



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL

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Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

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Submission to the
ACT's Inquiry into
Voluntary Assisted
Dying Bill 2023

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Introduction

Go Gentle Australia (GGA) 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 the introduction of VAD legislation in Australia, where all six states have now passed laws, as well as advocating for the recent Restoring Territory Rights Act 2022 (Cth). Through advocacy, evidence and storytelling, we work to ensure end-of-life care processes and systems are of high quality and protect choice at the end of life.

This submission follows our earlier response to the ACT's Discussion Paper on VAD in April 2023.

The ACT Government has drafted a bill seeking to thoughtfully build on state legislation to continue a tradition of incremental improvement in VAD law reform. The proposed bill largely follows the 'Australian model', departing only where the ACT Government believes improvements can be made.

We believe the accompanying statement of compatibility with the Human Rights Act 2004 has enhanced the bill, both in terms of articulating the legislative rationale and demonstrating proportionality. We praise the full explanation of decision-making capacity featured in the bill.

We feel the proposed bill honours the four principles we consider central to VAD reform:


- 1 Centre the dying person
- 2 Practise continuous improvement
- 3 Aim for consistency
- 4 Take a holistic view

Below, we explain where we consider the bill's strengths to lie, and highlight where we believe further consideration is needed. Our recommendations and positions are informed by the emerging evidence of VAD practice in Australia.

Throughout this submission, we refer to the inaugural trans-Tasman VAD Conference held in Sydney on 27-28 September 2023, co-hosted by Go Gentle Australia and VADANZ (the peak body for VAD professionals). Four hundred VAD clinicians and policymakers came together to discuss the practice of VAD and where improvement is needed. We asked attendees to vote on their top priorities for policy reform, and these are mentioned below.

'VAD is a gift'

Dan Colgan, pictured with his wife Laury, has been approved for VAD in Western Australia following a diagnosis of a brain tumour, glioblastoma multiforme.



“Now the dying has been taken care of, we can focus on the living. I could have spent my last months in fear and worry about myself and my family. Instead, I have gained self-determination and choice. Nothing has been taken away.”

Response to the bill

Eligibility requirements

'Advanced, progressive and expected to cause death'

Section 11(1)(b) of the bill explains that an eligible person must be diagnosed with a relevant condition (or combination of) that is 'advanced, progressive and expected to cause death'.

Section 11(4) of the bill defines a relevant condition as 'advanced' if:

- a. the individual's functioning and quality of life have declined; and
- b. any treatments that are available and acceptable to the individual lose any beneficial impact; and
- c. the individual is in the last stages of their life.

Given the eligibility criteria already require a person's condition to be 'expected to cause death', GGA recommends that s11(4)(c) is removed as it is hard to objectively measure. Although undoubtedly intended to improve clarity, the phrase 'in the last stages of life' is ambiguous and may actually increase uncertainty for the health professionals making eligibility assessments.

RECOMMENDATION

GGA recommends that s11(4)(c) 'the individual is in the last stages of life' is removed from the bill.

Removal of time frame to death

GGA is comfortable with the eligibility requirements set out in the bill. While the decision to remove a time frame to death is a departure from the 'Australian-model' of VAD, it is based on detailed consultation and extensive evidence from those working in VAD in other Australian jurisdictions. On this basis, the government has come to a position that both reflects experience and suits the unique circumstances of the ACT.

When Victoria's law passed, time frames were considered by lawmakers to be an essential safeguard that limited VAD access to people at the very end of life. Other states followed suit, with small expansions along the way (e.g. Tasmania's time frame exemption and Queensland's universal 12 month time frame). However, in practice it has become clear that time frames are arbitrary and do little to enhance the purpose of VAD, which is to offer end-of-life choice to people who are dying and suffering intolerably. On the contrary, they have led to perverse outcomes.

Time frames have acted as a barrier to access for some eligible patients, discriminated against people with certain diseases whose suffering is brutal but whose disease trajectories are unpredictable (e.g. neurodegenerative diseases such as Huntington's and Parkinsons, where people may lose decision-making capacity earlier), and have cruelly truncated the window of opportunity for people who are dying to begin the assessment process.

