

Dec 2020 End of Life Choices (Voluntary Assisted Dying) Bill Review

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1: Summary of issues discussed in this submission:

- Clause 6: removal of “injury and complications” from the list of medical eligibility criteria
- Clause 6: removal of the ability of the Commission to modify medical prognoses
- Clause 9: Commission determination as to whether medical practitioners have the necessary experience to assess VAD requests needs to be defined.
- Clause 12: capacity assessments *must*, not *may*, be considered in assessing VAD requests
- Clause 13: “voluntariness” needs to include assessment for vulnerability, coercion and exploitation. This assessment should be documented.
- Clause 14: “suffering” criteria should be aligned with other State jurisdictions by the removal of “anticipated suffering” and use of “unbearable (or intolerable) suffering” and the addition of “and no chance of improvement”.
- Clause 15: communication by another person: “certified interpreter only” should be specified; non-verbal communication should be allowed.
- Clause 15: communication by enduring guardian disallowed as person has lost capacity
- Clause 18: requests for VAD need to be defined as “clear” and “unambiguous” and “persistent”, as in WA and Victoria.
- Clause 18: (5) VAD information may be given out by medical practitioners, but this should be voluntary. Medical Practitioners objecting to VAD should be able to refer queries to the Commission.
- Clauses 27 (1) (a) and 34 (1) (a), 56 (a) &(b): Audio-visual assessments: Removal of audio-visual assessments as being inherently less safe than face to face assessments.
- Clause 27: insertion of a clause to inform the person’s GP if the person consents
- Clause 30: need for a written or audio-visual statement from the person to ensure voluntariness
- Clause 30, 53 (2): lengthen interval between 1st and 3rd requests to 9 days for consistency with WA and Victoria
- Clause 43: The CMP assessment must be independent and not solely reliant on PMP information. Both WA and Victorian legislation provide for this.
- Clauses 59-65: Qualifications of AHDs not sufficiently defined. (eg Victoria excludes nurses)
- Clause 85: Assessment of the contact person required, to determine if whether a fit and proper person
- Clause 86: Permission required for VAD substance administration by an AHP at other than at a person’s private residence
- Clauses 87 & 88: Consideration of only oral VAD substance administration, on autonomy and medical professional grounds
- Clause 87: Appointment of a witness if AHP does the administration of the VAD substances
- Clause 88: Repeat administration of VADs substance not to be used without re-assessing capacity and voluntariness.
- Clause 91: Self-administration of VAD substances should not be in public.

Self-administration elsewhere than at a person’s private residence should be at that other place’s voluntary discretion.

- Clause 93: VAD needs to be recorded on the death certificate as the mode of death
- Clause 113: Functions of the Commission: Data collection to ensure Review determines the effect of VAD on others; certification, supervision and support for health professionals involved and bereavement care after VAD.
- Clause 138: Deaths not Suicide for the purposes of law of State Suicide rates should be recorded as part of ongoing monitoring of this legislation.
- Clause 143: Review of the Act to include if criteria met, evidence of abuse, effects of VAD on vulnerable populations, underserved populations, suicide rates, effect on health services

2: Introductory Background Notes

- **Brief History of the Voluntary Assisted Dying (VAD) Bill to date**

The End-of-Life Choices Bill was introduced into the Tasmanian Parliament via a private members Bill in the Legislative Council in 2020. It underwent significant amendment in the Upper House and had the first reading speeches in the House of Assembly on December 3 and 4, 2020. It is a complex Bill of 171 pages with significant involvement expected from medical practitioners, witnesses, contact persons, nurses and pharmacists.

It was introduced based on choice at the end of life with stories circulated to members of Parliament of bad end-of-life experiences necessitating the need for such a Bill. There has been no independent review of these cases to see if improving care at the end of life and having better and more timely access to medical services could have mitigated the need for such a Bill.

The two issues that need to be addressed in the framing of this legislation are:

1. how to improve choice for people at the end of life without negatively affecting others and negatively affecting existing health services
2. how to improve end-of-life care

There have been no Bills introduced for other End-of-Life Matters such as Advanced Care Directives or codification of Consent to Medical Treatment.

- **The position of the Royal Australian College of Physicians and other medical bodies**

The RACP has a neutral position regarding VAD

The College has concerns about the potential for legalised voluntary assisted dying to jeopardise traditionally underserved populations, to be abused, to expose health practitioners to professional risk, to harm patients and families and to erode trust in the medical profession.

The position of the RACP on Voluntary Assisted Dying is found in the recent Submission from the RACP to the Queensland Law Reform Committee ¹. Appendix 1

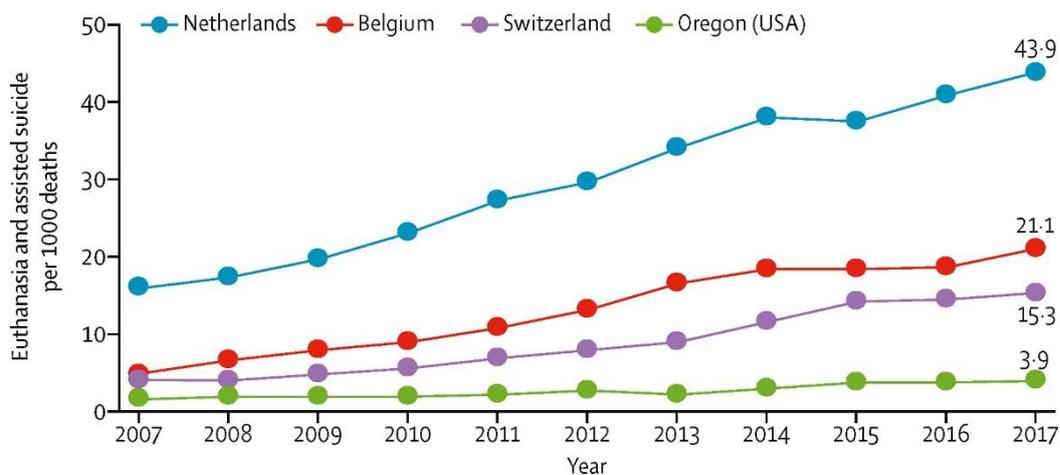
Peak Doctors' groups and Palliative Care Australia are opposed to or neutral to VAD, or do not have an official position.

- **Australian and New Zealand Society of Palliative Medicine²: opposed**
- **World Medical Association ³2019 opposed**
- **Australian Medical Association 2017 ⁴opposed**
- **Palliative Care Australia:2019⁵ VAD is not part of palliative care practice**
- **RACP or Royal Australian College of Physicians¹: 2018 neutral**
- **RACGP or Royal Australian College of General Practitioners⁷: 2019 neutral**
- **There is no official position from the Australian Pain Society, the Royal Australian College of Surgeons or the Australian and New Zealand College of Anaesthetists.**

Overseas Experience with Assisted Dying Practices

Rates of the various forms of assisted dying in overseas countries have all increased since relevant laws were introduced. They have increased less in places with tighter regulation and where VAD practices do not include euthanasia (death caused by lethal injection) .

