



## **HCCA Submission to the Consultation on Voluntary Assisted Dying in the ACT**

Thank you for the opportunity to provide consumer input into ACT Government's Consultation on Voluntary Assisted Dying (VAD) in the ACT.

To prepare our submission 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. Our consultation largely highlighted that consumers are seeking high-quality consumer-centred care that recognises individual choices for end-of-life care.

We look forward to reporting on the outcomes of this consultation and to the next steps in progressing Voluntary Assisted Dying in the ACT. We would be very happy to discuss further any of the issues we have raised in our submission.

Yours sincerely

A handwritten signature in blue ink, appearing to read "Darlene Cox".

Darlene Cox  
Executive Director

6 April 2023

### **Health Care Consumers' Association**

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**SUBMISSION**

**“It's a Choice”: consumer views  
on VAD for the ACT**

*ACT Government Consultation on  
Voluntary Assisted Dying in the ACT*

April 2023

# 1. Introduction

## Context for VAD in the ACT

The Health Care Consumers' Association (HCCA) has had a long-standing interest in the introduction of Voluntary Assisted Dying in the ACT. This is a key aspect of supporting consumer choice and exercising control of our own health.

The final report from the ACT Legislative Assembly's Select Committee into End-of-Life Choices in the ACT in 2019<sup>1</sup> explored a range of consumer views around what is now known as Voluntary Assisted Dying (VAD). Building on other Australian and international learnings in this space and following the passage of the Restoring Territory Rights Bill 2022<sup>2</sup>, the ACT can now consider the policy and legislative boundaries around enabling consumer choice for VAD in the ACT.

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>3</sup> describes the rights that consumers or someone they care for, can expect when receiving health care. These rights 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.

## HCCA's consultation process

HCCA sought feedback from members on the discussion paper on Voluntary Assisted Dying (VAD). We facilitated three focus groups consisting of 4 to 6 consumers and ten in-depth conversations with individuals. The questions asked during these discussions were based on those provided in the ACT Health VAD Discussion Paper.

Consumers shared their experiences of supporting friends and family members at end of life. Some consumers referenced personal experiences, including witnessing loved ones enduring undignified deaths due to the lack of access to VAD. 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.

We also reviewed many of the submissions made to the 2019 End of Life Inquiry from the ACT Legislative Assembly as this was raised by several consumers in our discussions.

Our submission is based on the feedback gathered from consumers, as well as discussions with the peak consumer bodies who have been involved in the design and implementation of VAD in other states.

### **Summary of VAD issues raised with HCCA**

While members expressed frustration at the pace at which Voluntary Assisted Dying (VAD) has progressed in the ACT, consumers reflected on how we are benefiting from the experiences of other jurisdictions. There was strong support for the Tasmanian model of VAD.

Consumers we spoke with overwhelmingly supported the introduction of VAD in the ACT. Consumers emphasised the need for effective and flexible regulation to avoid pitfalls experienced by other Australian jurisdictions where VAD is already implemented.

Eligibility for VAD should be broad, flexible, and prioritise access over safeguards. Consumers expressed concerns about the safety, quality, and meeting of legislative standards, as well as the burden of red-tape, administration, and reforms.

Consumers told us they would like to see the eligibility criteria for VAD including people with dementia, and minors with Gillick competence determination. Additionally, consumers diagnosed with cognitive impairment like dementia should have mechanisms to document their wishes for VAD through Advanced Care Planning while still competent to make decisions.

Consumers all supported the need for clear, relevant, and timely information and education across communities, health workers and the legal profession. There was support for the process Queensland Health undertook, working with consumers and carers to develop materials to support the implementation of VAD.

Consumers emphasised their desire for a broad scope of various health professionals to be involved in the VAD process. They thought this was important given the workforce shortages in the ACT. Consumers were very clear that they expect all staff involved in VAD to have completed the VAD training course.

Health professionals who are conscientious objectors should be clear about their position on VAD to consumers. An independent Care Navigation Service needs to be available to facilitate access for consumers seeking help.

Concerns were raised about faith-based providers' positions on VAD and their potential negative impact on service availability and access. The overarching view is that access to VAD should be facilitated if care is patient-centred, regardless of whether health care organisations consider themselves to be non-participating.

There is support for the idea of a specialist team for VAD available territory-wide or something like the Care Navigators in other jurisdictions. Consumers also support the

principle of respecting and valuing people's choices, including health professionals' choices not to be involved in VAD discussions if they are not comfortable.