At the recent national VAD Conference 2023, delegates identified the six-month time frame as too restrictive and an impediment to care. Tasmania's optional exemption was widely endorsed, as was support for Queensland's universal 12-month time frame, which although still arbitrary, provided better care outcomes. Almost half the VAD health professionals voted to extend the time frame as a top priority.

This evidence – and feedback from clinicians – supports the removal of a time frame. In tandem with criteria that stipulate a person must be diagnosed with an illness, disease or condition that is 'advanced, progressive and expected to cause death', we believe this law to be less arbitrary and more inclusionary than earlier versions of VAD law passed around Australia.

Timeframes caused Sue Parker needless anguish and suffering

Sue Parker, 75,
with her daughter Nicole

**“Now I can relax.
The burden of MND
has been lifted.
Life is wonderful.
I can now live
and enjoy my life
knowing when I
feel the quality
has gone... so too
can I go.”**

Case study:

“My mum wasted six of the 12 months she had left, rushing to get [the VAD process] done. It was so unnecessary,” Sue’s daughter Nicole said.

Diagnosed with motor neurone disease, Sue had to be examined by her GP and two specialist neurologists to meet the requirements of Victoria’s VAD law.

“I naively thought it would be an easy process,” Sue said.

It was hard to get appointments, and there weren’t many VAD-trained neurologists in regional Victoria.

The process was further complicated because all the consultations had to be in-person, due to a Commonwealth prohibition on using telehealth for VAD.

Nicole said although her mother’s death in November 2022 was “unbelievably peaceful”, the assessment process was far too arduous.

Sue’s biggest worry was that her health would deteriorate and something catastrophic would happen, like a MND brain haemorrhage, before she could complete the process. Nicole believes the ability to start the VAD application earlier would have given her mum peace of mind from the outset. When she was finally deemed eligible, Sue said:

“Now I can relax. The burden of MND has been lifted. Life is wonderful. I can now live and enjoy my life knowing when I feel the quality has gone... so too can I go.”

A full explanation of capacity

GGA strongly supports the inclusion of a full explanation of decision-making capacity, including the acknowledgement that a decision deemed 'unwise' does not in itself put a person's decision-making capacity in doubt.

Residency requirements

GGA supports the residency requirements in the proposed bill, including the equitable treatment of people before the law irrespective of their status as a citizen, permanent resident, New Zealand visa-holder or otherwise.

GGA's position is that all jurisdictions should move towards standardised access to VAD across Australia, including the removal of territory-specific residency requirements. That said, we appreciate that this may be impractical for the ACT at this time. As such, we support the residency exemptions for those with a substantial connection to the ACT.

Process for VAD request and assessment

First request

GGA strongly supports the duty to refer a person seeking VAD to another service if the first is unable or unwilling to assist. We suggest that the referral should be to the approved Care Navigator Service, which is best placed to help find a participating VAD professional who is able to accept their request without delay.

RECOMMENDATION

GGA is concerned that the wording at Section 26 'Referral for further consulting assessment' at present says the following:

If an individual's consulting practitioner (the original consulting practitioner) decides that the individual does not meet the eligibility requirements, the individual's coordinating practitioner **may** refer the individual to another health practitioner for a further consulting assessment.

We believe, given that the approval of two independent doctors is required to be considered eligible for VAD, that the conditional 'may' should in this instance be amended to a 'must'.

Requirement that a person's health record is updated

GGA strongly supports the inclusion of a requirement that a person's health record be updated in a timely manner, detailing their VAD request and next steps. We believe this is of particular importance for a person's first request – irrespective of whether it is accepted or refused by the health practitioner. This makes health practitioners accountable to their patients to refer them on, and prevents a single health practitioner – intentionally or otherwise – delaying or blocking an individual's access to VAD assessment.

Witnessing the final written request

In our earlier response to the ACT's Discussion Paper on VAD, we recommended that a single witness to a person's final written request for VAD would be sufficient alongside the coordinating practitioner.

For some people, finding two witnesses can pose a challenge, especially for people who are isolated or who prefer to keep their medical choices confidential. Voluntary organisations have responded to this issue by providing witness services in some states. In others, the Care Navigator Services assist.

Allowing witnessing via audiovisual link could help ease this burden, but it is unclear if this is compatible with the Criminal Code Act 1995 (Cth) as it stands.

