



# **Voluntary Assisted Dying Bill**

## **Submission**

**Prepared by  
COTA Victoria Policy Council**

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## COTA Victoria

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COTA Victoria acknowledges the contribution of its members' expertise and lived experiences through our end of life working group, Policy Advisory Committee and volunteers.

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## Introduction

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COTA Victoria welcomes the opportunity to contribute to the development of a compassionate, transparent and accountable legislative framework for Voluntary Assisted Dying. We also recognise there are areas within the discussion paper which are best resolved through regulations and guidelines and should not be placed within legislation.

As an organisation that represents the concerns and policy issues that impact on older people, end of life issues is a policy priority for COTA Victoria's work.<sup>i</sup> As stated in our submission to the Parliamentary Inquiry into end of life choices, COTA supports innovation, reform and investment in end of life and palliative care. COTA Victoria's board supports choice in end-of-life decision-making and the development of a legal framework that respects individual autonomy with safeguards against abuse for those that are vulnerable.

### Who we speak for

Members of COTA Victoria's board, policy advisory committee, interested staff and recently formed end of life working group have come together to consider the development of a compassionate and safe assisted dying framework. Our working group consists of older people who have volunteered as peer educators in our palliative care community education program, COTA Victoria members that have trained as facilitators to support COTA's dying to talk events and more broadly older people that have expressed a passionate interest in participating in discussions on end of life choices. Our volunteers bring years of experience as educators, nurses, and most importantly the lived experience of supporting and caring for a partner, parent or child who has died as result of a life limiting illness.

### COTA's role

Older people contact COTA for support, information and referral advice on a range of end of life issues. Many share their experiences as carers for their elderly parents and their experiences of end of life care and options. We receive requests for information and education sessions on planning ahead, talking to children about advance care plans, powers of attorney, wills and funeral information. We run a peer education program in partnership with Palliative Care Victoria on understanding end of life and palliative care. Older people expect COTA to advance and advocate for their dignity, to be treated with respect and their personhood and identity to be understood within a human rights framework.

### Our approach to discussion paper

Guiding principles and values provided an important touchstone in responding to the discussion paper.

In respecting the diversity of views and values on voluntary assisted dying, we referred to the guiding principles and values outlined by the Victorian Legislative Council Standing Committee on Legal and Social Issues Parliamentary Inquiry into End of Life

Choices. These included: valuing human life and the quality of life until death; relief from pain and suffering; the critical role of palliative care; patient centred care and informed decision making; safeguards and protections for people who are vulnerable and health practitioners; equality of access and support for carers and loved ones; clear and transparent laws that support end of life planning, decision making and the rights and responsibilities of all involved in end of life care.

We also took note of the *Ethical Principles and Associated Goals* by the Joint Centre for Bioethics, University of Toronto.<sup>ii</sup> These were developed to guide the implementation of physician-assisted dying (PAD) in Canada as a result of the unanimous *Carter* decision.<sup>iii</sup>

Our submission contributes the views of older people on issues of **eligibility, access and safeguards**, as it relates to the *Practical considerations in creating a compassionate and safe assisted dying framework*. The specificity required in answering the discussion paper questions means we have responded to the level of detail we feel able to make informed comment on.

We commend the work already undertaken by the Parliamentary Inquiry into End of Life Choices and the Ministerial Advisory Committee on Voluntary Assisted Dying. We welcome this opportunity to contribute and engage our members on this important policy area for end of life choices.

## SECTION 1 ELIGIBILITY

### 1. The Person

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

COTA believes the decision-making capacity test in the *Medical Treatment Planning and Decisions Act 2016* is appropriate and sufficient.

It should also be recognised that decision-making capacity is specific to the decision being made. This may fluctuate as a result of medication and environmental factors. This needs to be taken into consideration when assessing a person's making capacity.

#### **1.2 In what circumstances should a psychiatric assessment be required?**

The discussion paper outlines the four-part test for assessing decision-making capacity. Where there are concerns a person is demonstrating a lack of capacity to make informed decisions then an appropriate specialist referral for assessment should be required. Other circumstances include when:

- A person is expressing a request for Voluntary Assisted Dying (VAD) that conflicts with a previously held view or document such as an Advance Care Plan where a direction for medical intervention is requested or
- A person is not able to explain a change of view or where there may be grounds to believe the person is being coerced or is under pressure.