Change in number of assisted deaths in countries and US states that have legalised these practices. (Netherlands and Belgium allow Physician Assisted Suicide and Euthanasia, Switzerland and Oregon allow Physician Assisted Dying only, Switzerland allows Physician Assisted Suicide for non-citizens)⁷



- The VAD Bill in a Tasmanian Context

Based on Victorian statistics^{8,9} it is likely there will be approximately 17 deaths due to VAD in Tasmania per year. This is based on 151 deaths due to VAD out of a total of 41,000 deaths in Victoria (2019 figures), or a death rate of approximately 0.36% of deaths. In Tasmania with 4,654 deaths in 2019¹⁰ this would equate to approximately 17 VAD deaths. To put this into perspective, palliative care services in Tasmania will care for more than 2,200 palliative care patients¹¹ over a similar period.

As far as medical practitioner involvement, there are 125 doctors active on the VAD portal in Victoria⁸ out of 31,215 registered medical practitioners (2019 data)¹². There are 2,712 registered medical practitioners in Tasmania¹² so it could be expected that there would be about 11 medical practitioners willing to become involved in VAD in this State.

3: Detailed discussion of issues:

Areas for consideration to improve safety, protect the vulnerable, lessen the impact on other health services and health professionals and provide consistency of approach, whilst still giving people choice.

Clause 6 (2) ¹³Medical condition eligibility:

Clause 6 (2) (b) states that the medical condition can include **“disease, illness, injury or complications”**. **“Injury” and “complications”** lead to medical conditions that cause death so the added definition is unnecessary. It is organ failure or a medical condition, assessed by clinicians, that leads to death. Injury and/or complications is superfluous as they do not in themselves lead to death. These definitions are not present in Victorian¹⁴ or Western Australian Legislation¹⁵. The terms **“disease”, “medical condition” and “illness”** are used elsewhere.

Conclusion: “injury or complications” need to be removed from Clause 6 (2) (b)

Causes 6 (3), (4), (5):

The Commission has the power to change the eligibility criteria related to expected prognosis of 6 months or 12 months for a neurological condition Clause 6 (3) after application by the person if the commission is satisfied that the prognosis does not apply to them Clause 6 (4) and a second opinion is sought 6 (5) .

This does not occur in Victorian¹⁴ or Western Australian¹⁵ legislation and could be perceived as a form of legislative creep: changing the criteria before it is legislated for. If the person perceives a problem with prognosis then they can apply for VAD as many times as they like, so this clause is unnecessary (Clause 51(2)).

Conclusion 6 (3), (4), (5): should be removed

Clause 9: Authorised medical practitioners

These are the medical practitioners who will assess people for VAD and may administer VAD.

The person needs to be medically qualified and registered, be vocationally registered or hold a fellowship with a specialist medical college and have relevant experience in the medical condition expected to cause the death of the person and have completed VAD training. Also not be a family member or a beneficiary of the will of the person.

There are a number of skills required of a VAD assessor and as there is no specific specialist requirement in the Bill then the Commission will need to determine if the medical practitioner has the necessary skills and experience. The suggested skills are listed in Appendix 2 and informed by the RACP¹.

The RACP has suggested that there may be practitioners willing to be involved in the process in a limited way or for certain patients and that the Commission keeps a record of this¹.

Clause 9: The Commission has the responsibility to assess the experience of the medical practitioners and whether they have the necessary skills and aptitudes for the task of assessment.

My summary of the abilities required by medical assessors for VAD based on the Queensland RACP Submission¹ definitions are found in Appendix 1

Clause 12: when a person has capacity for decision making.

Capacity assessments are difficult in those thought likely to die due to the cognitive impacts of illness, organ failure, treatments, and the impact of anxiety and depression on perceptions and decision making. These factors will change over time, with less capacity as death approaches. It is not possible to predict when capacity will be lost.¹⁶

If there is any doubt about capacity then a capacity assessment should be sought. If this shows a lack of capacity then the VAD process should cease until either capacity can be assessed as regained or it becomes clear that capacity has been lost and the VAD process ceases, and the assessments **must** be taken into account. This is more important in Tasmanian legislation than interstate as the years of medical experience are less in Tasmania (only post Fellowship in Tasmania, 5 years post Fellowship in Victoria¹⁴ or 1 year post Fellowship in Western Australia¹⁵)

Clause 12 (5) *If a CMP, PMP or AHP refers a person in accordance with subsection (4) to another person, the CMP, PMP or AHP may adopt, for the purposes of the decision of the CMP, PMP or AHP in relation to which the person was referred to the other person, the decision of the other person as to whether the person has decision-making capacity at that time.*

The “may” needs to be changed to “must”

Clauses 12 (5) capacity assessments *must (not may)* be taken into account in determining capacity for decision making

Clause 13: When a person is acting voluntarily

For the purposes of this Act, a person is acting voluntarily if the person is not acting under duress, coercion or because of a threat of punishment or unfavourable treatment, or a promise to give a reward or benefit, to the person or another person.

Voluntariness requires assessment of coercion-and exploitation within the context of vulnerability¹⁷.

This is a key issue with regard to the safety of this Bill and needs to be clearly enunciated.

Coercion, or an undue negative influence exerted by one person on another can occur from family members. Most palliative care practitioners are used to having requests from family members to hurry things up for their dying relative: usually this is due to the transference of their grief and distress. Palliative care practitioners are aware of the pressures family put onto dying relatives to save money so there is more money available in the will for family members. Older persons are at more risk of coercion. This form of abuse is difficult to detect.

Evidence about prevalence of elder abuse in Australia is lacking, though if international indications provide any guidance, it is likely that between 2% and 14% of older Australians experience elder abuse in any given year. It is quite likely that VAD will be a means of elder abuse¹⁸.

Coercion can occur from institutions and health systems, who may see VAD as a means to improve bed stay numbers, cost shift or reduce staff costs. This coercion can be subtle “the funding for your bed will run out...”. The clause prohibiting health or care providers from initiating discussion about VAD (Clause 17) is helpful to deter this, however medical assessors will need to be aware of subtle influences on coercion and should enquire about the social circumstances of the person, especially with respect to housing.

Coercion works both ways. Attempted coercion of doctors to perform euthanasia by the person, the family or from societal expectations occurs in an estimated 80% of cases in the Netherlands¹⁹, whether the request is granted or not. There needs to be a mechanism for ceasing the process if doctors are being coerced, with protection and support provided to these practitioners.

Those considering VAD a favourable option need to consider the influences at play. The media stories of “bad dying” and personal experiences of relatives (often with a degree of transference of grief)

need to be considered as drivers for VAD. The fears engendered by these perceptions are often unrealistic or unfounded with regard to the person’s current clinical situation. This needs careful exploration to see what the person’s real wishes are and that they are not unduly influenced by “media hype” or “transference of grief”.

Many people feel that they are an unnecessary burden on their family or the health system even when well and so consider VAD a desirable option when they have a life- threatening illness^{20,21}. This feeling of burdensomeness lessens the person’s autonomy to make a true decision.

Exploitation:

Those who benefit from the early death or a death that may not be subject to the usual scrutiny and need to be identified, and their influence on the request mitigated by careful exploration and finding out what the person actually wishes.

Those who benefit may include the following:

- beneficiaries of the will
- those who are finding the care of the person burdensome for whatever reason and projecting this onto the person
- those who benefit by gaining accommodation at the expense of the person
- those who benefit if there are changes to a will mooted.
- Those who benefit in health care terms from the early death of the person (organ donation, medical negligence cases, medical or social research)

Clause 13: Coercion, exploitation and vulnerability should be specified clearly as required parts of a VAD assessment. A record of this assessment should be retained by the Commission.

