

Submission to the Joint Select Committee on End of Life Choices

From: Dinny Laurence

Inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices

If a doctor is willing to help a patient to die peacefully when the patient has made a careful and reasonable request for that assistance, whose interest is furthered by turning that doctor into a criminal?¹

Introduction

In 1978 I saw the Brian Clark play entitled *Whose life is it anyway?* This started me thinking about the vexed question of voluntary assisted dying, and one way or another I have been thinking about it ever since.

There are an estimated 2.67million people in WA². Most of them will not respond to this Inquiry, but which of them would not aspire to dying a good death³? Which of them, if they thought about it, would *not* wish to be able to make an informed decision about their own end of life choices? We are all going to die, so this Inquiry affects us all.

A recent poll shows that voluntary assisted dying is supported by 73% of Australians,⁴ and yet since the Northern Territory legislation was overturned in 1997, there have been numerous failed attempts to pass legislation on voluntary assisted dying in Australia. This reflects not only a dismal failure of courage and leadership on the part of our federal politicians, but also a derogation of their responsibility to represent the will of the people. As a result the states have had to step up to fill the void, as has happened in NSW and Victoria, and more recently, in WA, in which a recent poll of 6000 West Australians shows support for voluntary euthanasia at 83%.⁵

I know many people who have been tragically affected by the fact that VAD is illegal in the place in which they live. I have been personally affected too, when my mother died in South Africa in 2007. She had suffered a stroke in 2000 and said many times after that that she wanted to die. Instead she was moved to the frail care unit of her retirement village where the loving and professional care of the staff kept her alive for 7 years as her body shrank and her mind steadily withdrew further. I remember her skeletal frame near the end; she was incontinent, not eating or drinking, and whimpered in pain at the slightest touch or movement. I could not believe how long this dying continued. I watched and wished that every tiny bird like gasp would be her last. I returned to Australia leaving my sister at her bedside, waiting for her to die. What cruelty we dispense in the name of love.

¹ Peter Singer: *We should end the suffering of patients who know they are dying and want to do so peacefully*. The Guardian, 19 September 2017

² <http://www.population.net.au/population-of-western-australia/>

³ "A good death gives people dignity, choice and support to address their physical, personal, social and spiritual needs" - <https://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf>

⁴ <https://www.theguardian.com/society/2017/sep/01/voluntary-assisted-dying-supported-by-73-of-australians-poll-finds>

⁵ <http://www.perthnow.com.au/news/western-australia/wa-speaks-survey-shows-83-per-cent-of-west-australians-support-voluntary-euthanasia/news-story/35576b00f5614fbdda9b1463a55a84c7>

This submission addresses the broad question – do we need laws to allow people to make informed decisions about end of life choices - and the specific issues in paragraphs (b) and (d) of the terms of reference.

1. Do we need laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices?

Note: In this submission the term “voluntary assisted dying” or “VAD” includes voluntary euthanasia and voluntary assisted suicide. In the former a peaceful death is induced by a recognised lethal drug prescribed and administered by a medical practitioner; in the latter the drug is administered by the person him or herself. In both cases death must have been requested by the person who has satisfied all the relevant eligibility and assessment criteria of any contemplated legislation.

The term **MP** means a medical or health practitioner as the context requires.

As mentioned above, VAD is supported by an overwhelming majority of Australians, and the introduction of VAD law in Australia is well overdue. My reasons for this view include:

- Although VAD is unlawful in Australia, it already happens “not infrequently”⁶ in practice, but without any safeguards for either patient or doctor, and “*without regulation, without support, without transparency or accountability, and from the evidence received, sometimes without consent*”.⁷ Any law can be broken, but the risks are far greater if there is no law at all.
- In the vast majority of cases palliative care will reduce end of life suffering, but palliative care specialists themselves agree that it “*cannot relieve all pain and suffering even with optimal care*”.⁸ Assisted dying should be one of the palliative care choices available when all others fail, and the person most affected should be the one making the choice.
- A person may choose to refuse treatment, and it is not illegal to put patients with intolerable pain into an induced coma by “terminal sedation”. Meanwhile the patient may continue to suffer extreme physical and/or mental distress and confusion, and may lose consciousness and mental capacity. It is hardly credible that it should be “ethically acceptable for a patient to choose a slow, painful death by dehydration and starvation, but ethically unacceptable for them to choose a death that is quick and painless”.⁹
- Within the ambiguity of the existing legal system, patients dying in intolerable pain can be left in limbo between medical practitioners who are willing to help them die peacefully, and those who are not. Dying is our final rite of passage. It should be our choice, endorsed by law, to die in certain prescribed circumstances with the help of our doctors. Medical practitioners with conscientious objections to participating should have the right to opt out. The others should have the right to help us when we need it most.
- There is no evidence in jurisdictions where VAD is legal that this leads to an increase in the rate of suicide. On the contrary, the absence of such legislation can cause people to kill themselves while they still can, knowing that if they leave it too long they will lose the ability to do so. The recent death of Clive Deverall is a well-known case in point. The note beside his body said “suicide is legal, euthanasia is not”. And his wife Noreen Fynn said “ If there

⁶ <http://www.smh.com.au/comment/the-right-to-assisted-death-20130519-2juwp.html>. This article summarises the findings of the 2013 Brisbane Roundtable on the inadequacy of existing laws on the issue of VAD in Australia.

