



**LEGISLATIVE ASSEMBLY**  
FOR THE AUSTRALIAN CAPITAL TERRITORY

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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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## **HCCA Submission - Voluntary Assisted Dying Bill 2023**

Thank you for the opportunity to share with you consumer responses to and feedback on the ACT Government's Voluntary Assisted Dying Bill 2023.

Earlier this year, HCCA ran a number of focus groups with our members, as well as conducting a range of individual conversations with consumers who were keen to share their thoughts on VAD. It is our view that the Bill, as drafted, broadly meets the ideals that consumers shared with HCCA throughout this process and is likely to facilitate the high-quality, consumer-centred care that recognises individual choices for end-of-life care consumers were asking for.

This said, there are a number of exclusions which consumers have expressed disappointment with. In particular, HCCA's members are keen for the ACT government to revisit the potential for inclusion of people with dementia via a rigorous advanced care planning process as well as reconsideration of the inclusion of young people.

We trust that the planned review after three years will again seek consumer input on these issues to ensure the Bill is meeting community needs and continues to do so through consideration of consumer concerns, needs and preferences as well as the growing experience of other jurisdictions as their own legislation comes up for review.

Yours sincerely

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Executive Director

7 December 2023

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**SUBMISSION**

**Consumer views on the ACT's  
Voluntary Assisted Dying Bill 2023**

December 2023

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## 1. Introduction

The Health Care Consumers' Association (HCCA) has long had interest in the introduction of Voluntary Assisted Dying (VAD) in the ACT. We view VAD as an essential component of supporting genuine choice and control over our own health.

Existing national frameworks in health care support consumer choice for VAD. The National Safety and Quality Health Service (NSQHS) standards (particularly Standard 2 – Partnering with patients in their own care) outlines the importance of establishing:

*systems that are based on partnering with patients in their own care...[supporting] the delivery of care. Patients are partners in their own care to the extent that they choose.*

The Australian Charter of Healthcare Rights<sup>1</sup> describes the rights that consumers or someone they care for, have when receiving health care. Consumers can expect these rights to apply to all people in all places where health care is provided in Australia. The seven Rights outlined in the charter include the rights to access, safety, respect, partnership, and information – particularly relevant to providing consumers with choice around VAD.

We view the proposed Voluntary Assisted Dying Bill 2023 (the Bill) as a sensible extension of these rights and believe that the Bill presented to the Legislative Assembly broadly meets the needs and intent of consumers with some limited exceptions.

### **HCCA's consultation process**

Previously, HCCA sought feedback from members on the discussion paper on Voluntary Assisted Dying (VAD) through focus groups and in-depth conversations with individuals.

Consumers shared their experiences of supporting friends and family members at end of life. Their views were considered and focused on the need to make it as easy as possible for people who are in extremis, to exercise their right to end their life without undue suffering and distress.

Our previous submission, prior to the development of this Bill, was based on consumer feedback as well as discussions with the peak consumer bodies who have been involved in the design and implementation of VAD in other states.

In this submission, we consider if the Bill presented meets the needs and concerns expressed by consumers during that process. We also reflect on additional feedback on the detail of the Bill provided by those consumers who participated in the earlier processes.

## 2. Consumer Response to the Voluntary Assisted Dying Bill 2023

### Consumer Response

Consumers sense we are benefiting from the experiences of other jurisdictions but told us that the Bill is somewhat risk averse and shies away from consumer sought innovation in terms of access and eligibility.

In particular, consumers have highlighted their approval of the removal of any requirement to establish a timeframe to expected death and instead focus on the quality of life of the individual and their current and anticipated suffering. This is a more consumer centred approach than that taken in other Australian jurisdictions and will likely result in reduced suffering for those who chose to seek VAD earlier in their terminal illness.

While consumers generally noted a pragmatic satisfaction with the Bill there were certain inclusions that many consumers had argued strongly for in previous consultations missing from the Bill. This is a missed opportunity for a genuinely nation leading VAD program.