COTA notes that an individual might express feelings of depression that is proportionate to their health situation. This should be differentiated from clinical depression that may impair judgement. Medical practitioners are trained and should be competent in identifying when it is appropriate to refer an assessment or additional opinion. For example in circumstances where fluctuating capacity is due to medication and treatment, a specialist may better identify this.

A psychiatric assessment should only be considered in circumstances where the assessing medical practitioner identifies mental health concerns.

#### **1.3 Are there any other specialist referrals that would be appropriate for assessing decision-making capacity?**

Medical practitioners need to be aware (and trained) on informed decision making and ageing related 'assumptions' (*sic* ageism). For example, hearing and visual impairment should not be viewed as incapacity to make informed decisions.

*Capacity as a concept is fluid and decision-specific. Each transaction must be considered in relation to its particular character and circumstances.*<sup>iv</sup>

Where an older person is demonstrating signs of cognitive decline, referral to a neurologist/geriatrician may be appropriate. Clinical psychologists are also trained in assessing decision-making capacity.

## 2. Access and eligibility

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### Comment

The question of access and eligibility to VAD disproportionately impacts on older people. Statistics from overseas jurisdictions show that people between the ages of 65 – 75 are most likely to access VAD as a result of unbearable pain and suffering.<sup>v</sup>

We are aware of the evidence from those jurisdictions where VAD operates that loss of independence and autonomy features as a dominant precursor to requesting access. COTA members discussed the impact of limiting access to the final weeks or months of an illness for people with chronic and slowly debilitating diseases such as Alzheimer's, motor neurone and kidney disease. There was recognition across all viewpoints that dignity, personhood and autonomy in these circumstances will not be addressed through the following eligibility recommendation.

### ***2.1 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?***

It was the view of some members that 'end of life' should be broadened to include 'end of independence and autonomy'. Their concern was to enable a person who suffers from a disease which is a "serious and incurable condition causing enduring and unbearable suffering" that will inevitably lead to loss of competence as a direct result of the disease, to have access to the legislation at a point where they are competent.

Ideally, a consistent definition across all policies and health systems and legal frameworks on what constitutes 'end of life' should be possible. From an implementation and social reform point of view we recognise the need to specify eligibility less than twelve months.

### Comment:

A number of members expressed the view that eligibility to VAD should be broader than the recommendation made by the Parliamentary Committee as it excludes diseases and conditions where an individual loses decision making capacity.

COTA has sought to define end of life in a way that respects a range of views whilst reflecting the challenges of prognostication. There was general agreement within COTA Victoria's end of life working group that the question: "would I be surprised if this person died within the next six months?" acknowledged the challenges of a precise timeline.

A prognosis of no more than six months to live is also used in the jurisdictions of Oregon and Washington.

## **2.2 How should a 'serious and incurable condition' be defined?**

COTA strongly supports the individual person assessing what is tolerable and what is unbearable. No other person can determine this. This is central to person centred care and consistent with the principle of autonomy.

### **Recommendation**

COTA supports the following definition:

*Suffering from a serious and incurable condition which is causing enduring and unbearable suffering that cannot be relieved in a manner the patient deems tolerable.*

The Parliamentary Inquiry definition of "serious and incurable condition' is sufficient as it sits alongside "at the end of life... and causing enduring and unbearable suffering". This is strongly supported by older people that we consulted with (two meetings with peer educators and COTA volunteers).

*I feel that the individual person knows how much they are suffering and when it has become intolerable and when they should be assisted in their wish to die' (Isobel, 70's)*

### **Comment**

COTA acknowledges the language - 'grievous and irremediable condition' – whilst emoting greater pain and suffering than 'serious and incurable', provides the same eligibility scope. "At the end of life" could be replaced with "where the inevitable outcome of the disease is death" – but once again, the eligibility criteria (as described above), provides a clear definition.