Clause 14: Suffering criteria

Clause 14: That the person has or anticipates intolerable medical suffering 14. (b) (ii), (vi).

Both the Victorian¹⁴ and Western Australian¹⁵ legislation use the criteria of “intolerable suffering” only.

Public opinion is that E/PAS/VAD is not acceptable if a person is not actually suffering^{22,23}. A case for “anticipated medical suffering” could be made for anyone seeking to access VAD, but public opinion points to existing suffering as being important in determining access.

Overseas jurisdictions which use a similar prognosis have “intolerable suffering” or “unbearable suffering without prospect of improvement”²⁴ as their definition of suffering.

There are many therapies that are proven to improve existential suffering: hope centred, meaning centred and stress reduction therapies²⁵. These can be provided by qualified pastoral carers, psychologists, cultural and spiritual practices. This is an emerging field of study.

Pain and suffering are effectively reduced by good quality palliative care services²⁶. People have to consent to having palliative care or any other therapy, so palliative care assessments cannot be mandated. They should be recommended by the clinicians involved in care.

Conclusion:

For reasons of clarity, consistency with other States and congruence with public opinion the suffering definition of clause 12 should be changed to that of “unbearable suffering” or “intolerable suffering”. Adding the words “and no chance of improvement” would ensure that consideration is given to assessment of suffering and access not just to palliative care but other therapies to reduce for existential suffering

Clause 15 Communication by another person on behalf of the person requesting VAD ~~Clause 15.~~

In Victorian¹⁴ and Western Australian¹⁵ legislation, the only other person allowed to communicate on behalf of a person requesting VAD is a registered interpreter who is not to be related to the person, is not a beneficiary from the will and is required to endorse their communication with their interpreter registration details. This safeguard should be added to the Bill.

Clause 15 covers not just the use of an interpreter. It covers the use of a person to communicate for a person who is unable to communicate for any reason. This needs clarity. If a person cannot communicate because of disability or a speech impediment, then a clause should be inserted (as in the Victorian¹⁴ and WA¹⁵ legislation) to say that requests can be made by “*gesture or another form of communication available to the person*”. This increases the autonomy of the individual and lessens the risk of coercion or exploitation by involving another person, no matter how well meaning.

If the communication difficulty is due to a guardianship issue, then capacity can be assumed to be lost, which negates the VAD process

Conclusion:

Clause 15: Communication by another person on behalf of the person requesting VAD should be limited to registered qualified interpreters, who are not family members or beneficiaries of the will

Insert into Clauses 18., 30., 53.,78. “gesture or another form of communication available to the person” (Clauses involving communication)

Communication by a Guardian should be disallowed because of loss of capacity.

Clause 18 : Assessment of first request

In Tasmanian Legislation there is no definition of a request for VAD

In Victorian¹⁴ and Western Australian¹⁵ legislation the first request for VAD must be **“clear and unambiguous” and “persistent”**.

(An Advanced Care Directive cannot be used to replace a first request as the Directive only comes into effect when the person loses capacity).

It is common to hear one off comments such as “I wish I was dead” or “if I was a dog you would shoot me” from palliative care patients when distressed. These feelings dissipate as concerns are addressed, symptoms relieved and suffering is addressed. These are not, then, persistent requests.

Any request for VAD made soon after a terminal illness is diagnosed should be reviewed at a later date. Most people experience a range of intense emotions soon after diagnosis which dissipate with time as people start to navigate their care needs and deal with what really matters to them at the end-of-life. Depressive symptoms are present in about half and significant anxiety in a quarter of people soon after diagnosis^{30,31}. Sufficient time should elapse before a “request” can be considered to be persistent and considered.

Any request for VAD needs to be assessed for suicidality, depression, unresolved symptoms or pain before it can be considered clear and unambiguous. These issues should be addressed before a first request can be considered valid.

Clause 18 : there needs to be a definition of a request for VAD, which includes that it is “clear and unambiguous” and has been persistent and not associated with depression or suicidality or significant unresolved symptoms.

Clause 18. (5): Doctors required to provide VAD information even if refusing a first request

*“If a person has attempted to make under subsection (1) a request to the medical practitioner but has not received from the medical practitioner the relevant facts in relation to accessing voluntary assisted dying, the medical practitioner **must** give to the person the relevant facts in relation to accessing voluntary assisted dying.”*

This is an anomalous clause to have included in a Bill which purports to be voluntary in all aspects.

The RACP¹ position is that:

- A central information source on the scheme should be available to assist patient access.

In Victoria¹⁴, practitioners are not required to provide information about VAD. In the Tasmanian Bill all medical practitioners must provide information about VAD to any anyone who makes a first request even if they do not wish to be involved.

The Commission will control all the information about VAD, including the lethal substances authorised for use, the training required and the list of VAD-authorized health professionals. In Victoria most of this information is not made available to the general medical profession. In Tasmania the Commission is unlikely to make this available, either. The Commission, not the medical profession, should be the source of VAD information.

Suggested replacement phrase:

18.(5): *“If a person has attempted to make under subsection (1) a request to the medical practitioner but has not received from the medical practitioner the relevant facts in relation to accessing voluntary assisted dying, the person can be given the contact details for the Commission or ~~a~~ other central agency to obtain such facts “*

Conclusion: modification of Clause 18. (5) is required to ensure that instead of any medical practitioner being required to give information about VAD that contact details for the Commission be provided or details of where the VAD information can be found.

Clauses 27 (1) (a) and 34 (1) (a), 56 (a) &(b): Audio-visual assessments:

Audio visual means are not able to be used in assessment in Victoria¹⁴, and only able to be used in WA¹⁵ if there is no other means available.

Audio visual assessments cannot be used for complicated consent purposes and should not be used for the VAD assessments. These are complex and require expert assessment of capacity and voluntariness. There is a need to see who else is in the room and who is likely to be influencing the person. Audio visual consultations miss many of the nuances of communication within normal consultations. They are best used when the patient and patient are known to each other. This is unlikely to be the case with VAD assessments. For these reasons AV means should not be used in VAD assessments.

Conclusion: Removal of AV means of assessment in Clauses 27 (1)(a), 34 (1)(a), 56 (a) (b)

Clause 27: PMP contacts family of person if person consents:

In Victoria¹⁴ the PMP equivalent medical assessor notifies **the person’s GP** if the person consents. This would give an added layer of protection to ensure that the decision is safer as the GP may be aware of issues such as family coercion which should be taken into consideration. This could be inserted after Clause 27 (4) *“the PMP takes reasonable steps to contact and inform family if person consents”*

Clause 27 could include that the person’s GPs should be informed of the impending death of a person from VAD at the same time as the family is informed at the time of the second request, if the person consents.

Clause 30 (3) Personal record of reasons for accessing VAD

The processes described in the Bill in the main concern the requirements of medical practitioners and others to facilitate an early death. A recorded written or audio-visual statement by the person regarding their reasons for accessing VAD would improve the safety of the process. This could be kept by the Commission and be used if there is any doubt about the intent of the person or if the family express concerns if they have not been involved. It should be a mandatory part of the process.