⁷ Quoted by Andrew Denton from the Victorian Inquiry in his address to the National Press Club (10 August 2016): *The Damage Done: The Price Our Community Pays Without A Law For Assisted Dying*. http://www.gogentleaustralia.org.au/transcript_andrew_denton_s_npc_address

⁸A. Denton NPC address (see footnote 7)

⁹ Andrew Denton: *An Argument for Assisted Dying in Australia* - <https://www.wheelercentre.com/notes/an-argument-for-assisted-dying-in-australia-andrew-denton-s-di-gribble-argument-in-full>

had been voluntary euthanasia legislation, Clive would still be here. He would have known that he had the ability at a later date to pick up a drink of some sort [to end his life]. He wouldn't have needed to do what he did. He went far too early, and to me that was a real tragedy."¹⁰

- There is also no evidence in jurisdictions where VAD is legal that this leads to more widespread euthanasia (the “slippery slope” argument). There are safeguards to ensure that assisted dying is voluntary, and the request to die must be made by the person to independent medical professionals. The biggest safeguard of all is that “people do not want to die”.¹¹ Many who have been prescribed and supplied with a lethal drug under the law do not use it. Just having the option provides peace of mind.

2. Re (b) in terms of reference: proposed voluntary assisted dying legislation in Australia and existing VAD legislation in other jurisdictions

Victoria

Between May 2015 and July 2017 two extensive inquiries were conducted in Victoria. The first, the Legislative Council Inquiry (**LC Inquiry**), was an open inquiry which considered over 1000 submissions, held 17 days of public hearings and heard from 154 witnesses. It also reviewed the legislation in overseas jurisdictions that allow voluntary assisted dying.

The consensus of the Committee of the LC Inquiry was that “there was overwhelming evidence that the current legal and medical system in Victoria is not adequate to deal with the pain and suffering that some people may experience at the end of their life ... It also found that people want genuine choice about how they die and would like to be able to plan for their death.”

In general terms, the Committee recommended a framework that would allow “adults with decision-making capacity, who are suffering from a serious and incurable condition and at the end of their life, to be provided with assistance to die in certain circumstances”.

The second was a more targeted inquiry by the Victorian Ministerial Advisory Panel, which published its final report on 21 July 2017 (**MAP Report**).

The MAP Report made 66 recommendations, all of which were accepted by the Andrews government and these form the framework for the VAD legislation currently being drafted in Victoria.

Comparison between Victoria and Western Australia

Much of the groundwork into the issues relating to VAD has already been done in Victoria.

Were the Committee to recommend that WA proceed with VAD legislation, there are many principles set out in the MAP Report that it would no doubt support, for instance that the legislation should be “person-centred” and focus on what a “good death” may look like. This would include “knowing and understanding what to expect; dignity and privacy; symptom and pain relief; access to information; emotional support and palliative care; having your wishes respected; having control

¹⁰ <http://www.theaustralian.com.au/life/weekend-australian-magazine/final-act-clive-deveralls-decision-to-end-his-life/news-story/25976951faf97af3b777f3f35c3a40e>

¹¹ Andrew Denton - See footnote 9.

of who is present and having time to say goodbye; to be able to leave when it is time to go; and not to have life prolonged pointlessly”.¹²

Those principles apply to all of “end-of-life care, regardless of the choices people may make about the timing and manner of their death”,¹³ and inform the “Guiding Principles” adopted by the Victorian Panel (as Recommendation 1) in formulating the other 65 recommendations.

Some of the recommendations are, however, more controversial. If the framework recommended in the MAP Report is followed and the Victorian Bill passes, **it will make the legislation the most conservative in the world, with the eligibility criteria being more difficult to satisfy than in any other jurisdiction that allows VAD.**

I attach (Annexure 1) for the Committee’s consideration a summary of the MAP Report recommendations which (from my reading of the LC Inquiry and the MAP Report) appeared to be noteworthy or controversial. The Committee may find this helpful in deciding whether to follow Victoria’s lead or to go its own way. For ease of reference the MAP Report Recommendations are set out in full in Annexure 2.

Other Jurisdictions

Slippery slope: Voluntary assistance in dying is now available in 6 states in the USA, Colombia, Canada, The Netherlands, Belgium, Luxembourg and Switzerland. *We can draw on decades of experience with medical assistance in dying from other countries. They have been carefully studied and there has been no slippery slope to disaster.*¹⁴

The evidence from the extensive research on VAD carried out by TV broadcaster and producer Andrew Denton for his book *The Damage Done* was the same. Here are some of his findings:

- there is overwhelming support for the laws, but very few people use them (Oregon, one half of 1%; Belgium, 2%; Netherlands, 4%).
- In Oregon, 30% of those who qualify and are provided with the lethal medication do not use it.
- In Belgium two thirds of the requests for VAD are refused; in the Netherlands, 25%.
- There is no evidence of abuse of these laws. Complaints centre on their being too restrictive or discriminating against people with disabilities or affected by stroke or other paralysis.

Voluntary euthanasia vs Voluntary assisted dying: Voluntary assisted dying legislation in other jurisdictions is differentiated by being either physician assisted (voluntary euthanasia) or self-administered by the patient. There seems to be no reason in principle why legislation should not contemplate both depending on the circumstances of each case.

Residency: There is a residency criterion that must be satisfied in most jurisdictions, other than Switzerland. In the Netherlands the requirement can be satisfied pragmatically by the existence of a normal therapeutic relationship between person and doctor.

