Five year review of the operation of Victoria's Voluntary Assisted Dying Act 2017

Submission to the Centre for Evaluation and Research Evidence at the Victorian Department of Health

February 2024

dying with dignity victoria

Contents

Dying With Dignity Victoria's responses

Q1. Please briefly describe any involvement you or members of your organisation may have had with voluntary assisted dying in Victoria.

Founded in 1974, Dying With Dignity Victoria (DWDV) is a charitable organisation pursuing public policies and laws in the state of Victoria to enhance self-determination and dignity at the end of life.

DWDV's purpose is to relieve distress, helplessness and suffering for Victorians with untreatable, painful or terminal illnesses. In achieving its purpose, DWDV:

- supports end of life choices for people with untreatable, painful or terminal illnesses, and provides support to their families and carers;
- provides information, education and advice related to end of life choices to support people with untreatable, painful or terminal illnesses and the broader Victorian community;
- monitors and reports on outcomes and effects of end of life legislation and the quality of services provided for end of life care.

DWDV currently has 740 members.

DWDV advocated for legislation to make voluntary assisted dying (VAD) a legal end of life choice in Victoria. Following implementation of the *Voluntary Assisted Dying Act 2017* (the Act) in 2019, we have sought to support those seeking VAD and those who provide the service, while also seeking to inform the public of options now available.

Our board includes medical practitioners with significant experience providing VAD in Victoria, and a person with lived experience of supporting a family member to access VAD. It also includes people who have witnessed deaths in terrible circumstances before VAD was available, and a person with a family member who was unable to access VAD due to dementia, despite completing an advance care directive requesting VAD while they still had decisional capacity.

DWDV's General Manager is the first port of call for many people making general enquiries about VAD and for people traversing the process, their families and other support people. In addition, our board members and supporters provide the following services on a voluntary basis:

- witnessing of VAD written applications (approx. 435 applications witnessed since implementation by more than 130 volunteer witnesses)
- providing presentations on end of life options, including VAD, to various organisations and interest groups, such as U3A, Probus, retirement villages

- promulgating information about the availability of VAD, including creating a map showing Victorian residential aged care facilities that support VAD
- providing emotional support for the families, carers and friends of people who access VAD, including one-to-one peer support and a pilot program of VAD-specific bereavement support groups in partnership with Griefline
- interacting with government agencies, VAD statewide care navigators, and health practitioners involved in the provision of VAD in Victoria
- providing information and resources for people seeking information about VAD, including newsletters, podcasts, films, answers to frequently asked questions and submissions to inquiries.

Our responses to the following questions include several issues relating to the operation of Victoria's VAD systems, processes and practices that stem from the drafting of the Act. We are aware of the Victorian government's reluctance to consider changes to the Act. However, as an advocacy organisation, our role is to highlight all significant issues with the operation of Victoria's VAD systems, processes and practices, regardless of the source of those issues. In our view, some of these issues cannot be addressed effectively without legislative change, and we think it is extremely important that a full review of the legislation is scheduled as soon as possible, given no further review is mandated in the current Act.

Our submission is informed by feedback we have received over several years from people seeking VAD and their families and carers, the doctors on our board, other health professionals with whom we interact, and DWDV volunteers who provide witnessing services. We thank them for their generous contributions.

Q2. Do you think that Victoria's voluntary assisted dying systems, processes and practices meet the needs of people seeking voluntary assisted dying as well as their families and carers? Please explain.

In DWDV's view, Victoria's VAD systems, processes and practices meet the needs of some people seeking VAD in Victoria. Those who successfully navigate the VAD system are, undoubtedly, grateful to be able to choose the timing and manner of their death. We also acknowledge the positive aspects of Victoria's VAD system, including the assistance provided to people seeking VAD by a small cohort of compassionate and dedicated doctors, VAD care navigators, pharmacists, and other allied health professionals, and clear, regular reporting provided by the VAD Review Board.

However, there are many ways in which Victoria's VAD systems, processes and practices **fail to meet the needs** of Victorians who may wish to access VAD, as well as the needs of their families and carers, as outlined below.

Prognosis requirement

Victorians with a prognosis to death longer than 6 or 12 months are excluded from accessing VAD, even if they are suffering from painful or debilitating conditions. Suffering is not restricted to the last 6 or 12 months of life for people with incurable conditions.

Even for people who are close to death, the prognosis requirement can result in prolongation of intense suffering. By their own admission, doctors are reluctant to deliver a definitive prognosis. It is difficult to predict with certainty that a person has 6 or 12 months or less to live. Fear of criticism of an inaccurate prognosis, or 'diagnosing' death too early, can delay VAD eligibility. Often a prognosis is not delivered until death becomes imminent, and the person has little time or energy to complete the VAD process. A Victorian VAD provider has stated that doctors' reluctance to provide a diagnosis means they often wait too long, such that when a 6 month prognosis is finally delivered, the patient may have only about 6 weeks.