## SECTION 2 REQUEST PROCESS

### 3. Making a request

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COTA supports the Parliamentary Committee's recommendation that the ***Request must come from the person themselves and be voluntary and free of coercion ... and must be enduring (P8)***

#### **3.1 What safeguards are necessary to ensure that a request is voluntary? How should this be assessed?**

a) The request procedure as outlined by the Parliamentary Committee provides the following safeguards: an initial verbal request followed by a formal written request signed by two independent witnesses and a final verbal request. This is defined as enduring and made voluntarily.

b) An independent witness excludes family members or anyone where there is conflict of interest, either real or perceived. Even where witnesses do not actually benefit from the death they may be perceived to do so.

Each independent witness must be able to verify the voluntary nature of the request and sign a statement that no persuasion or coercion was used in the signing of the document. The patient will be informed that they are under no obligation to act on their request and can decide not to proceed at any time.

c) An individual has the right to a support person being present throughout the request procedure. The support person would be in addition to the two independent witnesses. They cannot speak for or on behalf of the person requesting access to VAD. It may be more relevant to place in regulations the role of a support person during this process.

d) There should be specific offences for failing to comply with the Act. This would give greater public confidence in the process and it is still up to the legal system how each case is dealt with.

Other considerations:

- Any **additional safeguards** must respect the personhood and capacity of the individual to make their own decision. Safeguards should not place unnecessary barriers to access or prolong suffering.
- Where an individual requires an **interpreter** to express their request, only accredited and independent interpreters should be used. The processes required to set this up requires the involvement of those services in developing appropriate guidelines.

- Where someone lives in **aged care or supported accommodation**, a health or allied health professional may qualify as the person receiving the initial verbal request. The assessment regarding eligibility and informed consent would then take place with one of the treating doctors. Once again the processes required for location specific circumstances need to be resolved through regulations or guidelines with those services.
- **Support, counselling and palliative care** (if not already accessed) need to be offered at the initial request stage. The opportunity to discuss this choice must be offered alongside the enduring request process.

*Comments on practice safeguards by COTA members:*

Upon the first request, an offer is made of appropriate emotional, spiritual/existential support. This is not to persuade for or against acting on the request but to support the processing and impact of this decision. This could be a psychologist, social worker or grief and bereavement worker. It was also suggested that a counsellor specialising in end of life should be part of the assessment process (to ensure the existential trauma of end of life is supported) if wanted.

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

The question of a prescribed time period was understood from a number of viewpoints. Firstly as a limited timeframe that could inadvertently place pressure to 'use' medication within a period of time. Secondly to create time between steps in the request process to test the endurance of the request and ensure it is well considered and not rushed. On both these counts, it was felt that when someone is diagnosed with a life-limiting serious and incurable condition, most people would take the required time to consider whether they may or may not access and implement voluntary assisted dying.

If the enduring request process (as defined earlier) were followed, there would be the practical time taken to respond to the first two requests and the assessment of competence. This would usually take some days to organise.

A third and important viewpoint is that there should not be unnecessary delay as this could cause further pain and suffering.

**Recommendations**

a) There should be practice guidelines on what constitutes a timely and sensitive response to the initial request to access VAD. The individual needs of the person should be considered.

b) There should be no prescribed period for the implementation of the request once the request for medication has been approved. At the time the medication is given to the patient for self-administration the health practitioner/doctor should make it clear that there is no time set for administration and the patient can change her/his mind without any consequences.

c) The length of time between steps in the process should be captured in information provided to the VAD Board for future review and research.

### **Comment**

We note that Oregon and Washington have recommended a minimum waiting period of fifteen days between an initial and second verbal request. A further forty-eight hour time period is then required between the written request and the prescription being provided. If any benchmark is set regarding timeframes, this should be subject to review and evaluation. Importantly, it should not extend someone's pain and suffering or jeopardize access if there are concerns that the person is losing cognitive capacity and therefore eligibility.

***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 or abetting suicide appropriate and sufficient?***

### **Recommendation**

COTA supports the development of specific offences.

New legislation provides opportunities for education on obligations and responsibilities for those that will be directly involved in VAD. It would also promote greater community awareness of the safeguards.

### **Comment**

Doctors are currently protected from prosecution where compassionate care and pain management is practiced in end of life care. We do not want to see the doctrine of 'double effect' come under such scrutiny as to change 'compassionate care' and pain management by doctors.