In Australia the consideration of VAD and the possible introduction of legislation to regulate it is a challenge that the Federal government should have risen to. Given the high level of support for VAD

¹² Age Concern England Report, cited in the MAP Report p. 9- *Health Care Group, Debate of the Age (1999), The future of health and care of older people: the best is yet to come*, Age Concern England, London, <<http://www.remedypartners.com/wp-content/uploads/2016/09/TheFutureofHealthandCareofOlderPeople.pdf>>.

¹³ MAP Report p. 9

¹⁴ Peter Singer: *We should end the suffering of patients who know they are dying and want to do so peacefully*. The Guardian, 19 September 2017

throughout the country an *Australian* citizen or permanent resident should not be discriminated against because they are unlucky enough to live in a state where VAD is not legal.

Condition criteria: In its interim report the Victorian ministerial advisory panel states: “Jurisdictions in North America allow a person to access assisted dying only if that person is terminally ill, whereas in European jurisdictions, the focus is on the suffering the person is experiencing. The Parliamentary Committee recommended that **both** criteria must be fulfilled for a person to access assisted dying in Victoria. In this respect, the bar for Victorians to be eligible to access assisted dying would be higher than in the North American and European jurisdictions”.¹⁵

A way to make any WA legislation less restrictive would be to allow either “intolerable and incurable suffering” or “terminal illness” within a specified foreseeable period as the criterion for eligibility. The former is a personal subjective test (consistent with any legislation being “person centric”) and the latter is always going to be a judgment call for the independent assessing MPs. Both are subject to the many other safeguards that will apply to VAD legislation.

Capacity is address in point 2 of Annexure 1.

3. The role of advance health directives and enduring powers of attorney in any proposed legislation

In WA both enduring powers of attorney (**EPA**) and advance health directives (**AHD**) are governed by the terms of the *Guardianship and Administration Act 1990*.

Many of those people most needing and wanting access to VAD may start the access process having full legal capacity but subsequently lose that capacity because of the progress of their illness. Some form of substitute authority is therefore necessary under any proposed legislation.

An EPA is often very broad and very often given to a close relative, thus making it inappropriate as an instrument of authority for VAD.

An AHD on the other hand is a legally binding directive made by a person with full legal capacity about future health decisions when that capacity is lost. For instance, a person may give a binding “do not resuscitate” instruction under an AHD and there seems to be no reason in principle why a similar instruction could not be given about VAD, subject to all the usual safeguards, medical assessments and other criteria of the legislation having been fulfilled.

Part 3 of the Victorian *Medical Treatment Planning and Decisions Act 2016* deals with the appointment of a medical treatment decision maker to be made at the same time as an AHD, and could be readily adapted for WA purposes. This would ensure that VAD would not be denied to many people who need it most.

Thank you for reading my submission.

Dinny Laurence
8 October 2017

¹⁵ Victorian MAP Interim Report page 4

Annexure 1

Summary of recommendations from the Victorian Ministerial Advisory Panel Final Report (July 2017).

Please note that only those parts of a recommendation that may be **noteworthy or controversial** are set out in this summary. For example, all the eligibility criteria in Recommendation 2 (R2) must be met before a person can access VAD, but only two of these are discussed in the table below.

Some of the recommendations have been summarised or paraphrased and words may have been italicised for emphasis. For ease of reference the full MAP Report recommendations appear in Annexure 2.

Definitions of words used in the submission have the same meanings in this annexure.

No	Recommendation Victoria	WA consideration
	Part A: Eligibility Criteria	
1	<p>R2: That to access VAD a person must be ordinarily resident in Victoria <i>and</i> an Australian citizen or permanent resident.</p> <p>The person must have been diagnosed with an incurable disease ... that is advanced, <i>progressive</i> and will cause death; and is expected to cause death within weeks or months but not longer than 12 months.</p>	<p>It would make more sense for the legislation to restrict access to citizens or permanent residents of <i>Australia</i>. Surveys throughout Australia show strong support for VAD and it is only because the Federal government has not had the courage to examine this issue nationwide that the states have had to fill the gap.</p> <p>Interpreting the word “progressive” could be problematic and is superfluous given the following words that the disease “will cause death”.</p> <p>Predicting when the illness is likely to cause death is problematic. Alternative wording might be: “The person is expected to die from the condition <i>or complications arising from the condition</i> in the foreseeable future, being a period not exceeding 12 months”.</p>
2	<p>R3: That the “decision-making capacity” test in the <i>Medical Treatment Planning and Decisions Act (MTPDA)</i> (section 4) is used to assess a person’s decision-making capacity in relation to VAD.</p> <p>In summary under s.4 the person must <i>understand</i> the information</p>	<p>In Australia the definition of “capacity” depends in each case on the type of decision being made.¹ In the <i>Guardianship and Administration Act 1990 (GAA)</i> which governs enduring powers of attorney and advance health directives in WA, the term “full legal capacity” is used</p>

¹ Law Society of WA: *When a client’s capacity is in doubt: A practical guide for solicitors(2016)- What is capacity?* (page 3)