One member shared the findings of their thesis<sup>4</sup> which looked at community views of VAD. This presented a comprehensive analysis of the views of 800 participants across all states, with proportional distribution by location, sex, and age. The findings suggest that older individuals and those who are non-religious are more likely to be in agreement with VAD for terminal medical conditions. Approximately 78% of participants definitely agreed with VAD for terminal medical conditions, while 19% definitely disagreed. Interestingly, income and education were found to be irrelevant in shaping people's opinions on VAD. Participants expressed more concern about non-terminal conditions, and for terminal conditions, people preferred GP-administered medication, while for non-terminal conditions, self-administration was preferred. These findings provide valuable insights into the public's opinions and preferences regarding VAD and can help inform policies and practices surrounding its implementation.

## 2. HCCA response to Discussion Paper Consultation Topics

### 2.1 Eligibility Criteria (from p7-13 in the discussion paper)

Eligibility for VAD should be broad, flexible, and prioritise access over safeguards.

While some consumers shared their belief that individuals should have the right to choose, others argued that the state should make the decision. Nonetheless, consumers are supportive of the ACT Government's commitment to drafting flexible legislation that provides people with access to VAD.

Consumers noted that the VAD discussion paper gives them the impression that ACT legislation on VAD is expected to harmonise with other Australian jurisdictions that have implemented VAD. This was not accepted by everyone we spoke with. While there is value in learning from the experiences of other jurisdictions, several consumers expressed that it is important that legislation in each jurisdiction be written considering each region's unique circumstances and not be constrained by criteria set in other jurisdictions. The legislation in the ACT may not necessarily reflect the legislation in other states as it is designed to meet the needs of Canberra communities.

#### Eligible conditions (p7 discussion paper)

Consumers emphasised the need for broad and flexible eligibility criteria that prioritises access. Many people we spoke to feel the balance between access and safeguards was problematic as there were too many barriers to providing timely access to VAD. They believe that the emphasis needs to be on providing patients with choice and autonomy.

One of the key issues raised by consumers is the difficulty in predicting death and the need for individuals to have more say in the decision-making process for end of life. As people age, they are more likely to have multiple co-morbid conditions, and one condition often cannot be confirmed as the cause of their suffering. While many conditions have a predictable path, such as Motor Neurone Disease (MND), some do not, and people should be able to choose when in that path they want to take action if they want to, rather than waiting until death is imminent. Consumers suggested that The Netherlands' approach to eligibility, which focuses on the anticipation of "intolerable suffering" rather than a fixed time frame, is more relevant to preventing the suffering of patients with terminal conditions and is an approach they would like to see the ACT employ.<sup>5</sup>

Consumers also discussed the inclusion of people with dementia in the eligibility criteria. There was strong support for this. They feel that people with cognitive impairment should have mechanisms in place to document their wishes for VAD while they are still

competent to make decisions. Such mechanisms could involve including VAD in Advanced Health Directives/Advanced Care Plans. There was also a suggestion for a pre-agreed, exhaustive list of criteria that, if met, would trigger an appointed Enduring Power of Attorney (EPOA) to seek VAD in the case of someone who has lost capacity (i.e., enacting VAD for someone with advanced dementia).

Additionally, people who chose to go through palliative care should not be excluded from accessing VAD, and palliative care needs to complement VAD. Diagnosis of advanced and/or progressive conditions, illness or disease should also consider longer-term effects and symptoms. For example, people should have a choice not have to live on a ventilator or with psychotropic medications for decades because their condition may progress slowly. Informed consent is foundational to this.

Consumers also emphasised the need for people's wish to access VAD for religious or spiritual reasons to be respected as a legitimate reason to want to die. There is a need to recognise that for some people, feeling that they would be better off dead does not necessarily indicate mental illness or cognitive impairment. They may hold comfort in knowing they will be joining loved ones who have died before them.

Consumers supported the inclusion of mental illness as a reason for someone to consider VAD, but it was felt that there would not be broader community support for this. There was interest in the current situation in Canada. You do not need to have a fatal or terminal condition to be eligible for medical assistance in dying (MAiD) in Canada. They are considering access to MAiD for people with mental illness. Under the law passed in March 2021, Canadians whose only medical condition is a mental illness, and who otherwise meet all eligibility criteria, will not be eligible for MAiD until March 2024. We recommend we review the inclusion of people with mental illness in light of the Canadian experience, once the ACT VAD program is established.

Overall, consumers emphasised the need for broad and flexible eligibility criteria that prioritise access over safeguards. The focus should be on providing patients with choice and autonomy while ensuring that the decision-making process is suitably considered and allows for review and evaluation. In essence people should be allowed to choose the way and time they die in the same way they choose to live.

### **Decision-making capacity (p10 discussion paper)**

Assessment of competence or decision-making capacity is a critical aspect of VAD. It ensures that individuals who seek access to VAD have the capacity to make an informed and voluntary decision. However, there are concerns about the fairness of the burden of proof on patients to repeatedly demonstrate their competence to decide.

To address these concerns, we need to establish a rigorous and fair process to assess the competence of individuals seeking access to VAD. Such a process should be non-discriminatory and considerate of the needs and circumstances of all individuals.