Suffering is too narrowly construed

Victoria's VAD system unfairly excludes people experiencing intolerable mental suffering who do not also meet the prognosis requirement. These may be people living with mental illness or people anticipating physical suffering from a terminal condition (or from treatment or complications of that condition).

It also excludes Victorians suffering, physically or mentally, from the interaction of their terminal condition with concurrent medical conditions and associated treatments. This is exemplified by the case of an individual diagnosed with a slowly progressing terminal illness, with a prognosis of several years until death. This individual may also suffer from multiple comorbidities, all of which are individually and specifically treated. The resultant suffering may be unbearable, but the individual must endure it until a time when they may be considered eligible for VAD based solely on their anticipated life expectancy from the underlying medical condition.

In addition, it excludes people suffering physically and mentally from multiple comorbidities but who have no terminal illness, including those frail elderly who feel they have lived a completed life.

'Gag clause'

Victorians who are unaware of VAD are effectively excluded from accessing VAD because registered health practitioners are prohibited from initiating discussion about VAD with patients. No other area of healthcare requires patients to know their treatment options in order to access them. The gag clause discriminates against people who lack information about VAD, whether this is due to low levels of health literacy, computer literacy or access challenges, or cultural and language barriers. See also our response to question 3.

Not enough doctors providing VAD

Victorians seeking VAD often struggle to find medical practitioners who have completed VAD training and are willing to provide VAD assessments, which is a source of significant distress for people seeking VAD and their families and carers. This is unsurprising, given the tiny number of doctors actively participating in VAD in Victoria (208 as at 30 June 2023, according to VAD Review Board data, out of some 35,000 medical practitioners registered in Victoria at November 2023). Sometimes these challenges delay the VAD process or result in Victorians being unable to access VAD at all.

Requirement for specialist assessment

The challenges faced by Victorians seeking VAD to find willing doctors are compounded by the Victorian government's interpretation of section 10(3) of the Act. The government has chosen to interpret this clause as requiring a specialist to be one of the medical practitioners involved in the assessment process, although the Act does not make this specification. This places a significant additional burden on people seeking VAD to locate a specialist, when there are many GPs with much expertise and experience, who may often have more expertise and experience than specialists in dealing with end-stage disease. Combined with the Federal government's ban on telehealth, this requirement greatly limits access to doctors by Victorians seeking a VAD assessment, particularly in regional and remote areas, and particularly for people with neurodegenerative conditions.

No choice of administration method

People seeking VAD are often anxious about mixing and swallowing the VAD substance on their own. The needs of people seeking VAD would be better addressed by allowing them to choose practitioner administration instead of self-administration, even if they are capable of ingesting oral medication.

Some VAD providers in Victoria offer to be in attendance when the patient self-administers the medication. When this is offered, a Victorian DWDV Board member and VAD provider has stated that around a third of patients accept. Patients want to know that the process will proceed effectively and are reassured by the presence of a doctor. In jurisdictions where patients are offered the choice, the vast majority choose intravenous administration.

Administration permit required

In Victoria, the coordinating medical practitioner is required to apply for a VAD permit for administration after having determined eligibility of the person. Most other states have removed this bureaucratic requirement. Many Victorians have died in suffering while awaiting the completion of this time-consuming, unnecessary step in the VAD process.

Institutional non-participation

Victoria's current approach to institutional participation in VAD does not meet the needs of people seeking VAD for consistent, person-centred care across the system. Institutions that object to VAD have the power to significantly curtail Victorians' ability to access what is a lawful medical service. At present, publicly funded hospitals, residential aged care facilities, hospices, and other institutions may simply refuse to participate in VAD, either entirely or in relation to specific aspects. Victorians seeking VAD have experienced considerable unnecessary suffering due to facilities denying individuals access to VAD information, consultations with VAD doctors or administration of the VAD medication, and, in at least one case that DWDV is aware of, refusing entry to the pharmacists delivering the VAD medication.

Victoria's policy approach has patently failed to meet the needs of people seeking access to VAD, who need legislative safeguards for their right to access VAD. If facilities providing health, residential aged care and personal services are permitted to retain the right to refuse to participate in VAD, they must also be required to meet defined obligations to people seeking VAD (e.g., not to hinder access to information about VAD; to facilitate reasonable access by VAD providers). These obligations may differ according to the stage of the VAD process and whether the individual is a permanent or non-permanent resident at the facility. See also our responses to questions 4, 5 and 6.

Residency requirements

Victorians who cannot produce documentation to prove they are ordinarily resident in Victoria are excluded from accessing VAD. The documentation requirements place an unnecessary burden on people at a time when they are often extremely unwell. With VAD now accessible in all Australian States, there is no longer a need to limit VAD access to Victorian residents. At a minimum, there must be flexibility for situations where a person who is otherwise eligible for VAD is unable to locate the requisite documentation. We also highlight concerns about the Australian citizenship / residency requirements in response to question 6.

