

9 February 2023

Honourable Vicki O'Halloran AO CVO, Co-Chair, Expert Advisory Panel
Duncan McConnel SC, Co-Chair, Expert Advisory Panel
C/- Project Management Office
GPO Box 4396
Darwin NT, 0801.

Submitted via upload to: vadinquiry@nt.gov.au

Dear Co-Chairs and Panel Members

Australia Psychological Society (APS) submission to the Northern Territory Government Consultation about Voluntary Assisted Dying

The Australian Psychological Society (APS) welcomes the opportunity to respond to the Northern Territory (NT) Government consultation about voluntary assisted dying (VAD). We commend the NT Government for identifying and consulting about a full range of VAD-related issues, especially those impacting health professionals involved in supporting and guiding the implementation of VAD with people who have life-limiting conditions. As noted in our previous submissions to VAD legislation consultations in other jurisdictions¹⁻⁵, the APS advocates for:

- Equity of access and choice for all Australians to a range of the highest quality end-of-life care options, including, but not limited to legal VAD,
- Legal foundations that protect and enable, rather than hinder, person-centred VAD-related decision-making and access, and
- Systems and processes that enable a multidisciplinary approach to end-of-life care, and enable health professionals, including psychologists, to work their full scope of practice in the provision of end-of-life care.

The APS is the leading professional association for psychologists in Australia. We are dedicated to advancing the scientific discipline and ethical practice of psychology and work to realise the full human potential of individuals, organisations and their communities through the application of psychological science and knowledge. Our work is informed by a human rights approach and aligned with the United Nations' Sustainable Development Goals (SDGs)⁷. We advocate for a fair, inclusive, and environmentally sustainable society, recognising the evidence that national and global prosperity now and in the future hinges on prioritising the health and wellbeing of people and the planet⁸.

By advocating on behalf of our members and the community, we strive to bring about meaningful reform in Australian health, wellbeing and social policies and systems. Our overarching objective is to ensure equitable access for all Australians to high-quality services that promote health and wellbeing through proactive measures, prevention, early intervention and treatment. As proponents of evidence-based practice, the APS draws on data and research. We also draw upon the experience and expertise of our APS members.

Please find attached our comments about the VAD matters raised in the Terms of Reference. If any further information is required from the APS, please contact me on (03) 8662 3300 or by email at z.burgess@psychology.org.au

Yours sincerely,

Dr Zena Burgess, FAPS FAICD
Chief Executive Officer

Terms of Reference for the Northern Territory (NT) Government Consultation about Voluntary Assisted Dying (VAD)

1. Who should be able to access voluntary assisted dying?

We note that the consultation documents, *VAD Discussion Guide 2^o* and *VAD Jurisdictional Comparator Table⁶*, outline some of the matters to be considered about who can access VAD and highlight specific elements of VAD legislation that vary across the Australian states. We offer the following feedback about some aspects of these VAD access criteria.

Medical eligibility

The APS supports the current approach throughout other Australian jurisdictions, that VAD should be accessible to a person who is expected to die soon because of an advanced and progressive condition, illness or disease, and who is experiencing unbearable suffering^{6,9}. The APS supports the position that unbearable suffering, due to a life-limiting condition, can be physical and/or mental, as is clarified in the Tasmanian and Queensland VAD legislation^{6,9}. We call for this level of clarity about the nature of suffering within the NT VAD legislation.

The APS also suggests that the NT clarify within their legislation that VAD is not suicide, noting this provision in all other Australian jurisdictions with VAD legislation, except Victoria⁶. Clarifying that VAD is not synonymous with suicide helps to address the stigma and misinformation surrounding suicide and end-of-life choices and fosters more informed and compassionate understanding in society about these matters¹⁰.

End-of-life prognosis

The eligibility criteria of being 'expected to die soon' from a life-limiting condition is operationalised across the various Australian jurisdictions as a person being likely to die within a range of 6 to 12 months, although the ACT legislation does not propose to specify a specific timeframe until death. The ability to apply for an exemption applies in a number of jurisdictions⁶.

The APS champions a flexible approach that ideally omits specific timeframes until death for individuals with life-limiting conditions and instead relies on other indicators such as those proposed by the ACT (i.e., having a relevant condition that is likely to cause death and is advanced and progressive)¹¹. This enables a person-centred approach to VAD that accommodates the diverse needs and experiences of individuals and acknowledges the challenges associated with prognostic accuracy for end-of-life predictions¹².