### ***Young people***

There was support for people under 18 years old accessing VAD.

Consumers have raised concerns about using age as the sole indicator of competence, as it is an arbitrary factor that may exclude some individuals who are otherwise competent. Instead, consideration should be given to how to assess competence for young people and children.

Consumers recognised that the inclusion of minors in the eligibility criteria is likely to be a contentious issue but felt that it is important to consider the best interests of terminally ill young people. They suggested that Gillick competence determination could be used to assess whether a young person can make decisions regarding VAD<sup>6</sup>. The use of Gillick competence assessment, which evaluates an individual's capacity to make a decision independently, could be a useful tool for assessing competence in young people over 14 years of age<sup>7,8</sup>.

Consumers emphasised that parents/guardians should be included in discussions throughout considering VAD, while at the same time respecting the young person's rights to choose if assessed as competent. For children younger than 14 years, parental rights should be considered, and the eligibility process for VAD should be taken forward under the supervision of a court-appointed guardian. While the inclusion of minors may be challenging, consumers felt it was essential to consider the best interests of terminally ill young people who would like the choice of accessing VAD.

It is also essential to ensure that young people considering VAD are health literate and understand their condition, their treatment or palliative care options as well as the consequences of VAD and the decision they are making. This may require additional steps in the eligibility process to assess the competence of young people, including their understanding of their condition and the consequences of VAD.

It is essential to involve a range of stakeholders, including young people, parents, health professionals, and legal experts, in the development of the eligibility process. Additionally, VAD programs should prioritise the safety and wellbeing of all young individuals seeking access to VAD.

### ***People living with dementia***

Consumers we spoke with felt strongly that people with dementia should be able to access VAD. The challenges of legislating for the inclusion of dementia were recognised such as the assessment of competence.

One of the concerns raised by consumers was the issue of respecting an individual's plan to access VAD made before their condition deteriorates beyond being assessed as having competence for decision making. It was noted that the criteria for accessing VAD should be able to be satisfied through a clinician (or clinicians) before the decision can be enacted by someone with Enduring Power of Attorney.



The importance of an Advanced Care Plan in pre-determining the specific circumstances in which a person would want to access VAD was emphasised. The plan would need to include the criteria that must be satisfied for VAD to be progressed, and consumers were clear that adequate processes should be in place to ensure that Advanced Care Plans are recognised and enacted. It is important for people with dementia to have an end-of-life directive included in their advanced care plan as they may not be able to communicate their wishes towards the end of their life<sup>9</sup>.

One consumer discussed the case of a friend who had made a decision about their future wishes for care, and put it in their Advanced Care Plan, but the decision was later overruled by family (where the family's wishes were instead respected and acted upon). Several consumers HCCA spoke to also shared a range of personal experiences relating to friends and family who died with dementia and who may have benefited from VAD if this had been a choice available.

Overall, the inclusion of people with dementia in VAD program eligibility should be carefully considered, and processes should be in place to ensure that their pre-determined choices are respected and enacted appropriately<sup>10</sup>. Clinicians and clearly-articulated Advanced Care Plans will play an essential role in making decisions about VAD for people diagnosed with dementia.

#### **Citizenship and residency requirements** (p12 discussion paper)

Consumers noted that the ACT's residency requirement could be problematic for those living in adjacent rural areas in NSW. People in the surrounding NSW region routinely access health services in Canberra as this is more accessible than traveling to Sydney.

Consumers felt that eligibility criteria for VAD should also consider residents of the broader NSW region and interstate. For example, consumers were concerned that friends or relatives from interstate, wanting to use VAD in the ACT to be closer to support of friends and family, would have the opportunity to do so. Residency requirements should not prevent this kind of access. The overall sentiment is that the ACT should implement legislation that is flexible, simple, agile, and accessible to ensure that people seeking VAD can access it without unnecessary delays or bureaucratic hurdles regardless of their home address.

## **2.2 The process for request and assessment (from p14-20 in discussion paper)**

### **Making a request (p17 discussion paper)**

Consumers felt that three requests are onerous and unnecessary. There was strong support for two requests. There were concerns that the model as presented would lead to delays. Consumers would like timely access to VAD and need the consent process and associated checks and balances to not compromise the timeliness of access.

Consumers felt that timely access to end-of-life care should be a key focus for policymakers and health care providers. The process of obtaining consent should be flexible enough to cater to the diverse needs of consumers, particularly people living with a disability and people who speak English as their second language. Consumers have suggested incorporating options such as video statements or non-written methods of obtaining consent and incorporating telehealth services to facilitate easier access to care for patients who are unable to travel to a physical location. By implementing these measures, policymakers and health care providers can ensure that everyone has an equal opportunity to express their wishes and make informed decisions about their end-of-life care.