## 4. Properly Informed

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**Older people want clear, direct information about their state of health, treatment options and likely consequences – particularly the impact on quality of life<sup>vi</sup>.**

Research supports the difficulty many doctors experience in communicating to patients about their prognosis, treatment options and likely consequences. This is particularly evident in communicating with people from culturally and linguistically diverse backgrounds.

*Doctors report struggles with conducting effective EOL conversations with all patients and especially with those whose ethnicity is different from their own. It is vital to identify strategies to mitigate barriers doctors encounter in conducting effective EOL conversations with seriously ill patients and their families.<sup>vii</sup>*

Quality of life (as defined and valued by the person dying) should direct what decisions they make. But this requires good communication skills on the part of the medical practitioner – not discretion. The role of trained social workers or psychologists in providing information and supporting the person to ask questions should be addressed through the guidelines and implementation processes.

**4.1 Should the legislation include prescribed information that a medical practitioner must provide to a person requesting a voluntary assisted dying and if so is the list recommended by the Parliamentary Committee sufficient?**

### Recommendations

- a) COTA Vic supports the Parliamentary Inquiry’s recommendation to provide guidance for health practitioners and services on properly informing the person.<sup>viii</sup> We do not think the Parliamentary Committee’s recommendation is too prescriptive to place within separate legislation. The more detailed version provided in the VAD discussion paper from the Vermont *Patient Control at End of life Act* is repetitive, potentially persuasive and too directive.
- b) In addition to the Inquiry’s recommendation we believe detailed guidelines should be placed within regulations as we recognize this can be more easily amended in the development of best practice.
- c) Information needs to be provided verbally and in writing in the person’s first language. This provides an additional safeguard for both patient and medical practitioner.
- d) If patients have not accessed palliative or hospice care, they should be provided with clear and direct information on the benefits and aspects of receiving end of life care regardless of their decision on VAD.
- e) “No obligation to ingest medication” must be stated at each stage of request and as part of the informed consent process.

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

### **Recommendations**

a) Alongside legislation and/or regulations, supporting resources need to be developed for medical practitioners in consultation with relevant health organizations. These should reflect best practice development and be subject to ongoing review and improvements.

b) Information for patients regarding giving informed consent should include what questions to consider asking; informing patients and medical practitioners of the obligation on practitioners to answer honestly and be aware of the ‘providing hope bias’ and how to step through the Conscientious Objection process if a practitioner is unable to provide clear and non-judgmental information on VAD.

c) Resources for people need to be developed in plain and easy English and accredited translations in community languages including Auslan. This includes print, video, audio, webinars, templates and likely questions.

### **COTA Vic recommends additional resourcing for community and health professionals, including:**

- The establishment of a ‘hotline’ and telephone information service for members of the community (including family, friends and cares) and the health professional.

This should be set up within the Assisted Dying Review Board to enable information to be used to assist the Board in reporting and reviewing.

- The development of peer education programs and community outreach for older people, culturally and linguistically diverse communities, people with disabilities and other groups that are identified as vulnerable and hard to reach.
- Ongoing professional development and accreditation for health practitioners.

## ***4.3 Who should undertake the assessments and provide information?***

### **Recommendation**

COTA Vic supports the Parliamentary Inquiry’s recommendation that two medical practitioners independently undertake the assessment and provide information to a patient both verbally and in writing. This includes the following parliamentary recommendation:

- The person will have a written copy of their assessment, including their diagnosis, prognosis, treatment options, palliative care and likely results.
- The person will also be informed of probable results and risks of taking the lethal drug and are informed at each stage of the assessment of the option to withdraw or rescind their request for VAD.

## 5. Confirming a request

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

#### **Recommendations**

a) COTA does not believe there should be prescriptive requirements about the qualification for medical practitioners to participate in voluntary assisted dying in legislation.

Whilst we support training and professional development in respect to understanding obligations, informed consent and procedures required, we believe that general practitioners should be able to provide access to VAD. This is particularly relevant in rural areas. The scarcity of specialists and the requirement that both primary and secondary doctors be qualified in respect to the patient's specific condition places significant and unnecessary barriers to access.

b) Medical training should include training in obligations and duties under VAD legislation. Training packages will need to be developed for those already practising.

c) The commencement of legislation will need to provide enough time for workforce skill development and confidence in the operation of the legislation.

d) As stated under question 4.2, access to an appropriate information hotline and resources would provide important support and a checklist to GP's and specialists.

