Voluntary Assisted Dying Bill 2017

Introduction

The introduction of a voluntary assisted dying (VAD) framework, if passed, will reform the ways in which death and dying are viewed and discussed in Victoria.

The decisions surrounding end of life care are emotionally charged and carry a range of potential challenges, particularly those relating to communicating the needs and expectations of an individual who is approaching the final weeks or months of their life.

Recently there have been advances in the planning and delivery of end of life care, including:

- the Victorian Government passing legislation to give statutory recognition to advance care directives and more clearly align and codify the medical treatment and decision making processes for patients and clinicians;¹
- a refreshed end of life and palliative care framework;² and
- the Legislative Council’s Legal and Social Issues Committee’s (the Committee) ‘Inquiry into end of life choices’ report,³ which has recommended the introduction of a Parliamentary Bill to establish a VAD framework.

The VHA notes that there are numerous considerations to be taken into account during the preliminary consultation and drafting of the Bill. We intend on providing input to these processes from the perspective of Victoria’s public hospital and community health service providers and ensuring that issues relating to governance are scoped and included as the process advances.

The VHA is a long-term and vocal advocate for palliative care services. We believe that providing care and support to people in the terminal stages of their illness is essential, and that the current availability of palliative care services needs to be improved. Existing palliative care services remain underfunded, and a concerted effort must be adopted – irrespective of the success or failure of the proposed Bill – to improve community literacy and understanding about end of life care and its availability.

The Victorian Government has made a commitment to address the other recommendations of the Committee, which includes improved access to palliative care services, training of health professionals, community education and developing a system that ensures optimal end of life care, no matter where people are residing, for all Victorians. The VHA commends the Government for its

support, and notes that these commitments require funding to ensure their seamless implementation.

Key Issues

1. Devolved governance and conscientious objection

Victoria’s public health system is characterised by a devolved governance model, with boards of directors setting the strategic direction of each health service. The discussion paper makes clear that no doctor, health practitioner or health service can be forced to participate in VAD.

The VHA supports this recommendation, both in its application at an organisational level within a devolved governance framework, and in terms of allowing individual staff members and clinicians within a health service to elect whether or not they will participate in VAD.

Public hospitals are closely linked to their communities and the VHA believes that they are well-placed to ensure that decisions made within the devolved governance framework meet the communities’ needs.

We note that irrespective of the independence of hospital boards and their role in governing health services, powers exist within the Health Act 1988 (Vic) that allow the Minister for Health and the Secretary of the Department of Health and Human Services (DHHS) to provide written directions to funded agencies. Further discussions about the types and extent of services provided by each public hospital are undertaken and agreed to in the annual statement of priorities process.4,5,6

A potential implementation issue relates to health service staff who are conscientious objectors to participating in VAD, but are then required to provide care to a person who has had a request for access to VAD confirmed. Clarity is needed as to whether conscientious objection relates solely to the act of assessing and confirming a request, or to future interactions with a patient who has had a request confirmed.

A broader consideration extends to the application of conscientious objection within tertiary education institutions, both for staff who may be required to teach medical and nursing students how to prescribe and administer lethal drugs and doses.

2. Consultation

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4 Health Services Act 1988 (Vic) s 40B
5 Ibid s42
6 Ibid s 66A
If the Bill is successful, the VAD framework will require a major consultation with the community, health services and their staff about its implementation and the numerous implications that will flow from its introduction.

The VHA acknowledges the depth and extent of consultation undertaken by the Parliamentary Committee when drafting its report. The community and stakeholders have had opportunities to discuss issues related to VAD and end of life care when contributing to the Committee’s inquiry.

While the Committee’s inquiry recommended the introduction of a VAD framework, the consultation on the issues to include in the draft legislation has been comparatively short.

The VHA’s response at this stage of the consultation will focus on what we consider to be high priority concerns as they impact on health services. We intend to address specific implementation issues in subsequent consultations with the Victorian DHHS as the Bill is drafted.

3. Access and eligibility

The VHA believes that the specific wording of the definitions for the phrases ‘final weeks or months of life’ and ‘serious and incurable condition’ are best determined with input from the medical professions, consumers and community members.

We note, however, that each patient’s condition and illness progression is likely to be unique and as such there are inherent advantages associated with allowing some flexibility in the legislated definitions of these phrases.

The proposed framework provides a number of safeguards to exclude vulnerable patients from accessing VAD, namely that it will not be available to people with conditions that include cognitive decline such as dementia. We note that introducing legislated timeframes may have the practical consequence of excluding otherwise eligible individuals from accessing VAD.

As recommended, the VAD framework is explicitly focused on serving the needs of patients who are in the ‘final weeks or months’ of a terminal illness. In a practical application, this fails to accommodate patients who have received news of a life-threatening or terminal illness, but have not yet reached the ‘final weeks or months’ of their life. It is likely that any bold demarcation in law of accessibility to VAD will be tested by patients in this group who are seeking to ensure they have control over their lives as their conditions progress.