To ensure a successful process of request and assessment for VAD, it is crucial to ensure timeliness, flexibility in consent, and appropriate (but practically workable) checks and balances. Policymakers and health care providers should consider the cultural and religious needs of consumers, and consumer representation must be included in the VAD training content for health professionals. Careful consideration of and respect for the needs and rights of consumers is key to ensuring a fair and equitable system for end-of-life care.

### **Allowing for time to reflect (p17 discussion paper)**

Consumers questioned the necessity of a cooling off period, citing the rigorous eligibility assessment and request processes already in place. The assessment will involve questioning, counselling, and probing of the patient's decision as well as a requirement for more than one request.

Consumers noted that individuals who obtain VAD medication are not obliged to use it and would have the option to 'cool off' for as long as they desire. However, clear procedures should be in place for reconciling the medication, whether it is used or returned, once someone approved for VAD passes away. Despite being aware of cooling off periods ranging from 5 to 9 days in other jurisdictions, consumers felt that such a duration is unnecessary given the other processes in place.

### **Accessing and using a VAD substance (p18 discussion paper)**

Consumers stressed the importance of having options for administration that suit their individual needs, whether that means self-administration (whether oral or another method of medication administration) or having a loved one or clinician administer the medication. However, they also emphasised that the choice of administration method should ultimately be up to the individual accessing VAD.

Regarding the need for a witness during administration, consumers had differing opinions. Some questioned the need for a witness, while others expressed concerns about last-minute changes of mind and potential legal challenges. While consumers felt that the decision to have a witness should be left to the individual accessing VAD and the person administering it, clinicians may prefer to have a witness present to avoid legal disputes. One person talked about their preference to have a medical practitioner present in case things went wrong.

Overall, consumer feedback on the method of administration will be crucial in the development of a fair and equitable system for end-of-life care. Policymakers and health care providers must carefully consider the diverse needs and preferences of consumers to ensure that the process of VAD request and assessment is accessible and respectful of individual autonomy.

### **Navigating the process (p15 discussion paper)**

To ensure equitable access to VAD, consumers advocated for a Care Navigator Service to assist in accessing end-of-life care. Care Navigators for VAD have already been established in Tasmania and Victoria. Consumers shared several features and offerings they would like to see provided through this service, including additional assistance and support from health professionals for those who do not have a wide network of support. To address this, one participant suggested providing advocates, such as death doulas, for such individuals. Others highlighted the key role of conversations, discussions, and consultation in the VAD process.

Consumers emphasised the importance of clinicians being required to refer consumers to the Care Navigator Service if they inquire about access to VAD. This would ensure that everyone has equal access to the service, regardless of their individual circumstances or capacity of their clinician to provide support. The Care Navigator Service could keep a register of health professionals who have completed training, providing a way to track and manage who consumers can reach out to for information and support for making a choice about VAD.

The Care Navigator Service could be an independent place for consumers to seek help in accessing VAD and can be adapted for the ACT from existing models of care from other jurisdictions. By providing a centralised hub for information and assistance, the service could also help to streamline the process for accessing VAD and ensure that the necessary training requirements are met.

## **2.3 The role of health professionals (p21-27 discussion paper)**

VAD is a complex issue that involves a range of health professionals. The role of these professionals is critical to ensuring that VAD is implemented safely and effectively for consumers.

### **Qualification requirements for health professionals (p21 discussion paper)**

Consumers reflected on the importance of workforce considerations and ongoing evaluation in the implementation of VAD.

There was acknowledgement that finding practitioners who are willing and able to be involved in VAD may be challenging and therefore it is essential not to put too many limits in place around these roles. One consumer highlighted the importance of reviewing the suitability of eligible practitioners after implementation of VAD to ensure the skill mix is appropriate.

The availability of medical professionals is crucial in supporting consumer decision making processes regarding VAD. Adequate staffing is necessary to ensure that people have access to the necessary health professionals. Consumers agreed that there should be a broad scope for various health professionals to be involved, especially with workforce shortages in the ACT.

Some consumers had concerns about requiring clinical specialist involvement because they might be reticent to refer to either palliative care or VAD from active treatment.

Consumers felt that the original diagnosis from the specialist should be enough for eligibility. This concern arose from the lived experience of some participants, where referral to palliative care had been unreasonably delayed by treating physicians or where palliative care providers had a religious affiliation that would be incompatible with VAD. Consumers also wondered if this concern remained true in the case of patients with dementia. However, they agreed that specialisation of professionals providing the coordinating and consulting role was not required.

Finally, consumers suggested that medical professionals involved in VAD should be required to undergo training to ensure they have the necessary knowledge and skills. Ongoing evaluation of the workforce involved in VAD is necessary to ensure that they are equipped to provide the highest quality care to patients.