#### **Comment**

Balancing safeguards without placing unnecessary barriers to access is central. Communication, empathy, duty of care and an understanding of legal obligations is central to professional practice in end of life care.

### ***5.2 Should there be a requirement for a palliative care specialist referral or consultation?***

#### **Recommendation**

If someone has not accessed or been referred to a palliative care specialist, there should be the requirement to provide information on the benefits of palliative care. However, it should not be compulsory to take up a referral to a palliative care specialist. A person should also be informed they can receive palliative care while they access VAD. One does not negate the other.

## 6. Conscientious objections

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No one should experience barriers to accessing VAD as a result of a service or medical practitioner holding a conscientious objection. Equally, no service or medical practitioner should experience negative consequences as a result of expressing a conscientious objection.

Quality end of life care should be provided up until death regardless of whether a person requests access to VAD or not.

This should also be stated in the preamble to legislation.

### Comment

The *Abortion Law Reform Act 2008* states a health practitioner who consciously objects to abortion must refer the woman to a health practitioner who does not have a conscientious objection.

Unfortunately there is evidence that this does not happen in reality. We are therefore concerned about the process for referring people to other doctors. In responding to the discussion paper's questions, we also considered: *What additional protections are required to ensure that when someone conscientiously objects they fulfil their duty of care? How can the legislation ensure there is not a disproportionate burden on those that do not conscientiously object?*

### 6.1 How should conscientious objection to VAD operate?

#### Individual practitioners

##### Recommendation

A medical practitioner has the right to express a conscientious objection to participating in or providing VAD. This must be communicated to the person as early as possible.

##### Comment

COTA members raised the issue of the potential impact of a pharmacist expressing a conscientious objection in rural locations with limited dispensing options.

#### Health services

##### Recommendations

- a) Health services with a conscientious objection must provide written information on how they intend to communicate this to people using their service and receiving care. There should also be a written statement that includes referral processes for supporting people to access VAD at an alternative service.
- b) Whilst services may conscientiously object to providing voluntary assisted dying they should not be able to prohibit their staff from providing information on accessing VAD nor prevent them from providing assisted dying services in another setting. To do so must be considered a severe breach of duty of care with a proportionate response.

c) All services whether they conscientiously object or not must sign up to a protocol regarding duty of care in referral and continued support for end of life care. A request for VAD should never result in cessation of end of life care. Conscientious objection by a service can only be expressed as the **place** where voluntary assisted dying occurs. An individual is entitled to continued palliative care or hospice care until they decide to take lethal medication.

#### **Comment**

COTA Victoria views end of life care as a continuum where VAD may be accessed and then possibly followed through – or not. Transferring people from hospice and palliative care services in their final weeks of life because they wish to access VAD, compromises quality end of life care.

The greatest area of impact is in aged care and supported living where older people are dependent on the care they receive.

#### ***6.2 Should health practitioners who conscientiously object be required to refer patients to other health practitioners?***

#### **Recommendation**

- a) Health practitioners who conscientiously object should be required to refer patients on. A patient should not have to source an alternative health practitioner.
- b) Expressing a conscientious objection means declaring their preference not to participate in VAD. All health practitioners, regardless of their views on VAD, have a duty of care to provide access to information and to refer on.

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

A person should be informed they can ask their doctor or health practitioner at any time for their position on VAD. A doctor that objects to implementing VAD, may still decide to provide information and participate in the assessment process.

#### **Recommendations**

- a) A health practitioner must declare their objection as early as possible in the provision of care when a person has been given a life limiting diagnosis. Where possible, a person must be informed prior to someone making a request.
- b) Health services must declare whether they hold a conscientious objection to VAD or whether the service leaves this up to individual health practitioners. In these instances, individual doctors must inform their patients and refer to another health professional that does not have a conscientious objection.

### Comment

Health practitioners should be encouraged to seek training and guidance on VAD before articulating a position.

With the implementation of legislation, health practitioners should consider how their views might form with further information, training and exposure to the issue and patients requesting access.

## SECTION 3 OVERSIGHT & SAFEGUARDS

### 7. Administering a lethal dose of medication

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

#### Recommendation

Self-administration of a lethal drug is a safeguard and reflects the decision is voluntary. In those rare instances a person is not physically able to self-administer, a medical practitioner should be able to assist – as recommended by the Parliamentary Committee.