RECOMMENDATION

Reduce the requirement of two witnesses to a person's final written request to one (see above).

Removal of waiting period

GGA supports the inclusion of minimum 'waiting periods' between first and last requests. However, these should be as short as reasonably possible to avoid further suffering. We strongly support the inclusion of an exemption, as is present in all state legislation, so cases can be expedited if the person is likely to die or lose capacity before the minimum waiting period elapses.

GGA's policy and advocacy is always guided by evidence. The VAD process in all states takes time to navigate – three or four weeks on average – and thus generally incorporates a 'cooling off period' during which a person can reflect on their choice and establish their decision as enduring. As such, it is likely that the removal of waiting periods as proposed in the bill will have little measurable effect on the time it takes people to move through the VAD process.

However, it is not inconceivable that someone could move through the process very rapidly. As such, we support the inclusion of a minimum waiting period that stipulates at least 48 hours must elapse between first request and administration. VAD is not emergency care and same day administration, for example, would not be desirable. Such a stipulation will offer reassurance and evidence of due care.

RECOMMENDATION

Include a minimum 'waiting period' of at least 48 hours to elapse between first and last requests.

Accessing the substance

Choice between administration methods

GGA strongly supports provisions to allow people the ability to choose between self or practitioner administration of the VAD substance, as is the case in Tasmania and NSW. This enhances self-determination and provides comfort and relief, and reflects the intention of the law.

GGA also strongly recommends that, should the law be passed, alternative self-administration methods be investigated such as intravenous self-administration. We are pleased to see no wording within the ACT bill that would preclude this method of self-administration.

Role of health professionals

Greater roles for nurses

GGA supports and has long advocated for nurse practitioners to be included among the healthcare professionals permitted to administer the VAD substance, given their training, autonomy and level of expertise.

The ACT bill allows nurse practitioners (with relevant experience) to fulfil one of the two assessing practitioner roles, so long as the other assessor is a medical doctor. This is a departure from the 'Australian model' of VAD. However, we acknowledge it is a result of detailed consultation with stakeholders, including a Clinical Advisory Group, about what is most appropriate for the ACT. It is also consistent with the feedback from VAD practitioners at the trans-Tasman VAD Conference in September 2023, where health professionals and policy experts were asked to vote on which reforms would most benefit patients; a greater role for nurses was one of the top three priorities.

On this basis, the government has adopted an evidence-based approach that suits the ACT's unique circumstances – particularly with the ACT's small health workforce in mind.

It should be noted that nurse practitioners and registered nurses already play a central role as administering practitioners in other jurisdictions. In Western Australia and NSW, nurse practitioners are permitted to administer the VAD substance, and in Tasmania and Queensland nurse practitioners and registered nurses can fulfil this role.

Contrary to what some have asserted, the ACT bill does not break new ground in allowing nurses and social workers to initiate conversations about VAD. In Western Australia, Tasmania and Queensland nurse practitioners can do this as long as, at the same time, they also inform the person of all other treatment options, including palliative care. In NSW, all registered healthcare workers can raise the subject of VAD along with other end-of-life options, with the proviso that they also refer the patient to a GP.

Role of health services and care facilities

VAD service development

GGA supports the development of a central VAD Pharmacy Service and dedicated Care Navigator Service. Evidence and experience from other jurisdictions shows these services are crucial to the effective operation of VAD delivery and support.

Obligations of care facilities

GGA has long lobbied for VAD laws to include clear guidance to institutions about their obligations to the people in their care regarding access to VAD. We believe this must include penalties for any institution or individual found to block, harass or attempt to coerce a person away from their legal choice of VAD, just as there are penalties for attempting to coerce a person towards VAD.

An individual's right to conscientiously object to participating in VAD is a cornerstone of the Australian model. However we do not believe this same right applies – or should be applied – to institutions. Institutions do not have a 'conscience'. Neither can an institution suffer in the way an individual can. The right of individuals not to participate in the provision of VAD services must not extend to institutions, allowing them to block access to VAD altogether.

There is a distinct difference between conscientious objection and obstruction. Enough evidence now exists from around Australia to show that a blanket right for institutions to conscientiously object to VAD leads to distress and suffering for some who are eligible for VAD, yet blocked in their efforts to pursue this legal medical care.

