the state’s Voluntary Assisted Dying services. If an entire organisation is not participating, it is best practice to inform that person before they enter the facility.’

Essential element 4: Comprehensive care

We suggest an additional paragraph:

‘People have the right to request voluntary assisted dying if they have a terminal illness and meet their state’s eligibility criteria. These decisions should be respected as a request for a legal medical treatment. If a healthcare professional conscientiously objects to a person’s choice, this should not affect the quality of care provided or how the person is treated.’

Essential element 5: Responding to concerns

We suggest as a fourth paragraph:

‘When assessing for voluntary assisted dying, an additional opinion should be sought if the person’s capacity is in question. If any pressure, duress or coercion to request voluntary assisted dying is detected, the process must be stopped immediately and details shared with the state’s voluntary assisted dying review body.’

Essential element 6: Leadership, governance and readiness

We suggest adding to the list at 6.3:

‘Approach to voluntary assisted dying, paying due attention to the obligations under state law and the variety of perspectives that exist on the issue in health and care settings’

Essential element 7: Support, education and training

We suggest adding to the list at 7.3:

‘Understand the voluntary assisted dying laws in the state or territory of practice and healthcare workers’ rights and obligations under these laws.’

Essential element 8: Care setting and bereavement support

We suggest as a third paragraph:

‘Grief and bereavement surrounding voluntary assisted dying are unique and should be treated with sensitivity. Bereavement support should be aware of existing stigma and, if possible, people should be referred to specialist support services provided or recommended by the state health department.’

Essential element 10: Systems to support high-quality care

We suggest as a third paragraph:

‘Organisations should refer to their state’s voluntary assisted dying law to make sure they adhere to their obligations. It is best practice to ensure a voluntary assisted dying policy has been developed and implemented and that dying people seeking voluntary assisted dying do not face additional barriers, even if voluntary assisted dying is not provided on the premises.’

Glossary

We suggest adding a definition for VAD:

‘The legal right for a terminally ill person who meets their state’s eligibility criteria and is suffering unbearably to request help from their doctor to end their life.’

Thank you for the opportunity to provide comments on the National Consensus Statement. For any questions about this letter, please contact Frankie Bennett, Campaigns Manager on 0493 084 461 or frankie@gogentleaustralia.org.au

Yours sincerely

Dr Linda Swan,
CEO