Incorporated into Clause 30. (3) there should be a written or audio-visual statement made by the person regarding their reasons for accessing VAD, retained in the patient's medical record, or by the Commission.

Clauses 30, 53: Time between first and last request for VAD

The time frames specified in this Bill are much shorter than those in other jurisdictions. A minimum of 96 hours is specified between first and last requests (Clauses 30. (2) and 53 (2)) with the proviso that it can be foreshortened if the person is expected to die within a week or lose capacity within 48 hours. The reality is that time will be needed for the two medical assessments, the gathering of independent witnesses to sign the second request, the gaining of more information or assessments, the completing of paperwork and informing the Commission will be much longer than 96 hours.

Then there will be time needed for the arrangement of the AHP, the final permission from the Commission, the issuing of scripts, obtaining the VAD substances from pharmacies, and sorting out witnesses or contact persons.

Foreshortening the process risks a bypassing of the checks and balances that are requisite in the process.

A longer time frame may be necessary for any symptom control measures to work, hence negating the need for VAD.

- In Victoria¹⁴ and Western Australia¹⁵ there is a minimum 9 days between first and final requests
- In Oregon²⁸ there is a minimum 14 days between first and third request
- In Canada²⁹ there is a minimum 10 days if death foreseeable or else 90 days between first and final requests

Conclusion: the minimum time between 1st and 3rd requests should be extended to 9 days. *“within 48 hours of the person making a second request”* should be replaced with *“within 9 days of the person making a first request”*.

Clause 43: The PMP provides reports and information to the CMP.

The ability of the consulting medical practitioner (CMP) to provide an independent assessment of the process is severely limited by the flow of information being only from the Primary Medical Practitioner (PMP). For a fully independent assessment the CMP needs to be able to access information separately to the PMP to ensure this is not just a tick-box exercise. In Victoria¹⁴ and

Western Australia¹⁵ the CMP provides an independent report and gains information independently and assesses the person independently and in person.

It is essential for the integrity of the Tasmanian assessment process that this provision be changed.

Clause 43: This should be removed and re-written. The CMP should provide an independent ~~their~~ own report based on information they have gathered, which may include information in the referral from the PMP.

**Clauses 59-65 : Appointment of an Administering Health Practitioner (AHP)
(This could be removed if patient self-administration were to be the only form of VAD permitted)**

In this Bill the AHP has different duties to those of the PMP and CMP. In Victoria¹⁴ the AHP is either the PMP or the CMP.

The Commission will need to ensure that whoever is appointed as an AHP to administer the VAD substance has the necessary skills, including assessing a patient's capacity and voluntariness, and their ability to swallow, and have the ability to perform an intravenous (IV) cut-down (if IV administration is required and accessing a patient's veins is difficult), and to perform CPR if the VAD administration is unsuccessful, and to investigate the reasons if the VAD fails to work.

This raises concerns about the role of nurses acting as AHPs. (In Victoria¹⁴ nurses are not able to be appointed as AHPs)

At present, under Clause 117 the Commission will have to decide this matter.

Conclusion: Legislative clarity would be helpful in this matter.

Clause 85: The role of the contact person: this person must be appointed by the person receiving the VAD substance, must be an adult, and must agree to the role.

The duties of a contact person include, in Clause 92, being responsible for notification of the death of the person after self-administration to the AHP, for contacting the police if the body is not at the person's home and returning any unused VAD substances to the AHP.

The contact person is a potential risk for exploitation and coercion and requires assessment and monitoring. The role should be filled by a fit and proper person. Conflicts of interest may arise should the person appointed be a relative or a beneficiary of the will.

Conclusion: Legislative clarity would be helpful in codifying this appointment.

Clause 86: VAD substance administration at other than a person's private residence.

the AHP should seek permission from the owner or manager of another residence, institution (including residential aged care facility), ward or hospital before administering VAD. The owner or manager can decline the request without any reason given. The AHP and person concerned will need to arrange another venue should the person wish to proceed.

Conclusion: If the VAD substance is administered at a place other than the person's usual place of residence then the administration will need to occur at the discretion of the owner or manager of the place or institution and permission should be sought.

Clauses 87 & 88: AHP administering VAD Substances

Discussion: The AHP takes the VAD substances from the pharmacist or safe storage and either administers the substances or supervises the administration of the substances.

It is not clear from the Bill whether oral or IV substances are to be used. IV use in terminally ill patients is burdensome and difficult.

There is a big difference for the AHP if the substances are self-administered (physician assisted suicide) or administered intravenously (euthanasia). There is greater moral distress created for clinicians when performing euthanasia procedures¹⁹, in contrast to assisting oral substance administration. There is a fear among the community regarding doctors and syringes at the best of times: the legalisation of intravenous VAD will reduce the trust that patients have in their clinicians. This is harmful to both the nursing and medical professions.

For those who want to have control over their end of life, (the reason most commonly given for accessing VAD^{8,29}) then self-administration would be more in keeping with such values. Euthanasia/IV substance administration should be removed from consideration, given the propensity for harm. Self-administration is the means of VAD that is used in most of the US. It has been used the longest in Oregon²⁸, where rates have slowly increased, suggesting it is safer in the long term.

Conclusion: Legislation for oral self-administration only of VAD substances would be consistent with patient autonomy. This approach is used in the Oregon¹⁸, USA VAD model. Consider specifying that lethal substances cannot be administered by IV means.

Clause 87: Witness to administration of VAD substance.

In Western Australia¹⁵ and Victoria¹⁴ legislation a witness to the administration of the VAD substances is required, if the AHP administers the substance, even if self-administered. This makes it safer for both the AHP and the person receiving the VAD.

Conclusion: A witness to the VAD substance administration should be appointed.

Clause 88: The responsibility of the AHP when the VAD substances do not work.

This clause is not included in the WA¹⁵ or Victorian¹⁴ legislation. If the substances do not work as intended, then the Bill states that the AHP can arrange for resuscitation or for another VAD substance to be administered. This is not in keeping with the basic principles of consent.

If the VAD substance does not work, then there needs to be an assessment made. Is the person conscious? Why did the substance not work? This is the medically responsible first step, to

determine what other VAD substance may be required if that is what the person wants after the failure of the initial substances to work.

If the person does not regain consciousness, then the Advance Care Directive (ACD) of the person will dictate what occurs: resuscitation attempted or allow for natural dying. VAD cannot be given again without again assessing capacity or voluntariness.

If consciousness is regained, then the reason for the failure of the substance needs to be investigated. Then if VAD is still being requested the process restarts with another round of capacity and voluntariness assessment, another VAD substance permit issued by the Commission and VAD substances issued by the with the doses or substances altered to ensure death on the next attempt. This is the responsibility of the AHP.

This is in keeping with the RACP position¹ that there needs to be a safe and clear process for if the substances do not work.

Conclusion: Clause 88: Either remove, or state that the next step outcome if the VAD substance does not work will be determined by the ACD of the person if the person is unconscious. If consciousness is regained, then the cause for the failure of the substances should be sought and a further assessment will be required before VAD can be considered again. This is the responsibility of the AHP, and ultimately the Commission

Clause 91: Private Self-Administration

(1) The person is allowed to transport the VAD substances

- (i) *“To the person’s residence”*
- (ii) *“to a place where the person is to self-administer the substance”*

(2) If there is a private self-administration certificate in relation to a person and the person has been supplied under section 89 with a VAD substance by the person’s AHP, the person must ensure that the VAD substance is kept in its original packaging and in a locked receptacle, that is not readily accessible by any other person, until the person self-administers the substance, returns the substance to the AHP or supplies the substance to the person’s contact person for return to the AHP.