	<p>relevant to the decision, <i>retain</i> it to the extent necessary to make the decision, <i>use or weigh</i> it as necessary and be able to <i>communicate</i> the decision.</p> <p>An adult is presumed to have decision making capacity unless there is evidence to the contrary (s.4(2)).</p>	<p>many times but it is not defined. The definition in section 4 of the MTPDA of “decision-making capacity” is clear and comprehensive and might usefully be adopted for any VAD legislation in WA.</p>
3	<p>R4: Where an assessing MP has doubt about capacity, “a referral must be made to an <i>appropriate specialist</i> for assessment”.</p>	<p>The Victorian Panel recommended that people <i>who have the relevant decision-making capacity in relation to VAD</i> should not be denied access to it by reason only of the fact that they <i>also</i> have a mental illness.² In other words a person will not have access to VAD if they only have a mental illness but that illness will not prevent access if they otherwise satisfy the criteria. This seems sensible.</p>
<p>Part B – Request and Assessment Process</p>		
4	<p>R7: That a request for access to VAD, or <i>for information</i> about VAD, can only be initiated by the person. Requests cannot be initiated by others, including family and carers.</p>	<p>This recommendation conflicts with the Guiding Principles in R1 that “open discussions about death and dying and people’s preferences and values should, wherever possible, be encouraged and promoted”; and “conversations about treatment and care preferences between health practitioner, a person and their family, carers and community should be supported”.</p>
5	<p>R8: that a health practitioner cannot initiate a discussion about VAD with a person with whom they have a therapeutic relationship.</p>	<p>See above – this attempts to control the relationship of trust between doctor and patient. For a doctor to talk about VAD as part of a discussion about end of life choices would be illegal if this recommendation were to be implemented. If VAD becomes a legitimate choice for a person by law it is absurd for that person’s doctor should be prohibited from initiating a discussion about it.</p>
6	<p>R10: That the person can withdraw from the process at any time but must begin from the beginning if they decide to make a subsequent request.</p>	<p>Alternative may be to allow person to put the process on hold. This recommendation may inadvertently encourage someone to go ahead with VAD if they know they will have to start again if they don’t.</p>
7	<p>R12/13/14: There must be two MPs who undertake <i>independent</i> assessments of the person’s eligibility, a coordinating MP and a consulting MP.</p>	<p>R12 is not clear. Interpreted in the context of R21 it means that the 2 assessments must be independent of the first MP the person asks to access VAD. Since this is likely to be the doctor with whom the person already has a therapeutic relationship, it cuts out of the assessment</p>

² MAP Report p. 81

	Both must be qualified as Fellows of a College (or vocationally registered) and at least one must have 5 years post fellowship experience; At least one must have expertise in the person's disease, illness or condition.	<p>process the MP who knows the patient's history and illness best, and who is best placed to support him or her through the process. Consider what qualifications are appropriate for WA</p> <p>This requirement will place a burden on the person, in terms of time, stress and money, since specialists are not easy to access and are expensive. The most important criteria are that the <i>person</i> is experiencing intolerable suffering and that the illness is terminal. The <i>specific expertise</i> requirement should only apply if one of the assessing MPs believes it to be necessary.</p>
8	R15/16: That both MPs "complete specified training" before undertaking an assessment of a person's eligibility for access to VAD. The components of the training are set out in R16	Do doctors have to do continuous medical education each year and could this training be incorporated into that? If not then it will be an additional burden on doctors that many may not get round to and an easy way to disqualify themselves from VAD. It will also be another hurdle in the path of access to VAD.
9	R18: That a health practitioner may conscientiously object to participating in <i>the provision of information</i> , assessment of a person's eligibility, prescription, supply or administration of the lethal dose of medication for voluntary assisted dying	<p>The law should require any MP who is approached by a person to discuss VAD</p> <ul style="list-style-type: none"> • To declare at once any conscientious objection they may have; and • to facilitate the transfer of the person to another MP and to hand over the medical records and information about the person to that doctor.
10	R19/20: That the person must make three separate requests to access VAD: (1) Verbal request to MP followed by 2 independent assessments; (2) Witnessed written declaration of enduring request to the coordinating MP; (3) Final request (verbal?) to the coordinating MP.	<p>(1) Involving 3 MPs is excessive (see 7 above). The person's own GP or the first person approached should not be excluded from the assessment process</p> <p>(2) Surely an "enduring" request endures unless withdrawn?</p> <p>(3) Consideration should be given to what happens if after (2) has been completed the person is no longer capable of making a final request. This is where a substitute decision maker could come in (see R16 & R23 below)</p> <p>Assessment time limits should apply so as not to retard the process.</p>
11	R21: sets out the information that must be provided to a person seeking access to VAD.	The information should include telling the person that if they withdraw they have to start again.