States differ in their handling of the issue. Victorian, Western Australian and Tasmanian laws are silent on the topic. South Australia was the first jurisdiction to guarantee 'permanent residents' of care facilities access to VAD, on the basis that the care facility is their home and no-one can dictate what legal medical treatments a person can access in the privacy of their own home. Queensland further strengthened these protections, guaranteeing access to external VAD providers for temporary residents if transfer to another care facility is not possible. The NSW law has similar provisions.

The ACT bill recognises that ideology should never be allowed to trump a dying person's needs and offers the strongest protections yet for dying individuals. We particularly support the obligations for care facilities to:

- Provide Care Navigator contact details to anyone seeking information about VAD
- Ensure reasonable access to VAD health professionals on or off site, and transfer to another site to access these services if desired or reasonable on-site access is not possible
- Ensure care is not withdrawn on the basis of a person's decision to seek VAD, or otherwise hindering access to VAD
- Publish a readily available VAD policy explaining how minimum standards will be met
- Pay penalties for non-compliance, including potential criminal liability.

Moving people at the end of life can cause serious harm

Gay with brothers Graham (left) and Jon (right) at Royal Brisbane Hospital



“Why would any healthcare environment argue and push for a transfer, knowing the terrible state of that dying person?”

Case study:

Gay Rayner endured 42 days of torture as cancer ate away at her body. She was diagnosed with stage 4 cancer, which had spread to her lungs, breasts, spine, lymphatic system, bowel and stomach.

She is an example of a dying person for whom transfer to a different facility would be impossible.

Even the slightest movement caused excruciating pain.

Surgeons advised that her spinal cord was at risk of snapping, leaving her paralysed.

Her brother Jon remembers arriving at the hospital to hear screams “ripped with such fear and terror, it sent shivers down my spine”.

“I cannot help but wonder about any ‘healthcare professional’ who would insist on trying to transfer any end-of-life patient in my sister’s situation to accommodate and appease the needs of an ‘entity’ or a ‘Board’ of an objecting institution.”

Peak medical bodies support the right to conscientious objection, but not at the expense of a patient's access to care

Both the AMA and Palliative Care Australia acknowledge that an individual's right to conscientiously object does not absolve them of their moral and professional obligations to the people in their care. In its position statement on conscientious objection, the AMA states:

Doctors have an ethical obligation to minimise disruption to patient care and must never use a conscientious objection to intentionally impede patients' access to care.¹

Palliative Care Australia similarly supports conscientious objection, but not at the expense of a patient's care:

People must be supported and respected as they explore their options and make end-of-life care decisions which may include voluntary assisted dying.

A person living with a life-limiting illness, their family and carers should not be made to feel judged, abandoned, or scared that care will be adversely affected if they want to explore VAD.

Health professionals, care workers and volunteers should ... ensure people living with a life-limiting illness do not have undue delays in accessing VAD when health professionals/ providers/ services exercise the right to conscientious objection.²

If institutions are seeking the same rights to object as individuals, then it is only reasonable that they carry the same obligations as individuals towards those who are dying.

1 Australian Medical Association position statement: Conscientious objection, 2019: <https://www.ama.com.au/position-statement/conscientious-objection-2019>

2 Palliative Care Australia, Voluntary Assisted Dying in Australia - Guiding principles for those providing care to people living with life-limiting illness, 2022 <https://palliativecare.org.au/download/29992/>

Oversight, reporting and compliance

Review mechanisms

GGA strongly supports the establishment of an independent oversight body, similar to those in other jurisdictions, and welcomes the proactive review timetable that establishes an ongoing three-year process to look at issues such as age requirements, advanced care planning and residency requirements.

Further recommendations

GGA broadly supports the ACT government's bill. Below we make **five further recommendations** that we believe would enhance the legislation and its implementation in the ACT.

An interim arrangement with NSW

Given the strong links between ACT residents and NSW, GGA recommends that – should the law be passed – the ACT government seek an interim arrangement with NSW to allow ACT residents access to VAD during the 18-month implementation period. The number of people using this interim arrangement is likely to be small, however the comfort, relief and prevention of suffering will be considerable.

Early consideration of health practitioner remuneration

The recent VAD Conference 2023 highlighted workforce sustainability as one of two key reform priorities for VAD. (The other was amending the Criminal Code Act 1995 (Cth) to allow telecommunications to be used in the VAD process).