Therefore self-administration can occur at a place other than the person’s usual place of residence:

The place where a person can privately self-administer needs clarification.

There needs to be consideration for self-administration of VAD substances to be disallowed in public places where others may unwittingly witness this.

In the same way institutions who have concerns should be able to disallow self-administration of VAD on their premises due to the potential impact on staff or other residents.

Hospitals, Hostels, Residential Aged Care Institutions, Disability Services, even hotels may all have legitimate concerns about how the person self-administers and should be able to say no without giving a reason. Being an entirely voluntary Bill, such a provision is reasonable and consistent.

Such a provision may reduce the impact on others who may not wish to see this, may protect the vulnerable, and may avoid ambulances being called where people see self administered VAD occurring and naturally want to prevent what they see as a “suicide”.

Self-administration is the only means of legal “assisted dying” in Oregon²⁸, which has had this method successfully since 1997. In Oregon, institutions can prohibit self-administration use on their premises (Veteran and Catholic institutions, for example, prohibit this on their premises)

This is, moreover, the usual method of” assisted dying” in the other States of the US where VAD is legal.

A summary of the Oregon Bill ²⁸can be found in Appendix 4

Conclusion: Clause 91 should be amended: Private self-administration should not occur in a public place. Permission should be sought from the owner of the place or the institution if a person wishes to self-administer at a place that is not their usual place of residence. The owner or institution can say no without giving any reason. Consider if private self-administration be the only means of VAD.

Clause 93: Reporting of the death to the coroner and issuing of death certificates

The Bill requires the AHP to reports a VAD death to the Coroner. The RACP¹ suggests that a Coroners or similarly trained officer within the Commission review all cases of VAD

The RACP¹ has also suggested that the mode of death be recorded as VAD, followed, as per standard practice, by the disease or illness leading to this. The VAD substances used should be recorded for transparency and for the accuracy of the certificate. The RACP¹ recognises that there may be stigma associated with this for the family, however as a legal document and a document used for planning health services it is essential that it is accurate.

Conclusion: Clause 93: The death certificate should record VAD and the substances used, as well as the underlying condition, as the cause of death.

After the death is reported to the coroner then the coroner or a member of the Commission be tasked with reviewing each case about the reasons for seeking VAD, and whether further medical treatments or palliative services could have improved the patient’s care.

Clause 113: Collection of data by the Commission for each request

There is considerable public interest in this matter and it is important that data is collected that accurately and transparently depicts what occurs

The RACP¹ suggests data be collected in a 2 phase process, : deidentified data for public use and scrutiny, and actual data kept securely for looking further into the impact on vulnerable populations, impact on people who are underserved by health services, impact on palliative and other health services used by those accessing VAD, evidence of abuse to the person or families and carers, evidence of bullying by the person or families to health professionals, evidence of harm to patients and families, evidence of whether relationships within health services have been damaged.

Conclusion: Comprehensive data needs to be collected and such data collection should be incorporated in the legislation.

Clause 138: Deaths not Suicide for the purposes of law of State

The relationship between suicide and VAD is complex as VAD combines the older practices of Euthanasia and Physician Assisted Suicide. Suicides are not prevented by having VAD and there has been evidence of normalisation of suicide in overseas jurisdictions³⁰ and increases in suicide rates where VAD became accepted as common practice within the community³¹. Suicide rates need to be monitored and there may be a need to review legislation if rates increase without explanation.

Conclusion: Suicide rates should be recorded and reviewed by the Commission as part of ongoing monitoring of this legislation.

Clause 143: Review of the Act

The review of the Act should include any matters raised by data collection as well as a review of the impact on vulnerable populations or people, impact on people who are underserved by health services, impact on health services, such as palliative care and emergency care, as to what changes need to be made to minimise the effect of VAD on others. RACP recommendation¹

4: Other matters relating to the bill

A: Regarding Medical Practitioner referral for VAD.

Medical referral for VAD is not specified in the Bill, and medical Referral for VAD is inappropriate for the following reasons:

- VAD is not a recognised medical procedure.
- There is no medical condition requiring treatment with VAD
- There are no randomised controlled trials or published data on VAD substances to guide good medical practice, as would occur with any other procedure.
- VAD is a legal process, albeit requiring medical assistance, and should not require incorporation into the medical system to proceed.

The Commission is in the best position help people navigate access, and should be the default agency for “facilitating referral”, rather than the medical or nursing professions.

Clause 113. (2)(3) provides for this:

The Commission may, with the permission of a medical practitioner or registered nurse, provide to a person the name and contacts details of the medical practitioner or registered nurse.... (of a PMP, CMP or AHP)

In Oregon²⁸, USA there is no governmental assistance provided to assist those who wish to access PAS to find an authorised PAS doctor

In Switzerland³² Exit and other groups facilitate access.

In Victoria¹⁴ there is no requirement for referral, instead nurses are employed by the State as “navigators” to facilitate access to doctors who will provide VAD.

Recommendation:

That the present exclusion of Medical Practitioner compulsion to refer for VAD should stand.

B: Protection for those not willing to be involved.

There are many reasons for clinicians not being willing to be involved in VAD: “it is against medical codes of conduct”, the “first do no harm rule”, community interest in protecting life and not intentionally taking life, or belief in the “intrinsic value of life”³³ The range of reasons goes well beyond just “conscientious objection”.

It is also known that there are a large number of Australian doctors who are unwilling to be involved personally in administering VAD, even though they may be supportive of VAD.

Summary of recent Polls of Australian Doctor's views of VAD

Date and Survey	group	Support for VAD	Willingness to be involved
Sheehan L, 2016 ³³	Palliative care physicians	3%	1.5%
Karapetis et al, 2018 ³⁴	ANZ oncologists and haematologists	34%	14%
Yoong et al, 2018 ³⁵	Victorian Hospital doctors	28%	15%
Munday et al, 2019 ³⁶	ANZ geriatricians	28%	12%

There are “conscientious objection” provisions in the Victorian¹⁴ and Western Australian¹⁵ Bills pertaining to doctors. There are many other health professionals who are not covered by this provision. As this is a Bill about voluntariness the same protections should be afforded to all affected by a VAD decision. This needs to include not just doctors and nurses, but all the ancillary and allied staff who work in hospitals, medical practices, and health services. All staff are vulnerable and need to be able to say “no” without fear of sanction or being bullied.

The same voluntariness needs to be applied to institutions, such as hospitals and residential aged care homes, hostels or hotels. There will be some who want to maintain a VAD-free zone for the protection of their vulnerable patients or residents. People wanting VAD are free to be transferred elsewhere.

It needs to be understood that there is considerable stress to health professionals caused by saying “no” to a request to die. This evidence comes from work performed in 2018 the Netherlands¹⁹. Those that experience this stress also find it hard to discuss and tend to keep quiet about this. There is a need for a system to be in place to provide support and a recognition that staff many be working with less capacity because of the internal distraction of this stress. There is also evidence of stress on practitioners in Canada³⁷ and Victoria³⁸.