In medical conditions where there is the possibility of medication not being swallowed or mal-absorption, then alternatives to oral administration need to be available and also medically supervised.

Where a health or medical practitioner is administering medication a final consent process may be required. A recognized witness (preferably another health practitioner) could ensure final protocols are followed and that the medication was taken voluntarily.

**7.2 Where should a medical practitioner administer the lethal dose of medication and what practical and other challenges would this create?**

As the VAD discussion paper notes: *The needs of each person accessing assisted dying will be different and it is not clear that prescriptive requirements in legislation would be appropriate.*

#### Recommendations

- a) Consideration to the time and place is not practical to put into legislation.
- b) If the person is not physically able to self-administer there needs to be flexibility in responding to their individual circumstances. This might involve health practitioners, trained in assisted dying, being present at the person's home or at a hospital or hospice.

#### Comment

Nurses are the front line of the health system and considered more skilled in communication and in the practical use of starting an IV or giving an injection. As one Intensive Care Specialist commented at a consultation on VAD:

*It's been over ten years since I set up an IV or gave an injection... I know who I would rather give me an injection ... and it's not the Doctor.*

## 8. Monitoring the use of a lethal dose of medication

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### ***8.1 How can a prescribed lethal dose of medication be effectively monitored without placing undue burdens of pressure on people accessing or using the medication?***

It is not possible to have legislation that covers all risks and all circumstances. The Californian model of requiring the completion of a form and having this available is the least burdensome requirement. The provision of this form would also alert authorities that someone was intending to take lethal medication.

#### **Other issues:**

There are a number of competing needs in monitoring the use of a lethal dose of medication, including:

- Tracking the request and use of medication (or not) in order to evaluate and review current processes for safety, oversight and access.
- Reporting breaches of processes
- Ensuring the safe disposal of unused medication
- Building an evidence base and supporting research into the impact of introducing VAD on end of life care.

#### **Comment**

The question of why pharmacists are not mentioned in this section was raised. Their role in dispensing and registering scripts is part of providing oversight. Pharmacists may also be able to provide medication in areas where medical practitioners are not able to deliver the medication. Their involvement would need to be reported to the Review Board. We raise this as an area for consideration.

## 9. Attendance

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### ***9.1 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 purpose of introducing legislation is so that health practitioners and anyone present during self-administration is not subject to criminal or civil liability.

If a person requests a health practitioner to be present their role is one of support person and observer. There should be no other obligations.

A medical practitioner who is present when the person self-administers medication, should take the usual steps in disposing unused medication.

### **Comment - if someone is alone:**

There is a duty of care to provide dignity, respect and support– until the end of life. A health practitioner or a VAD ‘support person’<sup>ix</sup> should be offered to be present during self-administration. This provides oversight, additional safety and follow-up to post death requirements.

## **10. Lethal dose of medication not effective**

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In those rare instances where self-administration is not effective then the health care practitioner should provide palliative care only and not attempt resuscitation. If a form were available this would explain the situation to any practitioner called on. (Refer to point 8).

## **11. After a person has died**

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### ***11.1 What safeguards are necessary to determine whether or not the person has ingested the lethal dose of medication and to destroy the medication if it has not been ingested?***

There needs to be a form signed by the person who intends to self-administer and at least one other person present to witness this.

After a person has died, the usual process for disposing of medication after death should be followed. If a person dies without using the medicine, this information needs to be captured along with confirmation on the disposal of the medication by the medical practitioner who signs the death certificate.

### ***11.2 What should be recorded as the cause of death for a person who has ingested the lethal dose of medication?***

#### **Recommendation**

The disease should be listed as the cause the death. There is no need to record VAD on the death certificate if there is provision for the health professional to report each case to the AD Review Board. This could be done through a separate form.

### ***11.3 Should death as a result of VAD be a reportable death?***

A death as a result of VAD would be reported to the AD Review Board for monitoring and review but not as a death to be investigated by the Coroner. VAD would only become a reportable death if it were clear the process was not followed.

If a VAD form such as that used in California is accepted, the information will be captured on this form.