Additionally, we emphasise that delays resulting from various system factors have been observed in other jurisdictions, impacting the right of individuals to access and implement VAD within stated time periods. For example, as indicated in a recent study on Victorian patients' encounters with voluntary assisted dying¹³, delays can arise due to lengthy application processes and challenges locating and accessing qualified doctors for eligibility assessments, all with significant implications for critically ill patients facing only limited time. There are also instances reported of individuals becoming too unwell to fulfill the necessary procedures to access voluntary assisted dying despite this being their expressed wish earlier in their disease progression (see e.g.,¹⁴).

Should specified timeframes until anticipated death be legislated in the NT, we call for access to exemptions to ensure a flexible and compassionate approach to VAD eligibility for terminally ill people which will provide them with sufficient time to make an informed decision and, if desired, to be able to fulfill all necessary steps for the approval and administration of VAD.

Residency requirements

Residency requirements for accessing VAD exist in the other jurisdictions, with some allowing exemptions on compassionate grounds⁶. Should residency requirements be incorporated into NT legislation, it is vital to include exemptions to ensure individuals meeting all medical eligibility criteria and who have a significant NT connection, including family or cultural ties, are not denied access to VAD in the NT solely due to residing interstate. Exemptions are especially crucial for Aboriginal and Torres Strait Islander peoples living in other jurisdictions who may wish to return to their traditional lands in the NT to access VAD, and for individuals living and working across borders.

2. What process should a person follow to access voluntary assisted dying?

As noted in the consultation documents, the *VAD Discussion Guide 3*⁵ and the *VAD Jurisdictional Comparator Table*⁶, VAD laws in each Australian jurisdiction provide for a staged process for a person to formally request access to VAD, and to have their eligibility assessed by at least two qualified registered medical practitioners. If the medical practitioners cannot determine a person's eligibility for VAD, they can seek another opinion from other eligible health professionals.

The APS is a strong advocate for VAD access processes that are safe yet no more complex than they need to be - first and foremost for people seeking access to lawful VAD and their family, carers and kin, and for health professionals who support the process. We offer the following feedback about some aspects of the VAD access process.

Balancing rights and protections for vulnerable people

The APS supports the position, as noted in the VAD legislation of all other Australian jurisdictions⁹, that a person is to have decision-making capacity throughout the entire VAD process. We also advocate for robust provisions to ensure protection from coercion from family members, carers, health professionals and/or others.

The APS position is that there should be a presumption of rationality for a person seeking access to end-of-life care, including VAD. Having a disability (e.g., cognitive or communication impairment), disease (e.g., dementia) or a mental illness (e.g., depression), or being less than 18 years of age, does not automatically render a person incapable of making an informed decision and should not automatically negate their right to access VAD¹⁶. An appropriate supported decision-making framework should be available to ensure potentially vulnerable individuals can still have equitable access to VAD. We acknowledge that supported decision-making for VAD can be particularly contentious, including for the decision supporter and health professionals, thus requiring a model that carefully balances rights and protections for vulnerable individuals and those who support them (see¹⁷).

Along with a clear supported decision-making framework, protections for all, including the potentially vulnerable, can include measures that are reflected in VAD legislation in other Australian jurisdictions⁶, for example:

- Requiring a person requesting VAD to make multiple requests to access assisted dying,
- Imposing a 'cooling off' period between first and final requests,
- Requiring VAD written or verbal requests to be witnessed by an independent witness,
- Making clear to a person that they can withdraw their VAD request at any time, and
- Seeking the opinion of another qualified health professional.

Assessment of decision-making capacity

Determining decision-making capacity is a complex medico-legal area that addresses matters associated with balancing respect for patient autonomy with the responsibility of protecting people from harm resulting from impaired decisional capacity¹⁸. Thus, the APS calls for VAD legislative provisions and ensuing systems in the NT that support an expedited assessment of decision-making capacity where such capacity is in question due to a condition or developmental considerations, or there are concerns about potential coercion. The legislation should make clear the situations requiring decision-making capacity assessment, the timeframes for assessment, and the skills and competencies of suitably qualified assessors who may be called on to provide a determination of decision-making capacity for access and implementation of VAD.

We highlight here that trained psychologists, including forensic psychologists, already play a pivotal role in medico-legal contexts, and are frequently called upon to assess and report on matters involving the application of psychological and scientific methods to legal issues¹⁹. This includes administering evidence-informed assessments of cognition and behaviour to ascertain decision-making capacity and identify undue influence^{20,21}. Psychologists are, therefore, already well-positioned to support medical practitioners in determining an individual's eligibility for VAD on the grounds of decisional capacity when required.