Recommendation:

a) Insertion of a clause guaranteeing protection for those who do not wish to be involved in VAD (for any reason)

A registered health practitioner, health care agency, health team , ward or institution who is singularly or collectively not willing to participate for any reason including conscientious objection to voluntary assisted dying has the right to refuse to do any of the following without any threat of sanction —

- a. to provide information about voluntary assisted dying;**
- b. to participate in the request and assessment process;**
- c. to apply for a voluntary assisted dying permit;**
- d. to supply, prescribe or administer a voluntary assisted dying substance;**
- e. to be present at the time of administration of a voluntary assisted dying substance;**
- f. to dispense a prescription for a voluntary assisted dying substance.**

b) If those not involved seek psychological or other assistance because of VAD (bullying, loss of work, PTSD) then the Commission (Clause 110) be notified to track the effect on others

C: Protection of medical practitioners who become involved in VAD

The RACP recognises that most doctors who volunteer to participate in VAD will wish to have their privacy protected. This will be maintained by the Commission with information only being given out with their permission.

The other protection is from bullying and sanction, as for those not willing to be involved.

There are risks to going out to the homes of patients, more so if carrying “medications” and most health services workers either do a pre-emptive safety check or go to the visit in pairs for safety especially on the first visit. There may be a need for an authorised medical practitioner or AHP to co-opt someone for help: again, this should be voluntary: there should be no coercion or exploitation of vulnerability.

The addition of a witness to any VAD procedure as occurs in Western Australian¹⁵ and Victorian¹⁴ legislation adds another legal protection for the VAD provider.

Those involved in VAD may experience considerable distress^{19,37,38}.

In the Netherlands those working on the End-of-Life Clinic mobile units have 1-2 weeks off after each euthanasia to recover.

The RACP recognises that there needs to be a support system in place ¹.

Recommendation:

Insertion of a clause establishing the provision of a support system for those involved in VAD into Clause 113: functions of the Commission:

D. The effect of VAD on other end of life choices

What matters to people at the end of life is that people have:

“Choice over who will be present, where people will die and what services they will get..... People want their symptoms to be well managed, and they want personal, social and psychological support. It is important to have the opportunity to say goodbye and leave when it is time to go without pointlessly prolonging life.” ³⁹ (Swerisson & Duckett 2017)

The ways for people to achieve this are to:

- develop an advanced care plan in collaboration with the people that matter to them and with their treating clinicians so that communication of wishes can be enhanced
- have access to appropriate medical, social, and psychological services at the end of life, which includes palliative care.

E: Advance Care Directives (ACD) and Planning:

In Victoria and Western Australia legislation to provide a framework for ACDs and Consent was enacted before VAD provisions provided.

Current situation:

Currently People in Tasmania can make plans with their clinicians (Goals of Care Plans, Medical Orders for Life Sustaining Treatment, or individual plans, and write their own Advance Care Directives, which will come into operation after a person loses capacity. There is no legal certainty about any ACD, and Advanced Care Directive Legislation will provide this.

GUARDIANSHIP AND ADMINISTRATION AMENDMENT (ADVANCE CARE DIRECTIVES) BILL 2020

A draft for this legislation was released for public comment in October 2020

This legislation provides a legal framework for people wishing to make a statement about their values and wishes about what they would consent to and not consent to as far as medical treatment is concerned for when they lose capacity. It needs to apply to all, not just those seeking access to VAD.

Important considerations for legislators:

- the ACD will be more effective if discussed with a medical practitioner and be written recently
- the ACD needs to be interpreted with caution if there have been significant changes in circumstances
- the appointed person (s) responsible need to have capacity
- there may be reasonable circumstances (readily correctable medical or surgical condition) where there needs to be an emergency medical or surgical override to the ACD
- the presence of an ACD should not limit or deny care
- ACD should be voluntary not mandatory
- Recognise that minors (under 18 years) wish to write ACD: the legally binding limitations to care will need discussion with parents or guardians and treating clinicians (the “triad of care” for minors concept). Suggest that the 18 year rather than 16 year age limit be maintained to be in keeping with the VAD legislation⁴⁰.

If VAD is enacted there will need to be the following provisions:

- **An ACD cannot be used as any part of a VAD process (VAD requires full capacity to proceed and is included in the Victorian legislation.**
- **A legal guardian cannot make a request on behalf of a person and the guardian acts due to lack of capacity of the person**

These have been incorporated into the Victorian Advance Care directive legislation ⁴⁰

CONSENT TO MEDICAL TREATMENT BILL 2020

This is another piece of legislation that could provide surety for people and health professionals has been prepared by the Hon Madeleine Ogilvie. It works with existing frameworks and will complement the Draft Guardianship and Administration Amendment Bill.

Victoria⁴⁰ has effectively combined aspects of both ACD and Consent to treatment into one Bill.

It provides protection and surety that people can access adequate pain relief and symptom control at the end-of-life if they have lost capacity. This is one of the fears that has driven the need for euthanasia and VAD²⁹. At present medical practitioners operate using clinical guidelines and best practice, for some practitioners it is a “grey” area and the expectation from some that their pain will not be relieved is one reason for delays in accessing pain relief.

Role of ACDs in Palliative care end end-of life planning

ACDs are useful for clinicians in formulating plans for the end of life and providing more certainty that that a person’s choices can be respected. Discussing the Directive with family, friends and clinicians will make it into a plan. There is good evidence that Advance Care Planning improves outcomes at the end of life for both the person and the bereaved carers.

Advance Care Plans are an integral part of state based palliative care services. Palliative Care Tasmania has been the advocate for Advance Care Planning and has been involved in education about advance care planning in the community and to professional groups for many years, dependent on funding.

F: Palliative Care Services

The potential impacts on palliative care services overseas are detailed in Appendix 6 ^{37,38,41,42}

The impact on palliative care services is likely to be significant with many clinicians reporting they would refer anyone making a request straight to palliative care^{34,35}. Palliative care services are a finite resource, with only 7 FTE (full-time equivalent) palliative medicine specialists employed across Tasmania at any one time. The services could easily be swamped by VAD requests, as occurred for a while in Melbourne until the VAD navigators started to operate. This risk could be minimised by the Commission using an agency to assist in managing this workload.

Palliative care services are already stretched and have not recovered since the loss of hospice@home funding in 2017⁴³ and made much worse by previous cuts to funding in 2013. There is a large need to provide better support to general practice palliative care and community nursing with the loss of community palliative care afterhours services in 2017-8.

The palliative care sectors need time to recover, rebuild and retrain. There is a large need to provide palliative care training to GPs who have not seen this as a priority. Palliative care is no longer a core part of GP training and university teaching is by clinicians with already large workloads. The problem is known^{44,34,46} and some solutions are known however basic palliative care training for all health professionals needs to be seen as a priority within health services and clinical education. Systems responsive to enable this to occur and for priority be given to those who are dying, especially the vulnerable, so they can die well. All these measures take time and VAD should not detract from this as a priority.

There needs to be a separation of VAD from the medical system and palliative care for all systems to survive and fulfil their purposes. The only way for this to work without impacting on existing services is for any VAD scheme to be kept separate. Palliative care practice involves seeking people to improve quality of life and gain as much potential growth as possible even though they are dying. This is the fundamental reason that VAD and Palliative Care Practices are different.