## 12. Oversight of VAD

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### ***12.1 What information should a medical practitioner be required to report to an oversight body such as the Assisted Dying Review Board?***

The Parliamentary Committee recommended an Assisted Dying (AD) Review Board be established to review the actions of medical practitioners.

#### **Recommendation**

COTA supports the Oregon model outlined in the VAD discussion paper as it provides oversight and records requests, prescriptions, dispensing, use of lethal dose and disposal of medication when not used.

The medical practitioner who received the written request should provide a copy of the signed and witnessed request to the AD Review Board at the time it is completed together with a brief summary of the patient profile and reasons for the request.

#### **Comment**

COTA believes that ‘medical practitioners’ should be expanded to ‘health practitioners’ so as to include nurses and where appropriate pharmacists and paramedics. All professionals participating in VAD will be required to report to an oversight body.

Further questions came up for COTA: What additional information should be collected to support responsible research, evidence, quality assurance and standards in improving procedures and processes of VAD?

### ***12.2 At what stage should medical practitioners or pharmacists be required to report to the Assisted Dying Review Board?***

#### **Recommendation**

A medical practitioner should report to an AD review board within seven days of writing a prescription. Similarly, pharmacists should notify the AD review board within seven days of dispensing a script for lethal medication.

### ***12.3 When should an oversight body be required to refer a matter to another agency?***

#### **Recommendations**

a) COTA is concerned with the efficient use of public resources, preservation of community confidence and avoiding duplication of cost and effort. Clearly allegations of breach of law or criminality should be referred to the Police at the earliest stage. Allegations of breach of ethics or malpractice or discrimination, after initial enquiries into their substance, should be referred to the relevant bodies established to investigate such allegations such as professional practice bodies or review bodies.

b) When trends or practices are identified that point to a need for further training or clarification regarding implementation of the framework.

***12.4 Should an oversight body have any investigatory powers, or should this be conducted by other agencies?***

**Recommendation**

The AD Review Board should investigate only to the point where it can determine whether a matter requires investigation. It should not duplicate the work of other bodies such as the Police and Medical Practitioners Board. The AD Review Board would have to be careful not to interfere with evidence where matters may require Police investigation.

**Comment**

The question of whether an oversight body should be able to hold investigatory hearings were raised. Reliance on other agencies to conduct all investigation may leave the oversight body unable to elicit necessary responses or information. Care would need to be taken as to who can request an investigation and on what grounds. The wishes and desires of the person who has died should not unnecessarily become the subject of investigation

***12.5 Should a stand-alone review board be established? What are the alternatives? For example, would it fit within the investigative role of the Coroner's Court or the quality and safety mandate of a consultative council?***

An oversight body must signal independence and uphold community confidence in its capacity to monitor and report on the operation of VAD. It must also address community concerns for the safety of vulnerable groups. Reporting to Parliament on the operation of the VAD would be part of its remit.

Would the AD Review Board deal with complaints related to conscientious objections or would they go to existing bodies, for example the Human Rights Commission? There may be complaints that a medical practitioner was discriminated against for views related to VAD.

**Recommendation**

There are arguments for a stand-alone board and alternatively placing a review board within a more experienced, better-resourced investigative body such as the Coroner's Office. However there should be a clear distinction between a reportable death if it was placed in the Coroner's office and a VAD process.

Placing a review board within the Coroner's Office may result in community perception problems. It may fit best within the Victorian Ombudsman's office.

## 13. Additional safeguards

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### **13.1 Does the Parliamentary Committee's framework provide sufficient protection to vulnerable people?**

The framework provides protections for all people. Assessing capacity, the process for informed consent and protections against coercion apply to all eligible people, regardless of age (over eighteen) and physical ability. Additional safeguards have been suggested under each heading in this submission. These include:

- Oversight when a person requires physical assistance to administer medication
- Independent witnesses (not family members) in instances where an older person may be vulnerable to elder abuse
- Older people from culturally and linguistically diverse backgrounds that require an accredited interpreter to express their wishes.