12	R23/24: That the final request may only be made if a period of 10 days has passed since the first request, unless death is likely to occur within that period	Arbitrary “cooling off” period? Seems unnecessary given (a) the substantial amount of evidence that people do not want to die and (b) that the person can withdraw at any time. The discussion in the MAP Report states “In other jurisdictions that have included a time period between requests, there is little evidence to suggest a particular time period creates a significant difference in the quality of people’s decisions”. ³
13	R25: That the final request cannot be made on the same day as the second independent assessment is completed.	Why not? The MAP Report states only that this is “as a clear safeguard” ⁴ without further explanation.
14	R26/27 – who may witness the enduring declaration: One witness may not be a family member. Neither witness <ul style="list-style-type: none"> • may “know or believe” him or herself to be a beneficiary • may own or operate any health care facility where the person lives • may be directly involved in providing health or professional care services to the person 	Bullet one seems reasonable. The others do not. The MAP Report ⁵ states that “the witnesses not be a member of the person’s healthcare team, which addresses the risk of collusion and impropriety among assessing medical practitioners and other members of a person’s health care team”, but goes on to say “During the consultation process, stakeholders were generally more concerned with coercion or undue influence from families than from health practitioners”. These arguments do not support excessive restrictions on witnesses.
15	R29: That the person appoint a contact person who will take responsibility for the return of any unused lethal medication to the dispensing pharmacist within 30 days after the person has died and act as a point of contact for the Voluntary Assisted Dying Review Board .	This would be useful but may not be practicable in every case. Failure to appoint such a contact should not impede the person’s access to VAD. These details about implementation, administration, and reporting etc may be best left to the regulations.
16	R32: That the dispensing pharmacist must attach labels and give information to the person.	This ignores the possibility/probability that the person will not be able to collect the medication themselves. Any WA legislation should allow for collection by a <i>substitute</i> modelled on s.26 of the MTPDA in which “an adult who has decision-making capacity may appoint another adult as the person’s appointed medical treatment decision maker” The substitute (amongst other things) undertakes to act in accordance with any “known preferences and values of the person making the appointment”; and must have read and understood “any advance care

³ MAP Report p. 124

⁴ MAP Report p.16

⁵ MAP Report p. 126

		directive that the person has given" (MTPDA s.29).
17	R33: That the person be required to store the lethal medication in a locked box	This may be impractical to monitor
18	R34: that the legislation not preclude health practitioners <i>from being present</i> when a person self-administers the lethal dose if this is the preference of the person.	Should go further to allow the MP to help the person or to administer the dose if so requested by the person. Family members should be allowed to be present.
19	R35: There must be protection in the legislation for an MP who is present at the time, and there is no obligation to provide life-sustaining treatment	Should also be protection for anyone else who is present and for <i>not preventing</i> the administration of the lethal drug - see point 26 below.
20	R36/37: That not being able to self-administer is defined as being <i>physically</i> unable to self-administer or digest the lethal dose of medication. 37: That <i>if the person is not able to self-administer</i> , the coordinating medical practitioner may administer the lethal dose of medication.	Too restrictive. The definition should be that the person is physically, mentally or emotionally unable to self-administer. In a person-centred process the person should be able to choose. Many people want the peace of mind of knowing that they have a lethal drug that they can administer when they feel the time is right. Others may want the peace of mind of knowing that their coordinating MP will be at hand to help them through the process of dying and to administer the lethal drug.
21	R38: That, <i>in the rare circumstance</i> the person loses the capacity to self-administer the drug, they must return to their coordinating MP if they wish to proceed with VAD. After the drug has been returned to the pharmacist, the coordinating MP may undertake the process to administer the drug.	This recommendation is ill thought out. Why would this circumstance be "rare"? For someone who has fulfilled all the criteria but whose death is not necessarily imminent, they may well want to have the drug available for when the time is right and is of their own choosing. As Andrew Denton says, people cling to life and many may leave it until it is beyond their capacity, either mentally or physically, to self-administer the drug. To recommend that such people "return" to their MP and have to return the drug before they can get help from their MP to die, overlooks the fact that they may have lost mental and/or physical capacity and throws additional hurdles into the path of those who need access to VAD the most.
22	R39: That, in the rare circumstance where both the coordinating and consulting MPs conscientiously object to administering the lethal dose of medication, the coordinating MP <i>can</i> refer the person to a new consulting MP willing to administer the medication. The new consulting MP must conduct their own independent assessment, after which the coordinating MP may transfer the role of coordinating MP to them.	See comment point 9 above. An MP who conscientiously objects to VAD and/or to administering a lethal drug to a person who is legally entitled to it, should declare their objection up front. This recommendation puts a hurdle in the way of a person who may need immediate access to VAD to prevent further intolerable suffering.

23	R40: That, if the coordinating MP administers the lethal drug, a witness who is independent of the coordinating MP must be present, and both <i>must certify that the person's request</i> [to go ahead] appears to be voluntary and enduring.	In many cases implementing this recommendation would put VAD out of reach for many people who need it. <i>Terminal sedation</i> – the administration of high doses of pain killing drugs <i>for palliative reasons</i> – is not illegal, even if its effect is to kill the patient slowly. Meanwhile the patient may continue to suffer extreme physical and/or mental distress and confusion, and may lose consciousness and mental capacity. ⁶ If the person has fulfilled all the criteria and been prescribed the drug, a substitute should be able to make the final request for them.
	Part C - Oversight	
24	R41-R53: monitoring after death and the VAD review board seem to be relatively uncontroversial but affect the MPs who participate more than those wanting access to VAD	MPs to comment
25	R49-53: monitoring of VAD – reporting requirements – as above	
26	R54: That the legislation provides clear protection for health practitioners who act in good faith and without negligence to facilitate access to VAD under the legislation.	Definitely necessary, as is protection for anyone else who is present and does not prevent a person from taking a legally prescribed lethal drug. Facilitation needs to be considered too.
27	R55/56: That a health practitioner <i>must</i> and any other person <i>may</i> notify the Australian Health Practitioner Regulation Agency if they <i>believe</i> that another health practitioner is acting outside the legislative framework.	This does not seem like a good idea at all – to oblige or allow someone to report a colleague or doctor on a “belief”. Perhaps more acceptable if “have strong evidence” were substituted for “believe”? A provision such as this is open to abuse on ideological rather than legal grounds.
28	R57: That there be an offence for administering a lethal drug to a person who does not have decision-making capacity.	See 23 above
	Part D- Implementation	
29	R56 - 66	Might be best left to subsequent regulation. Hon Robin Chapple's 2010 bill is a good model of the essentials to be included in any bill.