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Appendix 1: RACP: Policy statement on Voluntary Assisted Dying

Royal Australian College of Physicians

The RACP takes the following unified positions **if and where voluntary assisted legalised**:

- Every patient should have access to **timely, equitable, good quality end-of-life care**, with access to specialist palliative care where appropriate. These services must not be devalued.
- On the specific issue of a competent adult in the last stages of incurable illness requesting voluntary assistance to die, the RACP supports a clinical approach of **critical neutrality** to encourage reflective dialogue.
- Although physicians should not be forced to act outside their values and beliefs, they also should not disengage from patients holding different values and beliefs without ensuring that arrangements for ongoing care are in place.
- Patients seeking voluntary assisted dying should be made aware of the **benefits of palliative care**. Referral to specialist palliative care should be strongly recommended but cannot be made mandatory. Voluntary assisted dying must not be seen as part of palliative care.
- Legitimate concerns exist around protection of **vulnerable individuals or groups**. Government, society and physicians must ensure that specific groups have **equitable access to palliative and end-of-life care and that relationships of trust** are not jeopardised. Specific regard must be given to **cultural and Indigenous experience**.
- All physicians must affirm the value of all patients' lives, **exploring reasons for requests** for voluntary assisted dying while remaining alert to **any signs of coercion and reduced capacity**.
- Assessments must not follow a 'tick box' approach. They must be underpinned by **adequate physician-patient relationships, including appropriate training, skill and experience**.
- **Support, counselling, and conflict mediation services** must be available for individuals, families and health professionals involved.
- There must be **rigorous documentation and data collection** to enable review of any scheme and to assess changes in practice and the impacts on health professionals, patients and families

<https://www.racp.edu.au/advocacy/policy-and-advocacy-priorities/voluntary-assisted-dying>

Appendix 2: Skills needed to assess VAD

Skills needed to assess VAD

The RACP position is that the medical practitioner involved in assessment has to be a volunteer and have the:

- Relevant experience in the medical condition causing death*. Suggest a specialist requirement at the least*.
- Ability to assess prognosis□
- Ability to objectively assess any request (a position of neutrality)
- Ability to recognise the psychodynamic issues in making and receiving requests
- Ability to objectively consider the reasons given for accessing VAD
- Ability to assess the suffering component and if this can be eased
- Ability to communicate the benefits of palliative care or other care therapies to the person and assess the access to these services and encourage a person to self-refer if necessary
- Ability to assess not just the physical, also the psychological, social, spiritual and cultural aspects of the request
- Ability to assess for vulnerability, coercion, and exploitation
- Ability to assess mental state in terminally ill people
- Ability to assess capacity in terminally ill people (who have many reasons for reduced cognition)
- No use of tick-box assessments (the doctor must have experience, not just online training)
- Ability to alert to vulnerable people and ensure
- Commitment to record and collect data to improve end of life services
- Ability to communicate using interpreters, or means of communication that the person is using
- Ability to assess when a witness may be needed to protect the vulnerable and the practitioner and ensure transparency
- Ability to report instances of abuse and collect data

*most medical conditions will require a medical specialist opinion. Cancer treatments and options have increased with the use of the newer biologics over the last 10 years. Most GPs will not have the necessary knowledge.

* experience is important as well as specialist degree. A neurologist may only see patients with epilepsy or Parkinsons disease and have no experience in motor neurone disease and vice versa

□ Prognosis is not an exact science. Prognosis is only a median figure: half will be dead before the time and half will live longer than the prognosis estimate. Prognosis is most accurate when made by those with experience and more accurate if 2 independent assessors confer. The most accurate prognoses are for those in the last week of life and made by doctors or nurses with the most experience (approaches 90%) . Family and a person's estimate of prognosis are least accurate.

Appendix 3: Opinion polls on VAD, Euthanasia and PAS

- Public opinion polls are liable to bias from the group surveyed (SMS vs telephone) and question ordering (with the Morgan poll assume you are answering the same question as the one previously even though slight difference in wording).
- There is considerable confusion about VAD within the community, with support dropping once people realise there is no need to legislate to allow for treatment withdrawal or for adequate pain relief, which is currently legal and best practice, not what people assume.
- Some of these misconceptions could be corrected with publicity of palliative care and introduction of more formal advanced care planning
- Support for VAD is lower if family not informed or if person feels they are a burden or if a person is depressed.
- Support for VAD is low if there is not access to palliative care.

1. Morgan poll: (n=1,300) SMS poll 2017 Australia

87 % Australians agree with doctors 'letting patients die when they are hopelessly ill and experiencing unrelievable suffering with no chance of recovery' compared to 10% who say doctors should 'try to keep patients alive' and 3% who are undecided.

Next question:

85% Australians: allowing a doctor to 'give a lethal dose when a patient is hopelessly ill with no chance of recovery and asks for a lethal dose'

<http://www.roymorgan.com/findings/7373-large-majority-of-australians-in-favour-of-euthanasia-201711100349>

2. Confusion about PAS/VE NZ: Curia Poll 2017 (n=894) land or mobile phone

- 85 % thought VAD included turning off life support
- 67% thought VAD included stopping medical tests and treatment
- 79% thought VAD included do not resuscitate orders
- 62% thought included PAS
- 68% thought included E

<https://euthanasiadebate.org.nz/wp-content/uploads/2018/06/Euthanasia-Poll-Results-November-2017.pdf>

3. Situations when PAS/VE appropriate: NZ Curia Poll 2019 (n= 1048) land line or mobile phone

- 20% support VAD if loved ones not told
- If aware that legal to allow people to stop treatment and withdraw life support; 57% support VAD
- If aware that enough pain relief can be used to keep comfortable 27% support VAD
- If person feels a burden 25 % support for VAD
- If person feels depressed or life meaningless 35% support for VAD

4. Palliative care preferred option over VAD in rural WA:

- Poll of almost 2000 rural responders showed that 75% would like palliative care access before euthanasia legislation is considered in rural WA

<https://www.watoday.com.au/politics/western-australia/polling-reveals-country-voters-want-palliative-care-fixed-before-euthanasia-legalised-20190903-p52neg.html>

5. Attitudes toward assisted dying are influenced by many factors in polling:

- Magelssen M et al., Attitudes towards assisted dying are influenced by question wording and order: a survey experiment. BMC Ethics 2016 17:24 pp1-9 <https://www.menneskeverd.no/wp-content/uploads/2016/08/Attitudes-towards-assisted-dying-are-influenced-by-question-wording-and-order-a-survey-experiment.pdf>

Appendix 4: Summary of Oregon Law

The latest information on the law in Oregon can be found here

<https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/faqs.aspx#whocan>

The government of Oregon takes a neutral stance on the matter: the Bill was brought in after a referendum

The processes in the Oregon Model are simpler than both the Victorian, the Western Australian Bills and may provide some clarity.