4. Residential aged care services

The VHA considers that the discussion paper has not sufficiently addressed issues for residents of aged care facilities who request VAD, particularly those who reside in facilities that elect not to offer access.
We ask that the interim report considers the practical application of accessing VAD for residents of aged care facilities, such as the likelihood of a higher number of staff without medical qualifications receiving informal requests about VAD and the need to systematise how these requests are treated, and the management of any VAD medication prescribed to a resident in an aged care facility to ensure other residents are protected from mistakenly swallowing the medication (such as those with wandering dementia).

It is imperative that there is a specific consultation on the implications for aged care residents and service providers.

5. Home care programs

The majority of the VHA’s members deliver home-based care of some form, either via Commonwealth Government-funded programs such as the National Disability Insurance Scheme and the Commonwealth Home Support Program, or state-based services such as Hospital in the Home.

Consideration needs to be given as to how staff delivering these services might interact with people who are seeking access to, or have been prescribed, medication within a VAD framework.

One practical consideration is the extension of the hospital care environment to the home, and how this might interact with any restrictions about where medication can be administered.

6. Proactive guidance and leadership

The legislation would need to balance a person’s access VAD services with the need to protect health services, practitioners and individuals. In this context, it is important that the Victorian Government assumes a proactive leadership role, both in setting clear standards about the quality and safety of care within a VAD framework, and ensuring there is a consistent level of information for practitioners and the public.

Feedback from VHA members is supportive of the Government’s leadership role extending to providing specific instructions about what constitutes ‘good practice’ within VAD, rather than issuing a blanket set of issues for consideration.

This could include the provision of a centralised phone line for both the community and practitioners to access information about VAD, both from the perspective of accessing care and its delivery. This service would ameliorate some of the difficulties accessing specialist advice and support that are inherent in rural communities.

7. Interaction with existing health and end of life care services

If implemented, the VHA would like to see an approach to end of life care that closely integrates all aspects of care in a holistic manner, with an emphasis on integrating VAD with other health and social support and care.
A scenario that must be avoided is one that leaves VAD disconnected from the broader range of palliative, mental health, and pastoral care provided by public hospitals to people with a terminal illness.

The VHA supports a VAD model that promotes close integration with, and connection to, the broader health, social and palliative care supports that are available from public hospitals.

8. Oversight and information

If implemented, it will be critical for appropriate oversight and review to ensure the framework is critically evaluated and continually improved.

The VHA supports the establishment of an oversight body with a specific remit to set quality standards for care, mandate reporting of activity within a VAD framework and oversee the accreditation and training of practitioners responsible for assessing requests for VAD.

The oversight body may have within its scope the delivery of support and counsel to staff who are participating in VAD. We also note that the monitoring of VAD and its various components should not be the responsibility of palliative care services.

Consideration may be given as to whether this body is established outside of the existing health system, in recognition of VAD having broad social impacts across the community.

A fundamental strength of the public hospital system in Victoria is its familiarity with performance and data reporting, and importantly with accreditation against independent standards for care and governance. Given the sensitivity of VAD, the success of its implementation will be in-part reliant on it being a robust and high quality service in which participants, practitioners and health services have confidence.

9. Responses to consultation questions

9.1. Is the existing decision-making capacity test in legislation such as the Medical Treatment Planning and Decisions Act 2016 sufficient?

The VHA submits that the existing provisions for establishing decision-making capacity within law are appropriate and can appropriately be applied in the context of VAD.

9.2. In what circumstances should a psychiatric assessment be required? Are there any other specialist referrals that would be appropriate?

The VHA does not support a requirement for all VAD requests to undergo a psychiatric assessment. We note in particular that specialist psychiatric services are limited in rural Victoria, and requiring all individuals whose decision-making capacity has been confirmed to
undergo an independent assessment would, in practice, introduce another barrier to accessing care.

We do note, however, that the rate of diagnosed and undiagnosed depression is high in this particular patient population, and it may be unclear if undiagnosed (and therefore, untreated) depression has had an influence on the person’s decision-making. Safeguards must be in place to ensure there is adequate treatment available for any identified depression or related illness.

In our engagement with our members, one metropolitan health service suggested that practitioners should adopt a lower threshold for referring patients to psychiatrists. The health service proposed that doctors could provide an affirmative certification that the person is not affected by mental health issues, to the extent that such issues would affect their decision making capacity.

9.3. Is greater specificity required to identify what constitutes a person being at the end of life and, if so, how should that specificity be worded?

Our response covers this consideration earlier in this submission, however in summary: the VHA submits that broad definitions within the act may be advantageous given the need to address each request for VAD on its merits and in the context of the individual person.