Safeguarding access to VAD information and support

A VAD care navigator service has been established in Australian jurisdictions that have legislated for VAD to provide accessible information and support to people considering this option, as well as to their family, kin and carers and health professionals (see e.g., ^{22,23}). Dying people may be at the limit of their mental, physical and economic resources and find it difficult to locate factual VAD information and health professionals who can assist them with VAD-related matters. This is particularly true for individuals in aged care or palliative care facilities, where patients are entirely dependent on visiting medical practitioners and health professionals. Care navigators are, therefore, a critical part of the system to ensure that people have the right to access VAD if they wish. The APS strongly advocates for similar patient-centred and coordinated care navigator services to also be adopted in the NT alongside VAD legislation.

The APS also calls for additional mechanisms in the NT to safeguard access to factual VAD information, for example:

- Make clear the responsibilities of health professionals to provide information to people seeking access to VAD, including how to access their jurisdictions' VAD care navigator service.
- Community messaging about VAD and the care navigator service, ensuring communications are accessible to people from diverse social, economic, cultural and language groups, and made readily available in the key contexts where people may be seeking end-of-life care (e.g., GP and health clinics, aged care and palliative care facilities).

3. What are the legal and ethical obligations of health practitioners who provide services relating to voluntary assisted dying?

We note that the consultation documents, *VAD Discussion Guide 4²⁴* and *VAD Jurisdictional Comparator Table⁶*, outline some of the matters to be considered about the VAD-related roles and ethical and legal obligations of health practitioners. We offer the following feedback about some of these aspects.

Psychologists' roles

Health professionals are integral to the access and implementation of end-of-life care, including VAD, throughout all Australian jurisdictions. Psychologists, as Ahpra-registered health professionals, can support VAD-related processes in numerous ways, including:

- Providing psychological treatment and support to people around end-of-life matters, including at various points in their VAD journey (e.g., decision-making, family impacts, life review).
- Providing support and education to families, carers and friends of people at the end of life, including at various points in their VAD journey (e.g., when their loved one requests to access to VAD, post-VAD bereavement).
- Conducting decision-making capacity assessments and support to medical practitioners around VAD eligibility decisions.
- Providing tailored training, debriefing and bereavement support for health professionals and other key workforces (e.g., end-of-life care navigators, care workers) who work in or are impacted when providing end-of-life care, including VAD.
- Contributing to policy and program development and clinical governance structures that support quality end-of-life care decision-making and oversight, including for VAD.
- Providing research-based insights that inform the implementation of quality care options for people at the end of life, their families, carers and friends.

Restrictions on health professionals initiating a discussion about VAD

Each Australian jurisdiction regulates when VAD can be discussed, which health professionals can do this and in what circumstances. Breaches can result in a charge of professional misconduct and imprisonment in cases of inducement⁶.

Concerning the initiation of conversations about VAD, most Australian jurisdictions currently limit this role to medical practitioners and nurses, excluding non-medical and allied health professionals like psychologists. The exception to date is in NSW where all allied health professionals, including psychologists can initiate discussions if other essential information is provided to the person, including that they should discuss VAD with a medical practitioner²⁵.

The APS position is that the prohibition of a non-medical health care professionals, in our case a psychologist, from initiating a discussion about VAD with a person is reasonable because VAD is fundamentally a medical option to be discussed in the context of all medical treatment options, including palliative care. This ensures a patient can be fully informed of all medical options available. Non-medical healthcare workers are typically not in a position to provide this context or information.

The APS notes with some concern that it appears that in some Australian states the carer workforce are permitted to, or is not prohibited from, initiating discussions about VAD. As the carer workforce engages with some of the most vulnerable people in our society (e.g., people in aged care, people with a disability), we strongly advocate for clarity about this matter and/or the incorporation of necessary safeguards within the NT legislation to support and protect the workforce and the people they provide care to²⁶.

The APS would support provisions in NT legislation which allow VAD discussions to take place with an allied health professional, including psychologists if initiated/requested by the client. We note, however, reports of non-medical health practitioner uncertainty if a person's request for information about end-of-life treatment options is specific enough for them to provide information about VAD according to the legislation in their jurisdiction²⁷. The APS calls for clarity on this matter in NT legislation.

We also highlight the critical role for the NT Government in ensuring initial and ongoing training is provided for all health professionals, including non-medical health professionals and other key workforces (e.g., the care workforce) so they are aware of and supported to enact their obligations under the legislation.

Health professional conscientious objection

All Australian jurisdictions align with health professionals' codes and recognise, to varying extents, that a health professional may choose to conscientiously object to being involved in a VAD request, assessment and/or administration processes⁶.