### **Coordinating Health Professionals and Consulting Health Professionals (p21 discussion paper)**

Coordinating professionals play a crucial role in the VAD process. Consumers felt it essential that people interested in VAD are linked to one medical professional who can guide them through the process. The coordinating professional should be responsible

for overseeing the VAD process. Consumers emphasised the importance of the coordinating professional having completed the necessary training course for VAD to ensure that they have the necessary knowledge and skills to provide guidance and support to patients and their families.

Consumers also stressed that it is important to have an experienced and knowledgeable professional overseeing the VAD process to ensure that everything is done safely, accurately, and in compliance with legal and ethical requirements. While it was suggested that the coordinating health professional should have at least five years of experience in the field, consumers agreed that the most critical factor is that they should not be newly or recently graduated.

Consulting professionals are key to ensuring that consumers have access to the best possible care and support. Consumers stressed that they would like policymakers to take a holistic approach to regulation around consulting health professionals and recognise that an individual is more than their condition and symptoms. This may include consulting psychologists or psychiatrists to support a consumer's mental health. Consulting health professionals, such as psychologists or psychiatrists, should be available for consumers to discuss their options.

Consumers suggested that the role of the person getting the VAD process started should be different from the person who is coordinating. A physiotherapist or other health professional could refer the consumer to the coordinating professional. Consumers were in agreement that there should not be a requirement for two specialists to be in agreement regarding suitability for VAD. This has already proven an issue for access and timeliness in Victoria.

Consumers agreed that the coordinating person is more likely to be someone who has a relationship with the individual wanting to access VAD. Visiting community nurses, cancer specialist nurses, and occupational therapists could be consulted, as long as they have been through the VAD training. Consumers suggested that coordinating professionals should be medically trained and have a good knowledge of the systems in place around VAD but should not be required to be specialists in specific medical conditions.

Regarding legislation and consultations, consumers told us it was important that the legislation not dictate what happens in consultations – such as whether a clinician can raise the option of VAD with a consumer. They felt that the clinicians' only obligation should be to provide help or refer on. This is important because consumers can be reluctant about asking doctors questions and may not feel confident to raise the possibility of VAD.

Consumers also felt that the Care Navigation Service should be publicised, so consumers are aware of where to get help if they are not confident raising it with their treating team. Consumers also expressed concern about media coverage around Commonwealth-funded telehealth appointments in general practice prohibiting GPs from discussing issues related to suicide<sup>11</sup> and would like this to be explored further.

### **Administering Health Professionals** (p23 discussion paper)

According to consumers, administering health professionals for VAD should meet specific requirements. They suggested that Registered Nurses and Nurse Practitioners should be allowed to administer medication, provided they have a minimum of 2 years of experience and specialist VAD training, to ensure thorough understanding of the rules and legislation. Training packages that have already been developed in other jurisdictions can be adapted for use in the ACT.

Consumers emphasised the importance of having a coordinating medical professional, such as a doctor or nurse, involved in the process, regardless of who administers the medication. Additionally, they believed that any administering medical professional should be medically trained and have a good knowledge of the systems in place around VAD, perhaps specialist VAD training. While consumers felt that all clinicians involved in VAD should have general VAD training, they also believed that it should be sufficient for a specialist to have made a terminal diagnosis. However, it was not deemed necessary that coordinating medical professionals be required to have training in specific conditions.

### **Conscientious Objection** (p25 of discussion paper)

Overall, consumers stressed the need for clear communication and access to appropriate care for all consumers, regardless of health care providers' personal beliefs or values.

Consumers recognise that there are health professionals who are conscientious objectors to VAD. To avoid misunderstandings and potential delays, consumers stressed the importance of clear communication from health care professionals about their stance on VAD. While consumers recognised the right of health care providers to conscientiously object to VAD, they emphasised that clinicians who object should be obligated to state their position to patients and refer them to the relevant Care Navigation Service. Additionally, consumers noted that pharmacists should also have the opportunity to conscientiously object, but they need to clearly declare their position.

Consumers were clear that health care workers included those registered in the National Scheme, but also the many professionals who play an active role in health care but are not Ahpra-registered health practitioners, such as social workers.

## 2.4 The role of health services (p28-29 of discussion paper)

### Health services that decline to facilitate VAD (p28 discussion paper)

In our consultation, there was much discussion about these issues, and a focus on the need for them to facilitate access to VAD. Consumers strongly expressed their view that public health services and residential facilities receiving government funding should be required to allow on-site access to VAD services if a consumer has made a request. This should happen even if the facility has objections to providing such services. Consumers did not feel the need for regulation to specify a particular location for the provision of VAD services, and agreed that home, aged care facilities, hospitals, and palliative care facilities were all appropriate venues.

Furthermore, consumers emphasised that individuals should not have to move from their home or palliative care service to access VAD services. Instead, a service should be provided that can come to their location. This would enable consumers to remain in a comfortable and familiar environment while receiving the necessary care and support.