9.4. How should a ‘serious and incurable condition’ be defined?

The VHA considers the terminology and definition of ‘serious and incurable condition’ is primarily a clinical and consumer discussion, as such we believe the medical professions and consumer representatives are better placed to provide detailed input.

We do note, however, that a clear and consistent understanding of what constitutes these terms is necessary.

9.5. What safeguards are necessary to ensure that a request is voluntary? How should this be assessed?

Identifying circumstances where coercion or undue influence has occurred will be an important safeguard for individuals, family members and the prospective VAD framework more broadly. There is a risk that incidents of elder abuse and other forms of family violence could interact with requests to access VAD. Extreme care must be taken to ensure potential incidents are identified and support is made available to victims.

As discussed earlier in this submission, a significant onus is being placed on the assessing doctors to not only respond to the patient’s VAD request, but presumably to assess if the request is voluntary.

Not all health professionals are practiced or familiar with having discussions about end of life issues with their patients, nor about the prevalence of family violence in its various forms.
Regardless of whether the VAD Bill is passed and implemented, there needs to be a strong emphasis on training and supporting health professionals to conduct these discussions, and to ensure community knowledge of end of life care is improved.

One possible means of providing assurance of voluntariness is to include an affirmative assessment in each independent response to a VAD request. This assessment could be informed by consultation with health service staff experienced in identifying influence, coercion or elder abuse and family violence.

9.6. **Should there be a prescribed time period that must pass between the first and final request and, if so, what period?**

The VHA acknowledges the benefits of a ‘cooling off’ period between the first and final request for VAD, but submits that if mandated, any period should be short rather than long.

A number of pre-conditions for accessing VAD are in place and additional requirements placed on patients will only act as barriers to care.

A VHA member provided the following comment:

_The patient’s interests need to be paramount and patients in the terminal phases of their illnesses might lose capacity in a short time, due to the illness or the side-effects of analgesia. If analgesia is ineffective or partly effective, then a timeframe would simply extend the period of time during which the patient is required to endure the unendurable._

9.7. **Should there be specific offences for those who fail to comply with the requirements in the Act or are the offences of homicide or aiding and abetting suicide appropriate and sufficient?**

The issue of legal protections for the patient and health services and staff are critically important. The VHA suggests that a ‘good faith’ defence must be in place for doctors and staff working in participating health services.

Additionally, we note that in the context of the discussion paper the application of penalties could apply to relatives and friends of patients who are found to have coerced or influenced the decision-making of a patient requesting VAD.

The VHA recommends that the interim report, final report and Bill make clear the distinction between offences that apply to practitioners who may support VAD requests, and those of family members of people who are requesting access to VAD.
9.8. **Should the legislation include prescribed information that a medical practitioner must provide to a person requesting voluntary assisted dying and, if so, in the list recommended by the Parliamentary Committee sufficient?**

The VHA agrees there should be a standardised minimum set of information provided to a person requesting VAD. The VHA considers that the Parliamentary Committee’s list is appropriate.

9.9. **What resources should be developed to support legislative obligations to provide information that would be useful in practice?**

As discussed earlier in the submission, the VHA recommends that the Victorian Government assumes a proactive leadership role in setting minimum quality standards for VAD, which could include accessible information about the legislative requirements prescribed by the Act.

We note that consumer literacy as to the availability and processes involved in initiating a request will be critical.

9.10. **Should the legislation prescribe specialist expertise required for medical practitioners to participate in voluntary assisted dying?**

The VHA notes that many medical practitioners may not have the mix of broad and specialised experience required to accurately assess VAD requests, to confirm decision-making capacity and identify potential cases of influence and coercion.

This is not necessarily a risk, but highlights the onus that is potentially being placed on two individual doctors. As noted in the discussion about referral to specialist psychiatric assessments, the legislation could consider encouraging doctors to adopt a low threshold for seeking appropriate specialist advice and input.

There may be scope to prescribe an accreditation requirement for doctors to participate in VAD.

A submission from a metropolitan health service recommended that any doctors participating in VAD must have had at least five years of practice (after registration) before being allowed to assess requests.

9.11. **Should there be a requirement for a palliative care specialist referral or consultation?**

The VHA supports the role of palliative care in the Victorian health system and has been a strong advocate for its expansion and growth.
We do not want to see an end of life care framework that facilitates VAD being requested and delivered in a way that fails to integrate it with other parts of the health system, including palliative care services.

We note that patient consultation and engagement with palliative care services is of the most value when undertaken well before a decision to undertake VAD becomes necessary.

In all cases for people approaching the end of terminal illness, the VHA submits that a person’s access to health, social and end of life care must be protected and preserved, irrespective of having made a request to access VAD.