Exclusion of VAD from advance care directives

Victorians who lack decisional capacity at the time they become otherwise eligible for VAD, or who lose decisional capacity partway through the application and assessment process, are excluded from accessing VAD. This is a particular concern

for people living with a neurodegenerative disease (e.g., motor neurone disease, or any form of dementia) but cognitive impairment can occur unexpectedly at any age or stage of life (e.g., traumatic brain injury). In DWDV's view, Victorians should have the right to include VAD in their advance care directives while they have decisional capacity for VAD. See also our response to question 4.

Lack of VAD-specific support for families and carers

Until recently, there has been no specific VAD grief and bereavement support available for families and carers, either before or after VAD. People have been told to ring support organisations like Lifeline and Beyond Blue, but frontline staff in those organisations have not received appropriate training to provide tailored support for families and carers of people accessing VAD. DWDV and Griefline launched a pilot program of VAD-specific bereavement support groups in 2023. A permanent and sustainable approach to meet the needs of families and carers for tailored grief and bereavement support, before and after VAD, must be developed by the Victorian government, in consultation with community sector partners. See also our response to question 6.

Q3. Do you think that Victoria's voluntary assisted dying systems, processes and practices meet the needs of people from diverse backgrounds and geographic locations? Please explain.

In DWDV's view, Victoria's VAD systems, processes and practices fail to meet the needs of people from diverse backgrounds and geographic locations in Victoria for the reasons outlined below.

Not all Victorians are aware of VAD

Lack of awareness of VAD as a legal end of life choice is a critical issue in the Victorian community.

This particularly affects people with low levels of health literacy or who lack access to technology or skills to access electronic information about VAD. The VAD Review Board's demographic data on VAD applicants indicates they are significantly more likely to have completed year 12 (or equivalent) than the average Victorian, suggesting that access to VAD is currently concentrated among socioeconomically advantaged sections of the Victorian community.

People living in small communities with low population densities or in multicultural communities in which VAD is a taboo topic, and where information exchange often occurs through word of mouth or face to face interactions not via electronic mediums, also have reduced chances of becoming aware of VAD through social/community contacts.

For these Victorians who are unaware that VAD exists as a legal end of life option, the prohibition on health practitioners initiating discussion about VAD with patients is discriminatory. The work of the VAD statewide care navigators and locally appointed VAD coordinators has proved invaluable, but they are unable to address the needs of everyone seeking VAD information and advice. Further, someone who is unaware of VAD's existence is unlikely to know to contact the navigators for more information.

In addition to removing the 'gag clause' from Victoria's VAD legislation, there must be a concerted effort to increase VAD literacy across all sectors of the Victorian community. Information on VAD should be displayed in medical waiting rooms, amongst other medical literature. Face to face community education sessions should be promoted to increase VAD awareness and enable convenient access to general information on the VAD process.

Accessing VAD providers and supportive facilities can be difficult outside metropolitan Melbourne

DWDV has heard from individuals who regard themselves as having been discriminated against because of their geographic location in regional or rural Victoria. In these areas, there are fewer health practitioners, and local practitioners may be hesitant to involve themselves in VAD. This issue is compounded, as noted in question 2, by the Federal ban on telehealth VAD consultations, and by the interpretation of the Victorian VAD legislation to require one of the VAD providers to be a specialist in the underlying disease of the individual seeking VAD. It is further compounded in the case of neurodegenerative disease by the requirement for a second specialist opinion to be sought to confirm the expected time until death. The most recent report of the VAD Review Board shows that people with a neurological condition, most often Motor Neurone Disease, make up 9% of individuals who apply for VAD. The report also referred to the availability of only 1 neurologist in rural Victoria who has registered within the VAD portal.

These legislative restrictions result in some individuals with intense pain and discomfort, often burdened with medical equipment, being required to travel long distances to complete the mandatory VAD consultations. For some, the journey has been extremely traumatic. DWDV has been made aware of individuals who have refused, prior to their journey, to take pain relief medication in fear that their competency may be affected. For a few, the journey cannot even be considered an option.

Equitable access to VAD for people living in regional or rural areas is further exacerbated in Victorian towns serviced by only one residential aged care facility or retirement village that is faith-based and opposed to VAD, or where all attending GPs are conscientious objectors.

Strategies for improving access to VAD are needed for people in regional areas, particularly for those with neurodegenerative conditions. Resolving access to telehealth for VAD consultations would play a critical role in supporting people in rural and regional areas who wish to seek VAD. Consideration should also be given to targeted financial support for people outside metropolitan Melbourne who cannot access VAD-trained medical practitioners in their local area, similar to Western Australia's Regional Access Support Scheme.

Despite the issues outlined above, data from the most recent VAD Review Board report shows that over 36% of VAD applicants were from regional Victoria, although only 22% of the Victorian population live in regional areas. However, this data does not tell the full story of the extraordinary efforts that people from regional and rural areas have made to access VAD. A deep understanding of the experience of regional and rural VAD applicants is needed to inform tailored VAD support for regional and rural communities.