The APS appreciates the complexities in balancing the human rights to freedom of religion, conscience and belief with the human rights of others to access VAD. The APS, therefore, strongly supports psychologists' and other health professionals' right to conscientious objection, as enshrined in professional codes of conduct and the voluntary assisted dying legislative approaches across Australian states.

The APS does not support or oppose the position that health professionals who conscientiously object be required to declare their objection or non-participation in VAD processes.

However, we call for strong measures that safeguard the rights of people seeking support and access to VAD, irrespective of the requirement to disclose conscientious objection, for example by requiring health professionals to provide timely access to VAD information and supports and refer on should they conscientiously object or not wish to participate.

Health services that decline to facilitate voluntary assisted dying

The APS supports equity of access to all end-of-life choices, including VAD where it is legislated - irrespective of where a person is located, be that in a metropolitan, regional or rural area or residing in their home, health service, palliative care service or residential aged or disability care service.

The APS is especially concerned that people living in institutional care in the NT may be the most vulnerable in relation to equity of access to legal VAD, particularly when institutions may have strong objections to the provision of VAD on faith or other grounds. We call for particular attention to be given within NT VAD legislation to mechanisms that ensure people in these contexts:

- have appropriate access to relevant and independent VAD information and services via a professional care navigator service, and
- can access legal VAD services if they choose with clear and timely pathways available should the context they reside in or receive support and services from decline to facilitate VAD.

4. Other /questions issues

Health care equity considerations

The adequacy of health care may play an important role in a person's decision- making, such that a request for VAD may follow a failure of one or more parts of the health system to provide adequate care. Such requests may be made in the context of serious social inequities and access to resources such as basic medical care. The APS are strong advocates for addressing social and environmental factors that may influence requests for VAD and impact its implementation.

The APS is also clear that VAD is not an alternative to effective palliative care.

Access to VAD is about hastening death at the end-of-life. Palliative care does not seek to either hasten or postpone death and is focused on the quality of life for a person who is rapidly approaching death and identifies and treats symptoms that may be physical, emotional, spiritual or social²⁸.

The APS advocates for choice and access to the full range of high-quality end-of-life care and support options, including palliative care and VAD in jurisdictions where it is legislated. We have welcomed recent government commitments and increased investment needed to reform end-of-life and palliative care in many Australian jurisdictions²⁹⁻³¹. We call on the NT and all jurisdictions to continue the investment in high-quality end-of-life care options, including palliative care and work towards opportunities to align evidenced-informed approaches to end-of-life care across jurisdictions.

First Nations people's perspectives

There is limited research and inquiry about what VAD reforms mean for end-of-life care for Aboriginal and Torres Strait Islander peoples.

One recent analysis of the VAD law reform processes in Victoria and Western Australia highlighted disparate views towards VAD from different Indigenous organisations with a caution against universalising First Nations perspectives about VAD³². The APS calls for active, meaningful and continuous engagement with Aboriginal and Torres Strait Islander peoples about VAD laws including the implications and needed safeguards to ensure culturally appropriate end-of-life care for individuals, families and communities that respects Indigenous knowledges, traditions and end-of life practices, as well as personal agency.

Culturally and linguistically diverse perspectives

There is also a plurality of views across culturally and linguistically diverse (CALD) groups about VAD. The APS calls for active, meaningful and continuous engagement with CALD groups about VAD laws including the implications and needed safeguards, particularly in relation to culturally appropriate assessments of decision-making capacity, providing support for decision-making and ensuring that there is no undue influence. It is important to ensure that engagement and information about VAD is available in languages other than English. Likewise, people who may have limited English proficiency or literacy should be provided with appropriate supports through the VAD process, such as high-quality interpreter services.

Cross-jurisdictional consistency

The APS notes the inclusion of a summary in the consultation materials which outlines how other Australian jurisdictions have approached VAD⁶, with some notable differences evident. We take this opportunity to strongly advocate for continued efforts by the States and Territories to achieve cross-jurisdictional consistency in VAD legislation. This consistency is vital for providing clarity to the Australian community, individuals seeking access to VAD, and healthcare professionals involved in VAD-related process. Failing to achieve such consistency will create uncertainty and confusion for those seeking access to VAD and health professionals who are located near borders and operating across jurisdictions.

Access to a capable and skilled workforce

Implementation of any VAD scheme needs to consider the existing and future capacity of an appropriately skilled workforce to meet the needs of people approaching the end of their life. High-quality training, supervision and psychological support are essential for health professionals and other workers who may be involved in VAD implementation (e.g., the care workforce), noting that it should not be left up to professions and workers to simply adapt. The APS calls on the NT Government to help support, train and prepare the workforce, in close collaboration with professional bodies, and to ensure sufficient lead time before the implementation of VAD legislation.

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