⁶ Dr Alida Lancee: *Moral and ethical dilemmas in end of life care*. National Ethics Conference, Sydney University, 22 June 2017. <https://dwdnsw.org.au/i-stood-up-for-what-is-right-perth-qp/>

Annexure 2 - Recommendations in MAP Report

Guiding Principles

Recommendation 1

That the following principles are included in the legislation to help guide interpretation:

- Every human life has equal value.
- A person's autonomy should be respected.
- A person has the right to be supported in making properly informed decisions about their medical treatment and should be given, in a manner that they understand, information about medical treatment options, including comfort and palliative care.
- Every person approaching the end of life has the right to quality care to minimise their suffering and maximise their quality of life.
- The therapeutic relationship between a person and their health practitioner should, wherever possible, be supported and maintained.
- Open discussions about death and dying and peoples' preferences and values should be encouraged and promoted.
- Conversations about treatment and care preferences between the health practitioner, a person and their family, carers and community should be supported.
- Providing people with genuine choices must be balanced with the need to safeguard people who might be subject to abuse.
- All people, including health practitioners, have the right to be shown respect for their culture, beliefs, values and personal characteristics.

Part A: Eligibility Criteria

Recommendation 2

That to access voluntary assisted dying, a person must meet all of the following eligibility criteria:

- be an adult, 18 years and over; and
- be ordinarily resident in Victoria and an Australian citizen or permanent resident; and
- have decision-making capacity in relation to voluntary assisted dying; and
- be diagnosed with an incurable disease, illness or medical condition, that:
 - is advanced, progressive and will cause death; and
 - is expected to cause death within weeks or months, but not longer than 12 months; and
 - is causing suffering that cannot be relieved in a manner the person deems tolerable.

Recommendation 3

That the capacity test in the Medical Treatment Planning and Decisions Act is used to assess a person's decision-making capacity in relation to voluntary assisted dying.

Recommendation 4

That when an assessing medical practitioner is in doubt about whether a person has decision-making capacity in relation to voluntary assisted dying, a referral must be made to an appropriate specialist for assessment.

Eligibility considerations

Recommendation 5

That mental illness does not satisfy the eligibility criteria for access to voluntary assisted dying, nor does mental illness exclude a person from eligibility to access voluntary assisted dying.

Recommendation 6

That disability does not satisfy the eligibility criteria for access to voluntary assisted dying, nor does disability exclude a person from eligibility to access voluntary assisted dying.

Part B: Request and Assessment Process

Initiating a request for voluntary assisted dying

Recommendation 7

That a request for access to voluntary assisted dying, or for information about voluntary assisted dying, can only be initiated by the person. Requests cannot be initiated by others, including family and carers.

Recommendation 8

That a health practitioner cannot initiate a discussion about voluntary assisted dying with a person with whom they have a therapeutic relationship.

Recommendation 9

That a request for information about voluntary assisted dying does not constitute a first request.

Recommendation 10

That the person may withdraw from the voluntary assisted dying process at any time. When the person withdraws from the voluntary assisted dying process, they must commence the process from the beginning if they decide to make a subsequent request for voluntary assisted dying.

Recommendation 11

That the legislation support access to voluntary assisted dying for people who are from culturally and linguistically diverse backgrounds and for people who require alternative means of communication, by allowing appropriately accredited, independent interpreters to assist them to make verbal and written requests for voluntary assisted dying.

Receiving a request for voluntary assisted dying

Recommendation 12

That two medical practitioners must undertake independent assessments of a person's eligibility for voluntary assisted dying.

Recommendation 13

That the roles of the two assessing medical practitioners be clearly defined as:

- the coordinating medical practitioner; and
- the consulting medical practitioner.

Recommendation 14

That both the coordinating medical practitioner and the consulting medical practitioner must be qualified as Fellows of a College (or vocationally registered); and

- at least one of the medical practitioners must have at least five years post fellowship experience; and
- at least one of the medical practitioners must have expertise in the person's disease, illness or medical condition.

Recommendation 15

That both the coordinating medical practitioner and the consulting medical practitioner must complete specified training before undertaking an assessment of a person's eligibility for access to voluntary assisted dying.

Recommendation 16

That the specified training comprise of obligations and requirements under the legislation including:

- assessing the eligibility criteria under the legislation;
- assessing decision-making capacity in relation to voluntary assisted dying and identifying when a referral may be required; and
- assessing the voluntariness of a person's decision to request voluntary assisted dying and identifying risk factors for abuse.

Recommendation 17

That the coordinating medical practitioner or the person may request that the role of the coordinating medical practitioner for the voluntary assisted dying process be transferred to the consulting medical practitioner.

Recommendation 18

That a health practitioner may conscientiously object to participating in the provision of information, assessment of a person's eligibility, prescription, supply or administration of the lethal dose of medication for voluntary assisted dying.

Making a request for voluntary assisted dying

Recommendation 19

That the person must make three separate requests to access voluntary assisted dying: a first request, followed by a written declaration of enduring request, and then a final request.

Recommendation 20

That the formal process for requesting voluntary assisted dying proceeds for the person as follows:

- The person makes their first request to a medical practitioner.
- The person undergoes a first assessment by the coordinating medical practitioner.
- The person undergoes a second independent assessment by the consulting medical practitioner.
- The person makes a witnessed written declaration of enduring request to the coordinating medical practitioner.
- The person makes a final request to the coordinating medical practitioner.