There is a lack of tailored support for First Nations people

Data from the VAD Review Board indicates that less than 1% of Victorians who have used VAD since implementation self-identified as Aboriginal or Torres Strait Islander peoples. While there may be several reasons for this, it is notable that Victoria has not sought to provide any culturally sensitive information about the VAD process tailored to the needs of First Nations people in Victoria. By

contrast, New South Wales, Queensland and Western Australia have prepared tailored information sheets providing an overview of VAD for First Nations people, as well as guidance for VAD providers and other health practitioners to promote culturally appropriate care when discussing VAD with First Nations people.

Consideration and acceptance of cultural beliefs and values is vital to ensure the VAD process is person-centred. VAD providers and other health practitioners must acknowledge and respect the potential sensitivity for First Nations people of death and dying and the cultural significance of the end stage of life. Some First Nations people may wish to die on Country as part of their end of life journey, and this should be facilitated wherever possible in the VAD process.

VAD providers must also be aware that for many First Nations people, decisions about treatment and care are often made together with other family or community members. When supporting First Nations people through the VAD process, VAD practitioners must try and strike a balance between understanding the importance of family, community, and cultural roles and responsibilities as part of VAD decision making and ensuring that an individual's decision about VAD is made without coercion and reflects their genuine wishes.

The Victorian Department of Health should work with the Aboriginal community-controlled health and wellbeing sector in Victoria and First Nations communities to develop culturally appropriate VAD information for First Nations people, and specific guidance for VAD providers and other health practitioners who provide end of life care to First Nations people.

There are access challenges for multicultural communities

The current VAD system does not cater adequately for the needs of Victoria's multicultural communities, resulting in lower rates of access to VAD. For example, the demographic data on VAD applicants reported by the VAD Review Board indicates that a significantly greater proportion of VAD applicants speak English at home (92% since implementation) than the proportion of Victorians who speak English at home (67.2% in the 2021 census).

There are various barriers to VAD access for people from multicultural communities:

- **Language barriers**: VAD information can be difficult to access and comprehend even for people with English as their first language. Language barriers can lead to miscommunication which can have serious implications for health care delivery, possibly jeopardising patient safety. It is acknowledged that there are challenges associated with translating VAD information into non-English languages when some languages are unable to provide a specific translation for the term 'voluntary assisted dying'. The Victorian Department of Health provides general information on VAD in 18 languages. However, this does not address the needs of people who use less commonly spoken languages. It also does not ensure that information about VAD is widely accessible in multicultural communities.
- **Using interpreters**: When people require the assistance of an interpreter during the VAD process, the ban on telehealth for VAD requires the interpreter to be physically present for VAD consultations. This adds another layer of complexity to the process. Some languages

are served by a limited number of interpreters, who must be prepared to travel to locations all over Victoria. All interpreters must be accredited by the National Accreditation Authority for Translators and Interpreters (NAATI).

- **Cultural differences**: Cultural differences may also impact on VAD access and must be taken into consideration. Within some cultures, the topic of death and dying is taboo, making any discussion around the issue of VAD extremely unlikely. Even if such discussion can proceed it can be very difficult to translate the concept of VAD if it is non-existent in the public health setting of the relevant culture.

The Victorian Department of Health should work with multicultural communities to determine the most appropriate way to deliver VAD information to people whose first language is not English and to communities in which there may be cultural sensitivity around VAD. Legislative change that would allow accredited interpreters to participate in VAD discussion via telehealth would also support the needs of people from linguistically diverse backgrounds to participate in the VAD process.

Q4. Do you think that Victoria's voluntary assisted dying systems, processes and practices are timely, safe and compassionate? Please explain.

When Victoria's VAD model was finalised in 2017, it was described as 'safe and compassionate'. Undoubtedly, the 68 safeguards in the Act have ensured VAD is delivered safely for those who gain access. However, Victoria's VAD systems, processes and practices are not always experienced as safe, timely or compassionate.

Safety

While safety is a critical consideration, many of the Act's safeguards function, in practice, as impediments to VAD access. The focus on maximising safety impedes equal access to VAD for Victorians, as highlighted in this submission.

Some safeguards, such as the prognosis requirement, reduce safety for people ineligible for VAD on that basis. People with unbearable suffering, but a long prognosis to death, may turn to suicide as their only relief, greatly increasing the risk of adverse outcomes for them and their loved ones. This could be avoided by refocusing the eligibility criteria on suffering, rather than prognosis, which doctors have candidly indicated is an imperfect indicator, often influenced by their interpretation of the Hippocratic Oath to preserve life at all costs, and the emotional needs of patients and their loved ones.