Throughout our consultations, consumers have been consistently determined that eligibility for VAD in the ACT should be broad, flexible, and prioritise access over safeguards, relieving the burden of red-tape, and facilitating more efficient access. In general, we feel this has been achieved in the Bill, noting there remains potential for improvement.

### Missed Opportunities

Consumers told us that they would like to see the eligibility criteria for VAD include people with dementia, and older minors (14 years and over) with Gillick competence determination. Additionally, consumers diagnosed with cognitive impairment like dementia should have available to them mechanisms to document their wishes for VAD through Advanced Care Planning undertaken while still competent to make decisions and well before VAD is enacted on their behalf. We know that this is done elsewhere in the world<sup>2</sup> and we would like to see it explored in future reviews.

Consumers expressed their disappointment about its exclusion from the Bill, saying:

*'Can people make decisions ahead of time? ... I think this is an opportunity lost.'*

*'I am disappointed that the ACT will not be considering allowing adults to access the program using advance care directives.'*

Consumers are concerned that the three-year timeframe for review will leave many consumers at risk of missing out on the VAD service they need.

*'I am not at all happy with the three year review regarding implementing advance care directives in the case, for example, of dementia.'*

*'I have dementia in my family and I am worried 3 years is too long'.*

*'I am also disappointed that this issue will not be reviewed until the proposed legislation is in force for three years.'*

*'Some of our residents do not have the luxury of waiting several more years for the opportunity to end their lives with dignity'*

## **Reducing Red Tape**

Consumers tell us that they see the attempts the Bill makes to ease the burden of 'red tape' however believe there is scope to reduce this further and make VAD more accessible to those who are eligible and seek to access the program.

*'As I ploughed through the Bill's detail, though, I became concerned that the associated red tape might be onerous for practitioners who might otherwise be interested in assisting the dying'*

*'Wherever this administrative burden could be minimised it should, lest we end up with queues of interested parties dying before they can be helped with VAD'.*

One thing that consumers regularly highlight as an area for a reduction in red tape and swifter access to VAD for consumers is the requirement for making three separate requests.

Consumers have consistently told us that they believe that a procedure requiring two requests could offer sufficient safeguards and significantly improve timeliness of access and reduce health system burden.

Consumers have asked us:

*'Why, I wonder, given the burdens of this process, do people have to make a third request? Isn't it possible that two would suffice?'*

We are disappointed that the procedure set out in the Bill requires three separate approaches and urge that the potential of a reduction to two requests be considered as part of any review.

As one of HCCA's members said:

*'Wherever this administrative burden could be minimised, it should, lest we end up with queues of interested parties dying before they can be helped with VAD'*

## **Resourcing**

Consumers expressed to HCCA that they wonder how GPs may be resourced to support people through the VAD process.

*'I can just imagine all of those over-worked, kind-hearted GPs out there throwing up their hands in horror. I know nothing about how the MBS remunerates GPs for this, but unless it is considerable, we could have problems.'*

Willing health practitioner participation will be central to the success of the service. We cannot risk the bureaucratic processes and threat of health practitioner penalties contained within the Bill to result not in practitioner efficiency and compliance but rather in abstaining from participation due to a sense of burden and risk. There must be resourcing and support mechanisms in place to support practitioner participation, including primary health care.

## **Governance**

Consumers shared with us their concerns over the potential for vexatious interference in the VAD process through facetious ACT Civil and Administrative Tribunal reviews. We would like to be reassured that there are appropriate safeguards in place to ensure that bad actors are not able to impede an eligible consumer's timely access to VAD.

We would like to see the planned Voluntary Assisted Dying Oversight Board include consumer members to ensure management structures for VAD develop and retain a consumer focus and prioritise the needs of the vulnerable people who choose to access VAD. We would like to see consumer representation required by the Bill.

The proposed Care Navigator Service (CNS) is welcomed by consumers however some have expressed concern that its functionality may be more restrictive than is necessary. It appears that the CNS is intended only for circumstances where the process has broken down. We think it is vitally important that the service is also available to all consumers who need additional support activating and driving the process.

The process is, perhaps necessarily, bureaucratic and burdensome and not all consumers will have the knowledge, skills or health to navigate it independently even if the process runs smoothly. There is a good understanding of these varying needs throughout the Bill more generally and we think it is important that this is made clear in connection with the CNS.