Recommendation 21

That the coordinating medical practitioner and the consulting medical practitioner must ensure that the person is properly informed of:

- their diagnosis and prognosis;
- treatment options available to them and the likely outcomes of these treatments;
- palliative care and its likely outcomes;
- the expected outcome of taking the lethal dose of medication (that it will lead to death)
- the possible risks of taking the lethal dose of medication;
- that they are under no obligation to continue with their request for voluntary assisted dying, and that they may withdraw their request at any time; and
- any other information relevant to the person's needs.

Recommendation 22

That the coordinating medical practitioner and the consulting medical practitioner undertake independent assessments to form a view as to whether:

- the person meets the eligibility criteria;
- the person understands the information provided;
- the person is acting voluntarily and without coercion; and
- the person's request is enduring.

Recommendation 23

That the final request may only be made after a period of at least 10 days has passed since the first request.

Recommendation 24

That there is an exception to the 10 day requirement when the coordinating medical practitioner believes that the person's death is likely to occur within 10 days and this is consistent with the prognosis provided by the consulting medical practitioner.

Recommendation 25

That the final request cannot be made on the same day that the second independent assessment is completed.

Recommendation 26

That a person's written declaration of enduring request must be in writing, be signed by the person, and be witnessed by two persons in the presence of the coordinating medical practitioner. The two witnesses must certify that the person appears to be voluntarily signing the declaration, to have decision-making capacity, and to understand the nature and effect of making the declaration.

Recommendation 27

That one of the witnesses to the written declaration of enduring request must not be a family member. The two witnesses must be 18 years and over and cannot be:

- a person who knows or believes that they are a beneficiary under the will of the person making the written declaration of enduring request, or a recipient, in any other way, of a financial or other material benefit resulting from the person's death; or
- an owner or operator of any health care or accommodation facility at which the person making the written declaration of enduring request is being treated or any facility in which the person resides; or
- directly involved in providing health or professional care services to the person making the written declaration of enduring request.

Recommendation 28

That the written declaration of enduring request allows the person to make a personal statement about their decision to access voluntary assisted dying.

Completing the voluntary assisted dying process

Recommendation 29

That the person appoint a contact person who will take responsibility for the return of any unused lethal medication to the dispensing pharmacist within 30 days after the person has died and act as a point of contact for the Voluntary Assisted Dying Review Board.

Recommendation 30

That, to conclude the assessment process, the coordinating medical practitioner complete a certification for authorisation to confirm in writing that they are satisfied that all of the procedural requirements have been met.

Recommendation 31

That the prescription of the lethal dose of medication requires an authorisation process.

Recommendation 32

That at the point of dispensing the lethal dose of medication, the dispensing pharmacist must:

- attach labels clearly stating the use, safe handling, storage and return of the medication; and
- provide the person with information about the administration of the medication and the likely outcome.

Recommendation 33

That the person be required to store the lethal dose of medication in a locked box.

Recommendation 34

That the legislation not preclude health practitioners from being present when a person self-administers the lethal dose of medication if this is the preference of the person.

Recommendation 35

That there be protection in the legislation for health practitioners who are present at the time a person self-administers the lethal dose of medication, including that the health practitioner is under no obligation to provide life-sustaining treatment.

Recommendation 36

That not being able to self-administer is defined as being physically unable to self-administer or ingest the lethal dose of medication.

Recommendation 37

That if the person is not able to self-administer, the coordinating medical practitioner may administer the lethal dose of medication.

Recommendation 38

That, in the rare circumstance the person loses the capacity to self-administer the medication after it has been prescribed, they must return to their coordinating medical practitioner if they wish to proceed with voluntary assisted dying. After the previously prescribed medication has been returned to the pharmacist, the coordinating medical practitioner may undertake the process to administer the medication.

Recommendation 39

That, in the rare circumstance where both the coordinating and consulting medical practitioners conscientiously object to administering the lethal dose of medication, the coordinating medical practitioner can refer the person to a new consulting medical practitioner willing to administer the medication. The new consulting medical practitioner must conduct their own independent assessment, after which the coordinating medical practitioner may transfer the role of coordinating medical practitioner to them.

Recommendation 40

That, if the coordinating medical practitioner administers the lethal dose of medication, a witness who is independent of the coordinating medical practitioner must be present. The coordinating medical practitioner and the witness must certify that the person's request appears to be voluntary and enduring.

Part C: Oversight

Monitoring after death

Recommendation 41

That the death certificate of a person who has accessed voluntary assisted dying identifies the underlying disease, illness or medical condition as the cause of death.

Recommendation 42

That accessing voluntary assisted dying should not affect insurance payments or other annuities.

Recommendation 43

That the medical practitioner who certifies death must notify the Registrar of Births, Deaths and Marriages if they are aware that the person has been prescribed a lethal dose of medication or if they are aware that the person self-administered a lethal dose of medication under the voluntary assisted dying legislation.

Recommendation 44

That the Registrar of Births, Deaths and Marriages and the Voluntary Assisted Dying Review Board share information relating to voluntary assisted dying.

Recommendation 45

That a death by means of voluntary assisted dying in accordance with the legislative requirements not be considered a reportable death for the purpose of the Coroners Act.