Timeliness

People attempting to access VAD have limited time to live and are often severely incapacitated by their underlying condition and other comorbidities. Victoria should seek to remove unnecessarily onerous administrative requirements and minimise bureaucracy and delays faced by people seeking VAD. Several issues are contributing to delays:

- **Lack of specialists and telehealth ban**: Victorians seeking VAD often face long waitlists to see specialists. As discussed in questions 2 and 3, this is exacerbated by the current interpretation of the legislation regarding specialist assessments, and is especially challenging for people in rural communities and people who cannot afford to access specialists privately. Telehealth consultation would improve VAD access.
- **'Gag clause'**: As discussed in questions 2 and 3, doctors must withhold information about VAD from patients unless specifically asked, delaying some patients from receiving critical information about VAD. Earlier conversations with their doctors would allow people more time to consider VAD, to discuss it with their loved ones, and potentially less time suffering.

- **Inability to consent to VAD in advance care directives**: Despite VAD being a lawful end of life option, the *Medical Treatment Planning and Decisions Act 2016* (Vic) expressly excludes VAD from advance care directives (ACDs). This denies Victorians the opportunity to access VAD if they lose decision-making capacity for any reason, whether due to neurodegenerative conditions or otherwise (e.g., stroke). Disallowing consent to VAD in ACDs also significantly narrows the opportunity to request VAD.

  While the exclusion of VAD from ACDs affects all Victorians, it particularly impacts people with conditions affecting their decisional capacity for VAD. They cannot access VAD in any circumstances, even if otherwise eligible (e.g., a person with advanced cancer who lacks decisional capacity for VAD due to cognitive impairment). In DWDV's view, denying a person the treatment they consider dignified, solely due to their condition, is discriminatory and breaches Victoria's Charter of Human Rights and Responsibilities.

  Victorians should have the right to include VAD in ACDs while they have decision-making capacity for VAD. This would give people peace of mind that they can access VAD when their quality of life has declined, or their physical or mental suffering has increased in a way unacceptable to them.

- **Conscientious objection by healthcare practitioners**: There is no legislated requirement for conscientious objectors to refer patients to another practitioner, which slows the process for patients. It also creates an inequitable system where some patients will receive support when they raise VAD with a health professional, while other equally eligible patients may receive no support.

- **Limited number of VAD providers**: As discussed in question 2.

- **Delays following up with patients**: DWDV has heard examples of distressing experiences regarding timeliness. One member reported her mother waiting three months for permission to access VAD, after submitting her final request. The patient and their family received inadequate communication from the Department of Health during this delay.

- **Other factors affecting timeliness**: These include a cumbersome permit process, not required in most other states (see question 2), and centralised dispensing and delivery of the VAD substance adding to delay.

Compassion

A compassionate VAD system must recognise and respond to individual suffering. This requires a clear understanding of the needs of people who may wish to access VAD, and sufficient resources to address those needs. Victoria's current VAD system is not universally experienced as compassionate for various reasons:

- **Dementia**: Victoria's VAD system lacks compassion for people wishing to access VAD if they receive a diagnosis of dementia.

  Dementia satisfies the VAD eligibility criteria that a condition be progressive, incurable and terminal. However, people with dementia are highly unlikely to retain decision-making capacity for VAD

up to the point at which they meet the prognosis requirement and throughout the remainder of the VAD process.

While DWDV acknowledges the challenges associated with making VAD available to people with dementia, we feel compelled to raise this issue on behalf of our members and supporters, who consistently highlight it as their overwhelming concern. A survey of members and non-members conducted by DWDV in late 2022 indicated considerable levels of distress and frustration that VAD is unavailable to people with dementia. This appears consistent with broader community concerns expressed in recent media discussions of the topic.

Innumerable stories from DWDV members and overseas jurisdictions describe individuals diagnosed with dementia taking their own lives prematurely upon finding themselves ineligible for VAD. Research shows a high risk of suicide in the months immediately following a dementia diagnosis. Dementia is the second most feared illness in the Australian community after cancer (Cations et al., 2021).

The Victorian government must not ignore community concerns about dementia and VAD and must consider potential regulatory responses to support the right of every Victorian, including people living with dementia, to exercise choice in their end of life care options, including VAD. This may include reconsidering the disallowance of VAD instructions in ACDs, as discussed elsewhere, to enable people with dementia to exercise genuine choice and control concerning their end of life care.

- **Institutional objection / non-participation**: There is an urgent need to reconsider the regulatory approach to institutional objection to VAD to better balance the interests of patients and non-participating institutions. Safeguarding organisational choice to offer VAD services is not compatible with equal patient access to compassionate VAD services.

  Recent Victorian research on the impact on patients of institutional objections to VAD shows those objections undermine the timeliness and compassion of Victoria's VAD systems, processes and practices (White et al., 2023). The research graphically illustrates how institutional objections hamper Victorians' access to, or experience of, VAD. Institutional objections cause unacceptable delays in accessing VAD and limit patient choice, with people sometimes forced to choose between progressing a VAD application and receiving palliative or other care. Forced transfers out of objecting hospitals or other facilities cause delay and distress and may prevent people from dying in their preferred place.

  When a long-term aged care facility resident, who considers that facility 'home', is required to find another location to take the VAD medication because the facility objects to VAD, Victoria's VAD system is not compassionate.

