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Voluntary Assisted Dying Policy Team  
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Submitted via webform at YourSay

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To the VAD Policy Team,

## VOLUNTARY ASSISTED DYING IN THE ACT

The ACT Council of Social Service (ACTCOSS) welcomes the opportunity to provide a response to the consultation into the proposal to legislate Voluntary Assisted Dying (VAD) in the ACT. ACTCOSS advocates for social justice in the ACT and represents not-for-profit community organisations. Our vision is that Canberra is a just, safe and sustainable community in which everyone has the opportunity for self-determination and a fair share of resources and services. We would like to communicate support for the recommendations made by member organisations, particularly those that represent people with disabilities and carers. ACTCOSS does not seek to take a position on the proposal to create legislation on this matter. Rather, we propose that any legislation that allows VAD must prioritise safeguarding the human rights and welfare of people with disabilities, people experiencing mental ill-health and other vulnerable community members. The following submissions provides answers to selected questions from the discussion paper.

### Eligibility

#### Question 1: What should the eligibility criteria be for a person to access VAD?

As stated in the discussion paper, other Australian jurisdictions do not allow for people who only present with a disability or mental ill-health to access VAD. This criteria is acceptable and should form the basis of criteria for any VAD legislation in the ACT. Any suffering endured by people with disabilities and/or mental-ill health who are not otherwise diagnosed with an incurable disease should be managed through equitable and accessible healthcare and support. Any people seeking VAD who are ineligible under this criterion but are experiencing unendurable suffering should be referred for intensive supports in whatever area is required for alleviation of that suffering.

#### Question 4: How should a person's decision-making capacity be defined or determined in relation to VAD?

While we acknowledge that some people may find criteria disallowing advanced care planning in the case of, for example, a dementia diagnosis, to be restrictive, we are of the view that it is necessary to restrict VAD to those who are able to consistently express their personal wishes throughout the process up until the procedure takes place. While supported or advanced decision making is crucial for people who must plan for their own future care in case of loss of capacity, the risk of interference, manipulation or neglect is too great in societal circumstances that allow

vulnerable people to experience abuse, neglect, exploitation, violence and poverty at unacceptable rates<sup>1</sup>. The findings of the Royal Commissions into Aged Care and Disability both illustrate that VAD legislation is being created in an environment that accepts the abuse and neglect of people with limited capacity to advocate for or defend themselves from harm. Until access to safe living environments, high-quality care and financial security are guaranteed for people with limited current or future capacity to make and sustain complex decisions independently, VAD should only be accessible to those who cannot or will not meet those criteria in specific circumstances. For people who require a supported decision-making process, guidelines should ensure that support providers are suitably qualified and shown to be objective. While some people view access to VAD as a human right, the right to life is well-established and should not meet interference through legislated access to a choice of how and when to die.

Question 5: Should VAD be restricted to people above a certain age? (for example, people 18 and over?)

Yes, due to the potential for interference in or lack of capacity for decision-making, people aged under 18 years old should not be able to access VAD. Adulthood is a culturally and legally well-defined category with a multitude of associated rights and responsibilities afforded in kind, and those under the age of majority should have their lives and wellbeing protected by capable adults. As with others who lack independent decision-making capacity according to established medical, legal and social norms, children and young people under 18 should have universal access to safe and equitable care, particularly in cases of high support needs disabilities or chronic diseases that may cause pain and suffering.

Question 8: What process should be in place in the ACT to ensure that an eligible person's access to VAD is safe and effective?

Access to immediate, high-quality palliative care should be a priority for people who make a request for VAD, particularly for those who are ineligible. VAD policies should enable care providers to refer individuals and families to intensive services if they receive requests for access to VAD from people who are ineligible due to age, lack of decision-making capacity or lack of incurable or terminal diagnoses. Those who are eligible for VAD should also be shown to have all their needs met during the application process. Each applicants' circumstances, needs and outcome should be recorded in detail, tracked and independently verified. As VAD represents a social and legal acknowledgement that intense, unendurable or persistent human suffering should be avoided at all costs, there must be processes in place to ensure that no one seeking to access VAD is left without immediate investment in their wellbeing. Assessment of and enduring validity of eligibility should be ensured through independent verification from multiple medical professionals, and a holistic assessment of a person's life circumstances, medical history and potential future outcomes should be recorded. VAD legislation should not allow for eligibility decisions to be formulaic, automatic or bureaucratic procedures, as respect for the value of human life demands rigorous, consistent and holistic human involvement in the assistance of a death. The ACT Government must preserve recognition of their responsibility of care to ensuring that vulnerable and disadvantaged people's needs are met.

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<sup>1</sup> Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability (Disability Royal Commission), [Seventh progress report](#), Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability, 14 March 2023, accessed 29 March 2023.

## Process for Request and Assessment

Question 10: Should witnesses be required for a person's formal requests for VAD? If so, who should be permitted to be a witness?

Witnessing of formal requests for VAD is a necessary safeguarding against manipulation or interference in a person's decision making process. Witnesses to VAD requests should be adults aged 18 and over and be verified to have no stake in the outcome of the person's request. Financial beneficiaries of the death of a person should not be eligible, however other forms of benefit should also be disallowable. For example, an adult relative with caring responsibilities towards the applicant who may benefit from their death in terms of time or personal freedoms should also be ineligible. Witnesses who are known to the applicant should officially declare a lack of interest in the outcome in a manner that could attract penalties if it is found to be dishonest or misleading. Regulation of witnessing to VAD requests should prioritise protecting the interests of people with vulnerabilities in capacity to reduce the risks of requests being made without the full knowledge, involvement and understanding of the person making the request.