Vulnerability also includes individuals that choose to access VAD due to fearing the loss of independence and dignity and of burdening their family and loved ones. Elderly people and those that have been carers are more vulnerable to passive coercion. Research shows that older people (particularly in the fourth age) and those people that have been carers to others with chronic illness do not want to be a burden on others.<sup>x</sup>

#### ***What other additional safeguards could be considered?***

Alongside a legal framework, additional safeguards should include those resources and community education strategies that inform patients, carers and health practitioners about emotional, psychological and existential issues that may be triggered. In a culture that values independence and autonomy, to feel like a burden to others must be challenged through a more compassionate approach to those that require support.

The provision of quality end of life care for all people, particularly those living in rural areas, is also a safeguard to protect people where vulnerability is due to poor access to services.

When a person is physically unable to self-administer medication and requires assistance from a medical practitioner there should be an additional safeguard such as the attendance of an independent witness, preferably a health practitioner, particularly if this is at home.

## 14. Liability and insurance

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### ***14.1 What protections would be necessary for health practitioners who act in accordance with the new legislation in good faith and without negligence?***

New legislation will need to state that a medical practitioner will not face criminal or civil liability for providing treatment that causes death if they have acted in accordance with the requirements of the legislation.

The death certificate will show cause of death due underlying disease.

### ***14.2 How should insurance and other annuities of people who access voluntary assisted dying be protected?***

If there is a requirement that the cause of death be registered as the disease, not VAD, insurance and annuities should not differ from the case where the person died of the disease. The legislation should ensure that if proper processes are followed, VAD should not be treated as suicide.

## Any other issues?

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Currently, it is illegal to dispense Nembutal in Australia unless a doctor obtains permission via the Australian drug regulator, the Therapeutic Goods Administration (TGA)<sup>xi</sup>. Pharmaceutical access to lethal medication will have to be resolved.

The AD Review Board will have the statistics and profiles provided by the medical practitioner, which will give limited information on reasons. An oversight board would not capture the experiences of families and friends supporting a person through the VAD process. There should be the capacity for those close to the experience of VAD, for example partners, families to provide information to the Board on the basis that de-identified information can be used for research. The development of best practice compassionate and safe services must also be part of the remit for additional information collected.

Until the reform process becomes embedded and culturally accepted, lessons learned from the anti – abortion campaigns indicate the possibility of additional safeguards being needed for those involved in providing VAD.

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<sup>i</sup> [COTA Victoria Policy Priorities Statement 2017](#)

<sup>ii</sup> Incardona N, Bean S, Reel K, Wagner F, An ethics-based analysis and recommendations for implementing physician-assisted dying in Canada. Toronto: Joint Centre for Bioethics, University of Toronto, February 3 2016. Available: <http://jcb.utoronto.ca/news/documents/JCB-PAD-Discussion-Paper-2016.pdf>

<sup>iii</sup> Carter vs Canada (Attorney General), [2015] 1 SCR 331. This decision struck out those sections of the Canadian Criminal Code that prohibited Physician Assisted Dying

<sup>iv</sup> Law Institute of Victoria, Capacity guidelines and toolkit, concise edition taking instruction when a client's capacity is in doubt. October 2016, P2.

<sup>v</sup> *Oregon Death with Dignity Act: 2015 Data Summary*.

<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>

<sup>vi</sup> COTA Victoria's submission to the Parliament of Victoria, Legislative Council Legal and Social Issues Committee, Inquiry into end of life choices, Victorian Government Printer, June 2016, p5. This statement is based on qualitative data from public discussion forums with older on informed decision-making

<sup>vii</sup> Periyakoil VS, Neri E, Kraemer H (2015) [No Easy Talk: A Mixed Methods Study of Doctor Reported Barriers to Conducting Effective End-of-Life Conversations with Diverse Patients](#) PLOS ONE 10(4): e0122321. doi: 10.1371/journal.pone.0122321

<sup>viii</sup> Inquiry into end of life choices, *ibid* p220

<sup>ix</sup> Where it is not possible to provide a health practitioner, the development an alternative support service as developed with volunteers in the 2000s, [AIDS : Palliative Care : UNAIDS Technical Update](#)

<sup>x</sup> Gorvin, L. & Brown, D. [The Psychology of feeling like a burden: A review of the literature](#). Psychotherapy and Counselling Psychology Programme, University of Surrey. 2012

<sup>xi</sup> <https://theconversation.com/ruling-on-assisted-dying-drug-nembutal-sets-important-precedent-73362>