Voluntary Assisted Dying Review Board

Recommendation 46

That a Voluntary Assisted Dying Review Board be established under statute to review every case of voluntary assisted dying and report on the operation of voluntary assisted dying in Victoria.

Recommendation 47

That the role and functions of the Voluntary Assisted Dying Review Board be:

- reviewing each case of voluntary assisted dying and each assessment for voluntary assisted dying to ensure the statutory requirements have been complied with;
- referring breaches of the statutory requirements to the appropriate authority to investigate the matter such as Victoria Police, the Coroner, or the Australian Health Practitioner Regulation Agency;
- collecting information and data, setting out additional data to be reported and requesting additional information from medical practitioners or health services, for the purpose of performing its functions;
- monitoring, analysing, considering and reporting on matters relating to voluntary assisted dying.
- supporting improvement by facilitating and conducting research relating to voluntary assisted dying and maintaining and disseminating guidelines to support the operation of the legislation, in collaboration with other agencies and professional bodies and services; and
- any other functions necessary to promote good practice.

Recommendation 48

That the membership of the Voluntary Assisted Dying Review Board be appointed by the Minister for Health, and that the appointments reflect the appropriate knowledge and experience required for the Board to perform its functions.

Monitoring of voluntary assisted dying

Recommendation 49

That there is mandatory reporting by medical practitioners to the Voluntary Assisted Dying Review Board within seven days of:

- completing the first assessment (regardless of the outcome);
- completing the second independent assessment (regardless of the outcome);
- completing the certification for authorisation (which will incorporate the written declaration of enduring request and appointment of contact person forms); and
- when the lethal dose of medication is administered by a medical practitioner.

Recommendation 50

That, in order to monitor the lethal dose of medication, there is mandatory reporting within seven days to the Voluntary Assisted Dying Review Board:

- by the Department of Health and Human Services when the prescription is authorised;
- by the pharmacist when the prescription is dispensed; and
- by the pharmacist when unused lethal medication is returned by the contact person.

Recommendation 51

That reporting forms are set out in the legislation to provide certainty and transparency about the information that is collected. That these forms include a:

- first assessment report (which includes record of first request);
- second assessment report;

- written declaration of enduring request;
- appointment of contact person;
- certification for authorisation;
- dispensing pharmacist report;
- administration by medical practitioner report; and
- return of medication notification.

Recommendation 52

That the Voluntary Assisted Dying Review Board report to Parliament: every six months in the first two years after commencement, and thereafter annually.

Recommendation 53

That the voluntary assisted dying legislation be subject to review five years after commencement.

Protections and offences

Recommendation 54

That the legislation provides clear protection for health practitioners who act in good faith and without negligence to facilitate access to voluntary assisted dying under the legislation.

Recommendation 55

That a health practitioner must notify the Australian Health Practitioner Regulation Agency if they believe that another health practitioner is acting outside the legislative framework.

Recommendation 56

That any other person may notify the Australian Health Practitioner Regulation Agency if they believe that a health practitioner is acting outside the legislative framework.

Recommendation 57

That there be offences for:

- inducing a person, through dishonesty or undue influence, to request voluntary assisted dying;
- inducing a person, through dishonesty or undue influence, to self-administer the lethal dose of medication;
- falsifying records related to voluntary assisted dying; and
- administering a lethal dose of medication to a person who does not have decision making capacity.

Part D: Implementation

Voluntary assisted dying in the context of existing care options

Recommendation 58

That the implementation of voluntary assisted dying should occur within the context of existing care available to people at the end of life, and ensure voluntary assisted dying activity is embedded into existing safety and quality processes.

Implementation planning and governance

Recommendation 59

That work to establish the Voluntary Assisted Dying Review Board begin at least 12 months before the commencement of the legislation and is supported to develop a clear work plan to meet its legislated obligations including collection requirements and processes for receiving and recording data, procedural requirements related to its review, reporting and quality functions, and protocols for engaging and sharing information with other partners (such as the Department of Health and Human Services, Safer Care Victoria, and services and providers) for quality improvement purposes.

Recommendation 60

That the Department of Health and Human Services establish and support an Implementation Taskforce to investigate and advise on the development of voluntary assisted dying. The Implementation Taskforce should have the coordinating role in overseeing and facilitating the work set out in these implementation recommendations.

Recommendation 61

That the functions proposed by the Parliamentary Committee for End of Life Care Victoria be subject to a gap analysis in relation to existing entities and their functions to determine a clear role for the proposed agency.

Implementation support

Recommendation 62

That appropriate workforce support, information, clinical and consumer guidelines, protocols, training, research and service delivery frameworks to support the operation of the legislative framework are developed in a partnership between Safer Care Victoria, the Voluntary Assisted Dying Review Board and the Department of Health and Human Services in consultation with key clinical, consumer and professional bodies and service delivery organisations.

Recommendation 63

That the Implementation Taskforce establishes a collaborative coordination process across responsible agencies to periodically review the resources and frameworks that support the operation of voluntary assisted dying.

Research

Recommendation 64

That the Implementation Taskforce provide advice to the Department of Health and Human Services on engaging with a university to undertake research on the best practice identification and development of medications for use in voluntary assisted dying.

Recommendation 65

That a collaborative research program is developed with existing research entities to identify key clinical, policy and practice issues and align research with these priorities.

Commencement

Recommendation 66

That, in order to prepare for implementation, there is an 18-month period between the passage and commencement of the voluntary assisted dying legislation.