Question 11: Should the process for seeking access to VAD require that a person take time to reflect (a 'cooling off' period) before accessing VAD?

A 'cooling off' period between an application being approved and VAD being carried out would be an appropriate mechanism to ensure that an individual has an opportunity to reflect on their choice, access support if they experience doubt, or if their decision has not been made independently. It is significant that during any period of reflection or processing, the person is in receipt of support and care services as required. In particular, access to counselling services should be available at any point during the application process, especially during a period of reflection. While we are not at liberty to prescribe a specific time period for this part of the process, too short of a period of reflection may not allow those who are in need of support with their decision to access the necessary services.

## The Role of Health Professionals

Question 18: What minimum qualification and training requirements should there be for health professionals engaged in the VAD process?

In order for health professionals to make informed decisions regarding eligibility and care in partnership with the applicant, they must have a minimum standard of medical qualifications, experience and good standing in their professional community. It would not be protective to allow a medical professional who does not have knowledge and understanding of the diagnoses, prognosis, treatment and stated experience of their patient to approve a decision allowing their death. In addition, a health professional should be qualified and experienced in the prescription of controlled medications to oversee the care of a person seeking VAD. Healthcare professionals who are willing to provide VAD should be registered, and ongoing training would be appropriate to ensure that presenting patients are provided with the highest possible quality of care. As VAD is a unique process with multiple areas of risk to a patient, as well as complex eligibility and care requirements, accreditation requirements specific to medical professionals participating in VAD processes would be appropriate to ensure the safety and quality of

care provide to patients is of a high standard. This includes ensuring that medical professionals involved in VAD processes have and maintain suitable qualifications to respond to patient needs for trauma informed care and palliative mental health support.

Question 20: Should registered health practitioners or other health professionals be free to initiate a discussion about VAD, providing information alongside other treatment and management options such as palliative care, where appropriate?

Concerning the matter of potential coercion, it is a high-risk proposal to grant an external person of any qualification the legal authority to introduce the possibility of seeking VAD to a person experiencing a life-limiting or incurable illness. As a healthcare provider is unlikely to be fully informed of a person's mental or emotional state, personal beliefs or life circumstances, there is an enduring risk that a person may be negatively impacted by a suggestion that they may be eligible to seek VAD. While it may be argued that patients should be informed of their full suite of options by healthcare providers, the option to seek VAD should be disseminated to the community more broadly rather than to specific persons in difficult or vulnerable circumstances.

### The Role of Health Services

Question 26: If a health service wishes to not facilitate VAD at its facilities, what is the minimum the provider should be required to do so that a person's access to VAD is not hindered?

A healthcare provider who does not wish to facilitate VAD should be required to inform the applicant as soon as the request is made, and to inquire as to their current care arrangements. If they believe that the applicant is not receiving adequate care, or that they require further supports in other areas, they should be required to refer the applicant to appropriate care providers. If the provider has an ethical or personal objection to VAD, this should not be allowed to compromise the quality of care the person receives in other areas of their medical care.

### Oversight, Reporting and Compliance

Question 29: What sort of oversight mechanisms are needed to ensure VAD is safe and effective? In particular, should oversight focus more on retrospective compliance or prospective approval? Should oversight mechanisms be independent from government?

Oversight mechanisms for VAD processes must be rigorous, transparent and efficient. An independent body such as the Queensland [independent board appointed to oversee voluntary assisted dying](#) appointed to track, monitor and evaluate each VAD case and ensure compliance with all legislative and regulatory requirements may be an effective mechanism to establish in the ACT. We recommend that any independent board to oversee VAD compliance must include suitably qualified representatives with disabilities and/or lived experience of chronic illness to ensure that the interests of community members who may be impacted by VAD are heard. In addition, the ongoing consultation of the broad and diverse range of professional and community stakeholders in the outcome of VAD legislation should be delineated in oversight policy.

## Other Issues

Question 35: Are there experiences elsewhere in Australia or internationally that the ACT might usefully learn from in the development of its own approach to VAD?

Legislative development of VAD in the ACT should closely consider developments in countries such as Canada, that has seen concerning adjustments to VAD legislation over time. As of March 2024, people with a sole diagnosis of a mental health condition will be eligible to access VAD (known as Medical Assistance in Dying or MAiD in Canada), this causes significant concern to community members with disabilities and/or mental health diagnoses.<sup>2</sup> In addition, in the Netherlands legislation allows children aged 12-18 as well as parents of children aged under one year to access VAD.<sup>3</sup> While there may be assurances of age limits, restrictions to specific diagnoses or prognoses and safeguarding mechanisms, both Canadian and Dutch cases prove that once VAD is legal, the parameters for access may change over time. It is crucial that VAD legislation in the ACT include language that maintains key protections in the future, particularly in consideration of the wellbeing of people with disabilities and/or mental ill health.

Question 36: Are there any other matters you think should be considered in implementing VAD in the ACT?

In implementing VAD legislation in the ACT, the impact upon people with disabilities, chronic health conditions and mental-ill health must be acknowledged and prioritised through extra funded mental health supports, increased resourcing to suicide prevention services and effective, sensitive and prompt dissemination of information to stakeholders throughout the process.

Yours sincerely



Gemma Killen  
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<sup>2</sup> The Centre for Addiction and Mental Health (CAMH), [Medical Assistance in Dying \(MAiD\) and Mental Illness – FAQs](#), CAMH, February 2023, accessed 5 April 2023.

<sup>3</sup> BBC News, [Netherlands backs euthanasia for terminally ill children under-12](#), BBC News, 14 October 2020, accessed 5 April 2023.