Consumers also noted that health professionals may give biased advice, particularly if they conscientiously object to VAD. Therefore, they stressed the importance of trust, truth, and transparency in the provision of VAD services. Health services should ensure that consumers are provided with unbiased and accurate information about their options and the process of accessing VAD services, so that they can make informed decisions about their care.

#### ***Consumer comments specifically around faith-based health providers***

Consumers have expressed concerns over faith-based providers' positions on VAD and the potential negative impact on service availability and access. Consumers have repeatedly expressed concern about the capacity of these contracted public health and aged care providers to appropriately provide services that meet the rights of ACT residents who seek care under VAD legislation.

While many staff may not object to VAD in principle, individuals are sometimes bound to the service. This may affect consumer access to VAD services in facilities run by these faith-based providers.

Furthermore, some consumers have noted that religious organisations are the main providers of residential aged care, and that there is a financial benefit to them in prolonging the life of their residents. The facilities themselves are responsible for assessing the care that residents need. Consumers have expressed concern that organisations with a financial stake in people living as long as possible, even under circumstances of poor health/disability, shouldn't have a say in whether or not residents can access VAD. This is seen as a financial conflict of interest, and some consumers

feel that these religious organisations may have too much influence in these discussions.

Consumers have also highlighted that Clare Holland House and associated home-based palliative care services are currently contracted to a faith-based organisation, and the ACT does not currently offer an alternative service. The planned Canberra Health Service palliative care ward will be essential to providing judgement-free service in a hospital setting. As a work around, some participants suggested requiring Clare Holland House and home-based palliative care services to allow a third party to provide VAD services.

Overall, consumers have emphasised the importance of ensuring that all providers, regardless of their religious affiliations, are able to provide unbiased and non-judgmental care to those who seek end-of-life care.

## **2.5 Death certification and notification (p30-31 of discussion paper)**

There was support for Nurse Practitioners to sign death certificates, as this would streamline the process at the end of life. Consumers view the Nurse Practitioner profession as a growing and valued profession and allowing them to sign death certificates could be a timely and practical solution to the delays in arranging for medical practitioners to do this.

Another suggestion is that witnesses for the administration of VAD, if required, could potentially be family members. This would occur after the eligibility, coordination, and consultation steps have taken place. However, consumers have also raised concerns about the difficulty of getting health professionals to visit people's homes, especially in the context of home care. This could make it challenging to enact the certification and notification processes for VAD in home care settings. It may be easier to implement these processes in Residential Aged Care Facilities (RACFs), where some facilities have social workers available.

Some consumers suggested that a Care Navigator service could potentially issue death certificates, but further exploration is needed to determine the feasibility of this option and whether there is sufficient independence.

Overall, consumers have emphasised the need for a practical and efficient process for death certification and notification in the context of VAD legislation. The suggestions of allowing nurse practitioners to sign death certificates and using family members as witnesses for administration could be potential solutions to help address these concerns. However, challenges may arise when implementing these processes in home care settings, and careful consideration is needed. Additionally, consumers have emphasised the need for retrospective oversight of the VAD process to avoid potential



obstacles, as seen in Victoria. These issues highlight the importance of careful planning and consideration of all aspects of the VAD process, including death certification and notification, to ensure its smooth and effective enactment.

## **2.6 Oversight, reporting and compliance (p31-35 of discussion paper)**

### **Compliance monitoring (p31 of discussion paper)**

Regulation around Voluntary Assisted Dying (VAD) is a complex and sensitive issue that needs to be approached with the needs of those seeking access VAD in mind. Consumers feel that regulations around VAD need to focus on ensuring VAD is accessible and available to those who need it, rather than risk aversion and potential legal challenges.

The primary focus of regulation should be on meeting the needs of consumers seeking access to VAD. The human experience of those accessing VAD must be taken into account, and regulations should not inadvertently prevent the implementation of VAD in a way that meets patients' needs.

Several consumers provided feedback on the legislative arrangements for VAD in other jurisdictions, particularly Victoria and Tasmania. Many consumers felt that Victoria's legislation was overly restrictive and had long wait times, which limited access. In contrast, consumers felt that Tasmania has achieved a good balance by adopting a more flexible and less prescriptive approach. Consumers stressed that the legislation should focus on preventing the suffering of patients with terminal diagnoses, or degenerative conditions, for example, rather than relying on a time frame or prognosis-dependent eligibility criteria.

### **Review of eligibility decisions (p33 of discussion paper)**

Additionally, consumers emphasised that the legislation should prioritise patients' autonomy and dignity while including safeguards to prevent coercion, ensuring that decision-making capacity is not compromised, especially for people living with disabilities. One suggestion was to establish an independent statutory body to address concerns about competency, and that disability support should be incorporated into the decision-making process. However, some consumers expressed concern that having separate legislation for people with disabilities could result in politically active groups lobbying for specific disabilities, leading to further fragmentation. Instead, the legislation should be fit for purpose and cover everyone without requiring separate legislation for people with disabilities. As such, people with disabilities should be adequately represented in the decision-making panels to ensure their voices are heard.