9.12. **Should health practitioners who conscientiously object be required to declare their objection? If yes, when should this occur?**

The VHA’s membership consists of health services as entities, and as such we restate our support for health services to decide whether they will participate in VAD, which is consistent with Victoria’s devolved governance framework.

We believe that health services that object to providing VAD should make this objection clear in a way that is clearly communicated and understood.

A metropolitan health service member of the VHA proposed an approach whereby practitioners who object to participating in VAD should make their objection known to colleagues and patients as soon as that objection becomes clinically relevant.

9.13. **Are additional safeguards required when a medical practitioner administers the lethal dose of medication and, if so, what safeguards would be appropriate?**

The VHA acknowledges that the intent of a VAD framework is to allow persons to self-administer a lethal dose of medication, and that in some cases a person may not have the capacity to self-administer.

Feedback from VHA members recommends that in cases where a medical practitioner is required to administer a lethal dose of medication, there should be an independent witness to confirm that the patient has voluntarily consented to the administration of medication at all stages of the process.

The VHA notes that there may be situations where a medical practitioner is supportive of VAD and is willing to provide assessments and recommendations, but may be unwilling or unable to administer a lethal dose of medication.

In situations such as this, the needs of the individual should remain paramount, and there should be scope to refer the person to a doctor who is prepared to administer a lethal dose of medication.
9.14. Where should a medical practitioner administer the lethal dose of medication, and what practical and other challenges would this create?

The VHA notes that moving a patient to a different setting to facilitate a medical practitioner administering a lethal dose of medication may not always be practical.

Irrespective of the setting, the administration of medication and the person’s consent at all stages should be witnessed.

9.15. Should a health practitioner be allowed to be present at the time the person self-administers the lethal dose of medication? If so, what should their role and obligations be?

The VHA acknowledges that many people approaching the end of their lives establish important relationships with their doctors and carers, and in some cases may be comforted by their presence at the time of self-administration. We also acknowledge that some practitioners may not be comfortable with accommodating a request to be present at that time.

If health practitioners are restricted from being present at the time a person self-administers a lethal dose of medication, a practical implication will be the broad exclusion of health services as a setting for VAD.

As such, the VHA believes that there are no reasons to restrict practitioners from being present at the time when a lethal dose of medication is administered.

However; a practitioner’s presence raises some potential concerns, particularly in instances when the lethal dose is not effective, or if a patient vomits the medication before it is absorbed.

Provisions may exist in a patient’s advance care plan as to their preference for resuscitation (or not); however these considerations should be understood and mutually agreed in advance of self-administration, and any practitioners present in a professional capacity be suitably indemnified.

9.16. What should be recorded as the cause of death for a person who has ingested the lethal dose of medication?

Advice from VHA members is; if the regime operates as it is intended and a patient accesses VAD when in close proximity to death, it is preferable that the primary cause of death be recorded as the underlying disease.

This consideration is important from the perspective of maintaining robust and useful population health records, and facilitating ongoing research into disease incidence and prevalence.
Consideration may be given to recording the assisted dying process as a secondary factor.

9.17. **Should death as a result of VAD be a reportable death?**

As discussed earlier in the submission, the proposed oversight regime will need to have a clear understanding of how the VAD framework is operating in practice, including information about requests for VAD, assessment outcomes, including those that have been declined, medication prescribed and deaths that have as a secondary factor, VAD.

Consistent with the VHA’s recommendation that the cause of death be attributed to a person’s underlying disease or illness, there should be caution about requiring coronial investigation for all deaths that occur as a result of VAD.

The current categories for reportable deaths in Victoria include those where the death appears to have been unexpected, unnatural or violent, or to have resulted, directly or indirectly, from accident or injury; and where a death occurs during a medical procedure, or following a medical which is causally linked to the death AND a medical practitioner would not, immediately before the procedure was undertaken, have reasonably expected the death.\(^7\)

The VHA notes that neither of these categories immediately apply to deaths within a VAD framework, except in cases when the cause of death is unclear or a death certificate has not been signed by a doctor.

In instances when the cause of death is unclear, there may be scope to involve the Coroner via its existing processes as they relate to reportable deaths, but this should not be the norm for all deaths whose cause is known to be as a result of VAD.

We strongly support the broader principle of a transparent oversight body that reports de-identified information about VAD, however care must be taken to ensure that duplicated data submission and double-handling by different agencies is prevented where possible.

**About the VHA**

The VHA is the not-for-profit peak body supporting Victoria’s public health services to deliver quality care. We represent public sector health services, hospitals, registered community health services, multi-purpose services, and bush nursing services.

Our members provide care across the entire spectrum of health, aged care and social services in all Victorian communities and regions. Many are already funded to provide specialist end of life care, while others are closely involved in the care of patients who are approaching the end of their lives.

While we represent our members’ views as a sector, we acknowledge that there may be different views expressed by individual members.

As such, we note that this submission should not be seen as overriding those made by any of our members.

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