Fair remuneration for VAD practitioners is key to this sustainability. At present, VAD is only partially covered by Medicare. The MBS general explanatory notes (GN. 13.33) explicitly rule out "euthanasia and any service directly related to the procedure" from attracting Medicare benefits. The only exception is "services rendered for counselling/assessment about euthanasia".¹ VAD care is complex and time consuming with a large proportion of the work occurring outside standard consultations. Available funding for VAD doesn't generate enough income to cover costs.

The structure of the MBS limits remuneration for VAD care in three key ways:

1. VAD consults are often lengthy (i.e. greater than 90 minutes). There is no available MBS item number to cover the time required for this complex care.
2. MBS item numbers for home or institutional visits do not reflect the long time commitment involved in the delivery of VAD care at home. As most VAD assessments take place in a person's home this funding gap is particularly impactful on VAD practitioners .

1 Australian Government Department of Health and Aged Care, Medicare Benefits Schedule - Note GN.13.33 <http://www9.health.gov.au/mbs/fullDisplay.cfm?type=note&q=GN.13.33&qt=noteID>

3. There are no MBS benefits for any part of the process beyond "counselling/assessment".

This poses particular difficulty for GPs who are often the first port of call for people seeking VAD, take the bulk of cases, and often do not feel comfortable charging out-of-pocket expenses to dying patients. Many end up completing large parts of the assessment unpaid. A system relying on health practitioners' goodwill is not sustainable.

Options to be considered to ease this burden on health practitioners could include:

- A VAD remuneration model similar to New Zealand's, in which the VAD process is broken down into modules; each has a fixed price payment based on an estimate of the number of hours involved for the services. Additional payments are made available for extra duties such as obtaining clinical notes, travel allowance, complex cases and supporting other practitioners.
- A lump sum payment for completion of VAD training (a 6-9 hour commitment in other states)
- A longer Level (i.e. 90+ minute) consult within the MBS
- Additional government funding to support VAD provision.
 - » For example the NSW 'visiting medical officer' scheme sees clinicians employed in every local health district to provide VAD services, with the expectation that this will lighten the burden on other VAD practitioners, including GPs.

An information strategy to inform the public should this law pass

GGA recommends, should the law pass, the ACT government initiates a public communication strategy to inform residents of this new medical option.

The VAD Conference 2023 highlighted this lack of awareness as one of the main 'pain points' in the process for patients. Indeed, a lack of awareness remains one of the biggest barriers to access in other jurisdictions, and exacerbates existing health inequities.

An interim arrangement with NSW would prevent suffering in the ACT

Corinne Vale and father Jim with a photo of Corinne's mother, Ros Williams

“Canberrans have already waited far too long for the same end-of-life rights as other Australians. We cannot wait any longer.”

Case study

Ros Williams, diagnosed with motor neurone disease, took her own life to avoid suffering as she died.

Ros was receiving palliative care at Clare Holland House where an end-of-life care plan involving palliative sedation was agreed with clinicians. However, this was revoked by senior management.

Facing a death that Ros was told could take up to three weeks, she felt she had no option but to take her own life – while she still had the physical capacity to do so. VAD was not a legal option. Ros ended her life on the morning of 27 April 2023, while her family was out for a walk to avoid making them complicit in her death.

Her daughter, Corinne, said having VAD in place would have relieved her mother's mental anguish and allowed her family to be by her side when she died.

Should the proposed VAD law be passed, Corinne believes an interim solution must be found so ACT residents can access VAD in other states during the 18 months it will take for the law to come into effect.

A clear complaints mechanism

GGA recommends a clear complaints mechanism be established. This could be contained either contained within legislation or accompanying regulation, so that people who feel they may have been coerced, obstructed, or otherwise wrongly handled during the VAD process, know exactly how to complain, and who to complain to, in the knowledge that their complaint will be investigated. Possibly this complaint mechanism should sit within the Review Board's responsibilities.

Support for Cth Criminal Code reform

We urge the ACT government to continue its work alongside other jurisdictions to secure reform of the *Criminal Code Act 1995 (Cth)* so that telehealth and telecommunications can be used, where appropriate, in the VAD process.