Consumers have emphasised that regulations should avoid over-reliance on legal processes, which have the potential to remove the agency of individuals to make

complex decisions in their own best interests. The process for determining eligibility needs to be swift, and VAD must be available to those who need it, when they need it.

Consumers have highlighted the need for a clear review and appeal procedure for those who disagree with the assessment of their eligibility for VAD. One participant felt that it would be preferable to use regulation to set eligibility criteria in a way that is easy to evolve as our understanding of the issues around, level of need for, and use of VAD matures.

Finally, consumers felt it would be beneficial to review the ACT model two years post implementation to evaluate, readjust, and apply learning from other jurisdictions and internationally. This would then allow the opportunity to review the Canadian MAiD approach to including mental illness in eligibility. Overall, regulations around VAD must protect choice and prioritise the needs of those seeking access, while ensuring that appropriate safeguards are in place to prevent coercion of vulnerable people and defend capacity for individual decision-making.

## **2.7 Other issues (p35 of discussion paper)**

A range of additional issues raised by consumers were captured in HCCA's consultation process and are outlined below.

### **Implementation of ACT's chosen model of VAD**

Consumers also raised other important issues related to the implementation of VAD. Consumers suggest considering the VAD model presented by "Dying with Dignity ACT"<sup>12</sup>, as it has a different focus than what has been presented in the current consultation. There is also a need for preparation for implementation of VAD, including a curriculum for training for clinicians and a Model of Care for the Care Navigation Service. Consumers expressed concern about the long lead time and the needs and distress of people requiring VAD in the interim and suggested starting training now, using other states' training packages.

### **Concerns around Access for Aged Care Residents**

Furthermore, there are concerns about aged care residents potentially being underserved and/or vulnerable to misuse of the legislation. The role of 'significant others', including parents/guardians of children, also needs to be reconciled, and issues between significant others need to be considered. Consumers suggested that a specialist mediator may be useful or referral to ethics, but an oversight body could also have a mediation facility to deal with unresolved conflict.

### **Financial provisions**

Consumers raised concerns about the financial provisions related to VAD – there was an interest in understanding more about the potential costs involved. Consumers proposed a need for specific Medicare Benefits Schedule (MBS) items to support VAD.

Without these items, general practitioners may feel pressure to provide lengthy consultations related to VAD under bulk billing and accept a financial loss or may feel they are unable to provide the required time and services. The lack of MBS items could also make it difficult for consumers to access VAD-related services and support if the cost for services were beyond reach financially.

Consumers also discussed the issue of out-of-pocket costs for VAD, as while the government could potentially cover a significant portion of the costs, there may be a gap payment. It was suggested that there is a need for Medicare funding to facilitate equitable access to VAD services and support. It is crucial to ensure that financial barriers do not prevent individuals from accessing VAD services and the government needs to consider ways to make VAD accessible to everyone who needs it.

Moreover, it is essential to note that if the cost of VAD in the ACT is cheaper than other states, it may lead to an influx of people coming to the ACT seeking VAD. Therefore, financial provisions need to be carefully considered and appropriately managed.

Focus group participants suggested that one possible solution could be to have doctors work with the Care Navigator Service to support people who cannot afford the costs in the private primary care sector. This could help ensure that financial barriers do not prevent individuals from accessing the VAD services and support they need.

Financial provisions related to VAD need to be carefully considered to ensure accessibility for everyone who needs VAD. This includes the need for specific MBS items, Medicare funding, and mechanisms to manage financial barriers. By ensuring that VAD is accessible to everyone who needs it, we can help individuals to have a peaceful and dignified end-of-life experience.

### **Death Literacy**

Death literacy also needs to be built up in the community to improve comfort with VAD and understanding of when it might be appropriate, how to access it, and why it is of value. The group suggests that the Health Care Consumers' Association could produce consumer-focused, health literate information resources. Additionally, consumers identified there was support for the internal investigative capacity implemented in Tasmania to look into issues arising in the VAD process.

Lastly, the group wondered if the HCCA could work with Palliative Care through Canberra Health Service to provide consumer-centred training around death literacy for consumers and professionals. These issues highlight the need for careful planning and consideration of all aspects of the VAD process to ensure its successful implementation and use.

### **Co-design and Development of Resources**

In developing and implementing VAD in QLD, the QLD Government used a process of co-design including doctors, nurses, pharmacists, allied health professionals, consumers, and content experts from across Queensland. A wide range of health

literate resources for consumers, along with supporting materials for health professionals and other trained professionals have been developed and made available<sup>13</sup>.