  Institutional objections cause harm to the person seeking VAD in terms of their pain and suffering, and to their families, carers and friends who witness that pain and suffering, with lasting impacts on their grief and bereavement.

To ensure a compassionate and timely VAD system, Victoria must take steps to redress the power imbalances between institutions and people seeking VAD, as outlined in our responses to questions 2 and 6.

- **A further review**: Victoria was the first Australian state to introduce VAD legislation. Much has been learnt in the years since its inception. There is now sufficient experience of VAD to indicate where comprehensive changes, as outlined above, should be made to the Act.

  Our responses to other questions also highlight several serious issues in the current legislation that require thoughtful review. VAD legislation in Victoria has both bureaucratic and eligibility barriers that prohibit access to VAD by people with genuine need. In this sense, it fails palpably to provide timely, safe, and compassionate access for all Victorians.

  A comprehensive and thorough analysis is required to bring Victorian legislation up to national and international best practice standards.

- **Responsiveness and feedback**: VAD applicants should receive regular and timely communication on the status of their application and would benefit from a clear pathway for escalating complaints and/or requesting reviews of decisions.

  Feedback pathways are not clear, and we believe there is scope to improve the collection and reporting of feedback. The VAD Review Board should consider and make recommendations based on feedback received.

- **State funding for support programs**: As discussed in question 5, the Victorian government should fund VAD-specific bereavement support.

Q5. Do you think that Victoria's voluntary assisted dying systems, processes and practices meet the needs of organisations and healthcare practitioners who may be involved, or want to be involved, in supporting people who are seeking voluntary assisted dying? Please explain.

Medical practitioners' needs

The limited number of Victorian doctors willing to provide VAD is a key barrier for patients wishing to access VAD. Many doctors who are broadly supportive of VAD are not willing to be co-ordinating or consulting practitioners. Some impediments to doctors' involvement in supporting people who are seeking VAD are outlined below:

- **Remuneration**: The lack of adequate Medicare funding for VAD services is a significant issue. While we acknowledge that Medicare funding is principally a federal issue, it is important to highlight this issue as a barrier to increasing the number of medical practitioners who are willing to participate in VAD.

  The Medicare Benefits Schedule (MBS) notes specifically state that any service directly related to euthanasia will not attract benefits (GN.13.33). Services rendered for counselling or assessment about VAD will attract benefits but such services are not specifically referred to. Without an assigned Medicare number, the patient cannot receive a Medicare rebate for any fee levied by the doctor.

The time involved for doctors in relation to the VAD procedure can vary greatly, subject to the location at which it occurs, the time that the procedure is carried out, and the medical condition of the requesting individual. Even patients who are self-administering the VAD medication often prefer to have their doctor present.

General practitioners may be able to claim items relating to general professional attendances and, unlike specialist medical practitioners, can claim outside of clinical settings. Specialist medical practitioners therefore have limited options available to them when consulting with patients in their homes or other locations such as aged care facilities. However, every VAD case requires between 1 and 3 hours of work outside consultations, for which there is no Medicare payment. Whilst doctors can (and some do) charge for their time despite the absence of Medicare rebates, they are often reluctant to do so.

A DWDV board member and VAD provider has stated that, in his experience, attendance for practitioner administration of VAD medication, or to support a patient who self-administers, takes a

minimum of an hour and on one occasion over 7 hours, travel not included. As this is attendance 'for euthanasia', there is no Medicare benefit payable.

DWDV suggests that the Victorian government should advocate for the introduction of a comparable Medicare package to that of the New Zealand model that recognises the overall time and complexities involved in the VAD procedure.

- **Training**: Only 734 doctors had registered for VAD training as at 30 June 2023. Feedback from medical practitioners indicates that the current training is experienced as unduly legalistic and time-consuming and should be reviewed. Consideration should be given to providing funding support and professional development points for those undertaking training.
- **Administrative burden**: The current process involved in changing the roles between being the consulting and co-ordinating practitioner is complicated, as is the permit process, and both need to be streamlined to reduce the burden on participants.
- **Inflexibility in method of administration of VAD medication**: Self-administration of the VAD medication has been the default, with special arrangements required where the patient is physically incapable of self-administration or digestion of the VAD medication. Many doctors (and persons seeking VAD) would prefer the administration method to be a matter for the doctor and patient to determine.

  Some doctors are uncomfortable with practitioner administration of the VAD substance and view it as breaching long-held ideals and ethics. Permitting the use of a mechanism which allows the patient to self-administer, through activating the VAD medication using a doctor or nurse implanted IV line would overcome this issue. This is available in several other countries.
- **Nurse practitioners could share the load**: There is a need for more health practitioners to provide VAD, particularly in rural and remote settings. Presently doctors carry the total burden in the delivery of VAD services, while elsewhere nurse practitioners are able to share the load. In Western Australia, New South Wales, Tasmania, and Queensland nurse practitioners are permitted to administer VAD medication. The ACT's VAD Bill has made further provision for nurse practitioners by allowing them to fulfil the role of either co-ordinating or consulting practitioners with the stipulation that a medical practitioner should fulfil the complementary role to the nurse practitioner. DWDV views the inclusion of nurse practitioners in the VAD system as an important step to reduce the burden on doctors and help make VAD services more accessible.