- Aged over 18 years, residing in Oregon
- The person needs to have less than 6 months to live
- The person needs a certificate saying this from a GP
- The person finds an authorised practitioner who provides an independent assessment of prognosis
- If confirmed assesses mental state and capacity
- If depressed refers to a psychiatrist
- 3 requests made: 2 weeks between 1st and last and 48 hours between , can be speeded up if person dying
- Suggests seeking palliative or other care, suggests informing family
- Script written for lethal oral substance, Pharmacist warned, Authority informed
- Up to person to collect lethal substance
- Up to person when/if to take medication, expected to take substance at home
- Person has to complete ACD wrt resuscitation or natural dying if found unconscious/substance does not work at home, otherwise will be resuscitated
- Person expected to take lethal substance at home
- Death Certificate states the underlying illness as per normal
- Authority keeps tract of scripts and prescriptions issued and if person dies presumed to have taken the substance then separate death certificate reissued.
- Authority keeps tract of paperwork for a year
- Authorised practitioners details kept private, no referral needed, Authority will not help in referral or give out details for the authorising practitioner
- About 30-40% scripts unfilled /substances unused each year
- Some institutions prohibit it on their premises: Veteran and Catholic institutions

This may provide a better framework for assisted dying: as the person is more in charge of the process, then the process can be assumed to be voluntary (less opportunity for coercion or exploitation). There are less people affected by the assisted death: the authorising doctor and the pharmacist only.

The percentages of deaths due to this form of death have remained low, which suggested it is being used by those who actually want it, not for other reasons

Appendix 5 : Data Collection for VAD

RACP informed suggestion of data collection by Commission

Deidentified data (should be published):

- Evidence that request is persistent at first request
- How did the person find out about VAD
- How did the person access VAD
- Numbers of requests with reasons for the request
- Number of withdrawal of requests by people (with reasons)
- Number of declined requests (with reasons)
- Number of final determinations
- Number of scripts issued, number of doses of VAD substances issued
- Type of VAD performed
- Number of contact/witnesses
- Effectiveness of VAD substances (for each type)
- Deaths from VAD with time since issue
- Non- VAD deaths occurring after issue of script
- Non-VAD deaths occurring after first request, with time between recorded
- Place of VAD death
- Number of late first requests (within 2 weeks of death)
-

Other data that could be collected from the paperwork:

- ACD present
- How long has the person consider VAD
- Basic demographics (age, sex, occupation, address, marital status)
- Housing arrangements
- Access to medical care
- Access to palliative care
- Access to other care services
- Medical assessment
- Medical treatments offered and treatments declined
- Palliative care offered and refused
- Symptom control medications
- Other assessors involved
- Suffering assessment
- Use of interpreters
- Written statement made by person
- Mental health assessment
- Mental health treatment
- Suicidality assessment
- Capacity assessment or concerns
- Vulnerability assessment
- Coercion
- Exploitation: who benefits from the will

- Doctors/nurses involved and level of experience
- Pharmacists involved
- Type of substances used and doses
- Effectiveness time
- Reason for ineffectiveness
- Involvement of emergency services and police
- People changing their mind
- Tracking of medications
- Unused medications
- Bereavement care
- Suicides in people accessing VAD

Royal Australian College of Physicians, Submission on the Queensland Law Reform Commission's legal framework for voluntary assisted dying: consultation paper November 2020 Accessed 27/12/20 https://www.racp.edu.au/docs/default-source/advocacy-library/e-20-nov-qld-vad-draft-racp-submission_egm-approved.pdf?sfvrsn=7e97f91a_4

Appendix 6: The Effects of VAD legislation on Palliative Care in Other Jurisdictions: Canada and Victoria

Effect of Medical assistance in Dying (MAiD) on palliative care in Canada

The impact of Assisted Dying practices on palliative care is best seen in Canada: with a **diminution of effective services**

Canada introduced Medical Assistance in Dying (MAiD) in 2016 as a “**right to die**” bill and has now achieved rates of 2% of all deaths. There are conscientious objection provisions for individuals however all state funded services and facilities are expected to provide MAiD. This is the experience of one state based palliative care facility over the first six months:

- Reluctance among patients to take pain medications and clinicians to prescribe pain medications in case the person needed to consent to MAiD. This was leading to both patient and provider distress.
- New difficulties in conversations: Most patients wanting MAiD wanted to be alive for as long as possible. Difficult to know what to say in conversation in case it was misinterpreted (that the process should be hurried up or that the process should occur soon). It was noted that it added to the burden of vulnerable patients, so the topic of dying was avoided. This eroded trust as communications became less open and more strained. Palliative care providers were giving a large amount of individual support to patients especially to those who were ambivalent about the process.
- Reports of patient’s struggling to make decisions and seeking guidance from staff.
- The emotional and personal impact on staff was large:
 - with reports of staff feeling sick on the day of any MAiD procedure, even if not directly involved.
 - There was uncertainty about any involvement (whether they would be required to or expected to be involved, and should they be involved)
 - A fear of stigma if their families and friends knew what they or their institution had been involved in MAiD. Staff not being prepared to say where they worked, even if not involved.
- MAiD changed the patient-palliative care provider relationship. Conscientious objectors were perceived to be “not for” the patient by patients. Conscientious objectors were saying they were not prepared to openly state this as it was damaging patient relationships. Denial of conscience leads to moral dissonance and ultimately burnout and resignations.
- The MAiD process consumed considerable palliative care resources. Once a case of MAiD was occurring all staff (administration, cleaners, attendants, health professionals) were caught up in the process for the one person, to the detriment of the care of other patients. “Would MAiD occur in time for this patient?” was the priority for staff, not how can staff provide the best experience and death for everyone else.

Mathews JJ et al, Impact of Medical Assistance in Dying on palliative care: A qualitative study. Palliat Med published online Oct 30 2020 <https://doi.org/10.1177/026921632096851>
<https://journals.sagepub.com/doi/10.1177/0269216320968517> (need online access)

Pesut B et al, The rocks and hard places of MAiD: a qualitative study of nursing practice in the context of legislated assisted death. BMC Nursing (2020) 19:12 <https://doi.org/10.1186/s12912-020-0404-5>
<https://bmcnurs.biomedcentral.com/articles/10.1186/s12912-020-0404-5>

The effect of VAD on palliative Care in Victoria

Victoria has only had 18 months experience with VAD which was introduced in June 2019. Already there are reports of

- disruption of palliative care teams: those involved and those not involved having to be rostered differently on all shifts whenever there is a patient undergoing the VAD process, even if the person does go through with the process. This lessens the effectiveness of teams (which rely on a team approach), it removes a sizeable part of the workplace from doing their jobs and patients are less well looked
- the emphasis is all on VAD and not on providing good care at the end of life
- moral distress among those who have volunteered to be involved
- difficulties with communication about legitimate end-of-life concerns with palliative care patients due to the availability of VAD and risks of being misinterpreted.
- negative effects and anxiety among other patients and families on the palliative care inpatient units Palliative Care where VAD has occurred.
- Patients are being transferred elsewhere or to their homes for VAD because of all these concerns.

Spruijt O, Assisted dying: push for removal of safeguards alarming Insight plus MJA 2020 (30) August 3 Accessed 30/12/20 <https://insightplus.mja.com.au/2020/30/assisted-dying-push-for-removal-of-safeguards-alarming/>

Waran E, William L, Navigating the complexities of voluntary assisted dying in palliative care Voluntary assisted dying is not part of palliative care. Med J Aust 2020; 213 (5): 204-206.e1. doi: 10.5694/mja2.50729 <https://www.mja.com.au/journal/2020/213/5/navigating-complexities-voluntary-assisted-dying-palliative-care>