HCCA also recommends the use of co-design<sup>14</sup> as a valuable resource for consumer and stakeholder engagement for the ACT Health Directorate in development and implementation of VAD. We would be delighted to work with ACTHD on co-design for VAD.

### **3. Conclusion**

Based on the feedback from consumers about VAD consultation, it is clear that eligibility criteria, the process for request and assessment, the role of health professionals, the role of health services, and death certification and notification are crucial factors to consider in the implementation of VAD.

Consumers emphasised the need for clear and consistent eligibility criteria to ensure that individuals who meet the requirements have access to VAD, while also ensuring that vulnerable populations are protected. The process for requesting and assessing VAD should be streamlined, transparent, and sensitive to the needs and preferences of the individual.

Consumers also highlighted the important role that health professionals and health services play in the VAD consultation process. Health professionals should be trained in VAD and should provide non-judgmental and compassionate care to individuals seeking VAD. Health services should provide adequate resources and support to ensure that VAD is accessible and delivered in a safe and effective manner.

Finally, consumers stressed the importance of clear and timely death certification and notification processes to ensure that the wishes of the individual are respected, and their loved ones are informed of their death.

Overall, the feedback from consumers highlights the need for a comprehensive and patient-centred approach to the implementation of VAD in the ACT. By considering the input of consumers and addressing their concerns, policymakers can ensure that VAD is implemented in a way that upholds the principles of patient autonomy, safety, and dignity, ultimately supporting consumer choice.

## About HCCA

The **Health Care Consumers' Association (HCCA)** is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations;
- training in health rights and navigating the health system;
- community forums and information sessions about health services; and
- research into consumer experience of human services.

HCCA is a Health Promotion Charity registered with the Australian Charities and Not-for-profits Commission.

## References

<sup>1</sup> ACT Legislative Assembly Inquiry into End of Life Choices in the ACT.

<https://www.parliament.act.gov.au/parliamentary-business/in-committees/previous-assemblies/select-committees-ninth-assembly/end-of-life-choices/inquiry-into-end-of-life-choices-in-the-act#tab1143329-2id>

<sup>2</sup> Restoring Territory Rights Bill 2022.

[https://www.aph.gov.au/Parliamentary\\_Business/Bills\\_Legislation/bd/bd2223a/23bd005#:~:text=The%20Bill%20proposes%20to%20remove,voluntary%20assisted%20dying%20\(VAD\)](https://www.aph.gov.au/Parliamentary_Business/Bills_Legislation/bd/bd2223a/23bd005#:~:text=The%20Bill%20proposes%20to%20remove,voluntary%20assisted%20dying%20(VAD))

<sup>3</sup> Australian Charter of Healthcare Rights. <https://www.safetyandquality.gov.au/our-work/partnering-consumers/australian-charter-healthcare-rights>

<sup>4</sup> Dalby S 2014 'To die or not to die... attitudes towards euthanasia Australia, [Unpublished Thesis], University of Canberra, Canberra

<sup>5</sup> [Euthanasia, assisted suicide and non-resuscitation on request | Euthanasia | Government.ni](#)

<sup>6</sup> [RACGP - Children and consent for medical treatment](#)

<sup>7</sup> Corporate Governance and Risk Management 2020, *Consent to Medical and Healthcare Treatment Manual*, NSW Ministry of Health, Sydney, pp 43-48.

<sup>8</sup> For example, the age of 14 as a possible age for competence in decision making is supported by: Grootens-Wiegers P, Hein IM, van den Broek JM, de Vries MC. *Medical decision-making in children and adolescents: developmental and neuroscientific aspects*. BMC Pediatr. 2017 May 8;17(1):120.

<sup>9</sup> The Canberra times (2023) [Grieving husband Roy Harvey pitches end-of-life directives to ACT Assembly as it considers voluntary assisted dying.](#)

<sup>10</sup> Queensland Law Reform Commission 2020, *A legal framework for voluntary assisted dying*, Consultation Paper, Dementia Australia, Queensland.

<sup>11</sup> ABC News (2022) Voluntary assisted dying's 'prohibitive' communication laws face GP legal challenge. <https://amp.abc.net.au/article/101292042>

<sup>12</sup> Submission from Dying with Dignity ACT to ACT Legislative Assembly Inquiry into End of Life Choices in the ACT [https://www.parliament.act.gov.au/\\_data/assets/pdf\\_file/0010/1190656/118-Dying-with-Dignity-ACT.pdf](https://www.parliament.act.gov.au/_data/assets/pdf_file/0010/1190656/118-Dying-with-Dignity-ACT.pdf)

<sup>13</sup> QLD Health VAD resources. <https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/voluntary-assisted-dying>

<sup>14</sup> HCCA Co-design position statement. <https://www.hcca.org.au/publication/co-design-position-statement/>