Organisations' needs

- **Guidance on internal opposition to VAD**: DWDV is aware of situations within institutions in which staff who oppose VAD have sought to obstruct or intimidate those involved in providing VAD services. While we understand some institutions have taken steps to remedy this, official guidance on this matter is necessary.
- **Clarity on institutional participation**: Organisations would also benefit from greater clarity on institutional participation in VAD. In 2022, DWDV surveyed all residential aged care facilities (RACFs) in Victoria to create

a map showing RACFs in Victoria that support VAD. This process revealed that many RACFs were reluctant to publicise their approach to VAD, including some who were supportive of VAD, but were uncertain about whether they were permitted to state this publicly.

- **Reliance on volunteers**: VAD service delivery relies on volunteers and volunteer organisations for gaps existing in government-funded services. As discussed elsewhere, these include providing general information and support, providing witnesses and contact persons for VAD applicants who cannot provide them themselves, and funding VAD-specific bereavement support. Organisations like DWDV provide these services without charge to the applicants and without government financial support, which is not sustainable.

- **Funding for VAD-specific bereavement support services**: Organisations and healthcare practitioners involved in VAD would benefit from the development of government-funded referral pathways for tailored grief and bereavement support for the families, friends and carers of people who choose VAD. This support must be available to anyone experiencing grief associated with VAD, both before and after their loved one uses VAD.

  This tailored bereavement support also needs to be accessible outside palliative care services. Given that 20% of VAD applicants are not connected with a palliative care service (according to VAD Review Board data), this leaves some families, carers and friends of people who access VAD outside the standard pathways to access bereavement support.

  As discussed in question 2, DWDV has funded a pilot program of VAD-specific grief and bereavement support groups, currently being delivered in partnership with Griefline. However, a sustainable VAD service system cannot rely on ongoing funding from charitable / not-for-profit organisations. Service delivery of VAD-specific bereavement support must be funded by the Victorian government.

Q6. Are there any unintended consequences of the Act's current implementation? If yes, please describe.

In DWDV's view, the current implementation of the Act relies on some interpretations of the legislation that are excessively conservative or manifestly unnecessary in light of the first four years of the Act's operation. There are also some examples of unforeseen consequences of the Act's implementation that have come to light since implementation.

"Australian citizen or permanent resident"

Section 9(1)(b)(i) requires a person seeking VAD to be "an Australian citizen or permanent resident". Neither concept is defined in the Act. There are various definitions of 'permanent resident' under Commonwealth law, and Victoria's policy guidance on this topic is complex. The interpretation of these terms to require particular forms of documentation (e.g., residency certificates) has caused unnecessary trouble, and even exclusion in some cases, for people who have lived in Australia for decades, as demonstrated in the case of YSB v YSB *(Human Rights)* [2020] VCAT 1396.

These issues are compounded by the lack of a legislative mechanism to review a decision that a person is ineligible to access VAD because they cannot satisfy the 'Australian citizen or permanent resident' eligibility criterion. VCAT's jurisdiction does not extend to reviewing such decisions because the Act did not confer that power (YSB v YSB *(Human Rights)*).

The citizenship and residency requirements were included to prevent 'VAD tourism'. We are not aware of any applications being made by persons ordinarily resident overseas. Other states have provided alternative pathways for people to demonstrate that they have been ordinarily resident in Australia for a period of time before making the first request, and to allow exemptions from the citizenship / residency requirements on compassionate grounds where a person can demonstrate a substantial connection to the state.

Expertise of medical practitioners

Section 10(3) requires at least one of the co-ordinating or consulting medical practitioners to "have *relevant expertise and experience* in the disease, illness or medical condition expected to cause the death of the person being assessed" (emphasis added). Although these terms are not defined in the Act, they have been interpreted to require one practitioner to be a specialist (i.e., a doctor who has completed recognised medical speciality training) in the relevant disease, illness or condition. In fact, many general practitioners, particularly those in regional or rural Victoria, have

considerable experience and expertise in diseases such as cancer (which is the disease most likely to result in application for VAD). Such GPs often have more experience in managing end-stage disease than the relevant specialists.

This interpretation of the Act has proved extremely problematic for people seeking VAD in Victoria. Even in Melbourne, it can be difficult to find a specialist willing to participate in VAD, particularly for neurodegenerative conditions (in which case, a second specialist assessment is mandated by the Act). There are also relatively few specialists practising in regional and rural Victoria. Given the ban on telehealth consultations, people seeking VAD are forced to travel sometimes vast distances to consult face-to-face with a specialist, causing unnecessary suffering for people nearing the end of life.