The CNS, its make-up and functions, should be developed through a co-design process. We would urge consideration of the co-design format recently used for other Care Navigation Services as this has been a very effective model for developing services that are fit for purpose and meet consumer need.



Consumers are concerned that ‘interested parties’ who are not the person who wishes to die may appeal decisions at every stage, including when the applicant might have supposed that the process had been finalised in their favour. We have made the assumption that this clause exists primarily to protect applicants rights to review when they have been denied access to VAD. If this is correct, it is worth considering its potential to enable bad actors to impede access to VAD.

One consumer asked:

*‘I’m wondering whether something should be added that would protect applicants’ rights to be protected from vexatious litigation, which could actually prevent their ability to access VAD after it’s been approved.’*

### **3. What next?**

HCCA is pleased to see VAD progressing in the ACT. We look forward to working closely with the ACT Government to develop and implement a VAD service which centres consumer needs and experiences. HCCA anticipates an opportunity for health services to undertake a rigorous and valuable co-design process in full collaboration with consumers.

In addition, we look forward to the continuing discussion around outstanding issues and options. Canberrans have indicated what they want, and while some elements have been excluded from this Bill, we expect to revisit these decisions in the near future.

We hope consumers are central participants in reviews of the Bill in coming years. There is more work to be done to achieve what consumers really want and need from VAD. And more work to be done to ensure that the ACT VAD legislation continues to lead the way nationally.

## 4. Specific consumer comments on the Bill

All comments shared here are direct quotes from HCCA's consumer members.

### **Part 2, Clause 9:**

*'No obligation to continue...' I like this. The tone is flexible, consumer-oriented and sensitive to what it'd be like to be in this position.'*

### **Part 2, Clauses 10 and 11:**

*'At first I was worried that eligibility was all around actual suffering, but was relieved to note (p8) that suffering also included the anticipation or expectation of this. This is kind, and how it should be, I believe.'*

### **Part 2, Clause 12:**

*'This is where it becomes obvious that a person with advanced dementia would not be eligible for VAD, although I note that the drafters of the Bill have bent over backwards to accommodate people who may be a little cognitively-impaired but able, with support, from time to time, to give directions. I especially like how the drafters specify that a person must be assumed to have capacity, unless it is established that they haven't. I got the impression the drafters would've liked to have a go at allowing people (in their advanced care directives) to say that they'd like VAD if they should develop dementia, but I understand that legally this is complicated.'*

### **Part 3, Clause 23:**

*'Again, here is a welcome emphasis on efforts that must be taken to ensure individuals with impaired decision-making capacity are given a good chance to benefit from the VAD Bill.'*

### **Part 7, Clause 102:**

*'Re access to VAD for people residing in care facilities, conjures a nightmare scenario of conflict between a dying person's wishes, facility operators, and health practitioners. The Bill declares that the facility operators will have to 'make it happen', and there are penalties, but given how many things fly under the radar at such facilities, I wonder how this could be effectively policed, and how many people, as a consequence, will miss out on the chance to have a peaceful death.'*

### **Part 8, Clause 107:**

*'Re the VAD Board, I'd like to see here the specification that at least one member of the Board be a member of the HCCA.'*

### **Part 8, Clause 113:**

*'Re disclosure of interests of Board members. I wondered here whether people who are perhaps closet objectors to the purposes of the Bill could wind up on the Board. Would we want to exclude unsympathetic people? It is said that, sometimes, it is more politic to keep your enemies close.'*

**Part 9, Clause 128:**

*'I love that the Bill specifies that ambos who do not resuscitate a person who has taken a VAD substance are to be protected from criminal or civil liability for their failure to interfere.'*

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<sup>1</sup> Australian Charter of Healthcare Rights. <https://www.safetyandquality.gov.au/our-work/partnering-consumers/australian-charter-healthcare-rights>

<sup>2</sup> [Euthanasia, assisted suicide and non-resuscitation on request in the Netherlands | Euthanasia | Government.nl](#)