Institutional objection

Institutional objections to VAD have been a significant issue in the first four years of the current Act's operation. DWDV has heard distressing stories from Victorians who have experienced or witnessed unnecessary suffering caused by such objections, including patients in hospitals and residents of aged care facilities that did not support VAD.

The Act is silent on how institutions should deal with residents or clients in their care seeking VAD on their premises. Victoria's policy approach to regulating institutional participation in VAD has failed to ensure consistent, compassionate, person-centred care for people seeking access to VAD. This approach suggests, at a minimum, that objecting institutions should provide information and support to those seeking VAD. In practice, many organisations have adopted blanket policies prohibiting VAD in their facilities.

A policy approach is inadequate where the proposed policy response conflicts with deeply held views of the targets of regulation, such as faith-based organisations like Catholic Health Australia, the largest non-governmental grouping of hospitals and aged care providers in Australia. A legislative approach is the optimal regulatory response to institutional objection to VAD. The VAD laws in South Australia, Queensland and New South Wales contain detailed regulatory provisions addressing institutional objection to VAD, which aim to balance the competing interests of individuals wishing to access VAD with those of non-participating facilities. Victoria's VAD system could be greatly improved by learning from the regulatory responses in these states.

In DWDV's view, institutions that choose not to provide VAD services should be required to publish this information on their website for the benefit of current and prospective consumers of their services. In the case of residential aged care facilities, this information is vital to enable prospective residents to make an informed choice about where they wish to live out their final years, when they may wish to have the option to seek VAD.

Telehealth prohibition

The Act did not contemplate that conversations about VAD could not legally occur via telephone, email or telehealth, as confirmed by the recent Federal Court decision in *Carr v Attorney-General (Cth)* [2023] FCA 1500. The telehealth prohibition negatively affects all people seeking VAD, but especially those living in regional and

rural areas, as discussed in question 3. We acknowledge that federal action is required to amend the *Criminal Code Act 1995 (Cth)*. The Victorian government should support federal legislative change to allow discussions and consultations regarding VAD to occur via telehealth. The Victorian government could also take immediate steps to offset the negative impacts of the telehealth prohibition.

Cumulative delays: people die waiting

Victoria's VAD process is long, intricate and arduous. The Act presupposes that individuals will have the skills and confidence to effectively navigate the health system to access VAD, but this is not necessarily the case, particularly at a time when individuals are likely to be very sick.

If people are not deterred by the length and complexity of the VAD process, they may still experience an unintended consequence of the many steps involved - that is, significant cumulative delay. These steps include:

- prohibition of health practitioners from initiating discussion of VAD, which creates a lottery for patients where some people find out about VAD much later than others (if they find out at all)
- difficulty in locating a VAD-trained doctor
- difficulty in locating a suitable specialist
- prohibition on the use of telehealth
- cumbersome, unnecessary permit process, not required in some other states (see our response to question 2)
- centralised dispensing and delivery of the VAD substance adding to delay. At present all VAD medication is dispensed from The Alfred Hospital pharmacy. While this ensures centralised control, it sometimes creates delays, particularly for people seeking VAD in rural areas. This was a particular issue during COVID lockdowns. Some decentralisation could help overcome such delays.

In some cases, cumulative delay has resulted in people being unable to access VAD despite wishing to do so, whether because they have died, become too unwell or lost decision-making capacity before completing the process. All of the above can have a bigger impact on those seeking VAD outside the major cities.

Witnessing & contact person requirements

The Act presumes that VAD applicants will be able to arrange two witnesses for their final written declaration and a contact person to return any unused medication, each of whom must meet specific eligibility criteria. It has become evident in the first four years of the Act's operation that these well-intentioned requirements pose problems for many VAD applicants, who often turn to DWDV for assistance. DWDV provides independent witnesses for VAD applicants, on a voluntary basis, and offers assistance in finding a suitable contact person. In the first four years of the Act's operation, DWDV volunteers acted as witnesses for the written declarations of 367 VAD applicants, which represents a substantial proportion of applications made in that timeframe. We are very grateful to our volunteer witnesses and contact people, who generously offer their time at no cost to VAD applicants.

However, the effective and safe functioning of Victoria's VAD system should not rely on the goodwill of DWDV and its volunteers. DWDV cannot guarantee that it will be possible to provide these services at no cost indefinitely. Demand may outstrip

the supply of volunteer witnesses. The Victorian government should recognise the valuable contribution of DWDV's members and supporters in providing witnesses and contact people to VAD applicants who cannot provide their own, and offer financial support to offset DWDV's costs in providing this essential service.

Safeguards can be barriers

As noted in our response to question 4, some of the 68 safeguards in the Act have the unintended consequence of doing the exact opposite of keeping the community safe.

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dying with dignity victoria

www.dwdv.org.au
dwdv@dwdv.org.au
0491 718 632

For media enquiries, please contact
Michelle Hindson on 0414 207 049
or email review@dwdv.org.au