

# **Submission to**

## **UTAS VAD Review Panel**

addressing the processes allowed by the legislation, safeguards and protections for vulnerable people; and the interrelationship between the VAD Bill and other end-of-life choices.

**January 2021**

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## Go Gentle Australia: prefatory notes

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Go Gentle Australia (GGA) was established by Andrew Denton in 2016 to improve the national conversation around dying and to work for the introduction of safe voluntary assisted dying laws, appropriate to the circumstances of Australian medical, political, and social culture.

GGA grew out of a ground-breaking series of podcasts compiled by Andrew Denton and his production/research team. The Better Off Dead series presented first-hand accounts of Voluntary Euthanasia/VAD law in action around the world and is considered to be unique.

This experience and knowledge mean we bring a strong perspective on how a law practically works.

GGA's extensive experience in South Australia in 2016, Victoria in 2017 and Western Australia in 2019 as VAD legislation was being debated means we have a strong understanding of the political realities – and the pitfalls – of developing a law acceptable to both politicians and the general public.

In saying this, we want to underline that the first principle of any legislation is that it needs to be practically useful for the eligible person: providing sufficient safeguards to protect the wider good, but not to the point that the law becomes too onerous for those who need it.

The Victorian and overseas experiences demonstrate that laws need to be clearly written, in language which is unambiguous and easily understood. Local experience demonstrates that uncertainty around key terminology (e.g. suffering as a subjective concept) can cause confusion among legislators and lead to suggested amendments to a law which work against this first principle. The formulation and expression of the eligibility criteria, and how the law operates in practice, is critical.

Since its first anniversary, we have explored how the Victorian law operates, what are the experiences of both family members whose loved ones have accessed the law, as well as doctors who have operated within its framework to facilitate or participate in the assisted dying process. This has provided extremely valuable feedback.

In framing legislation, we must never lose sight of the fact that the aim of voluntary assisted dying is to support a person – who is already in the advanced stages of dying and who is suffering intolerably – to control the manner of their death.

## How we have responded

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The terms of reference this submission is being asked to address are:

- the processes allowed by the legislation,
- safeguards and protections for vulnerable people;
- and the interrelationship between the VAD Bill and other end-of-life choices.

We think the most useful way to do this is by addressing those parts of the bill which speak to the terms of reference. Many clauses are, in our view, self-explanatory or unremarkable, and there is sufficient evidence of how they operate in practice available from Victoria and elsewhere. Therefore, we are restricting comments only to those clauses, or sections, we believe require them.

Throughout, we have sought to illustrate our responses with examples of how VAD law has operated in practice in Victoria. These we have gained from several months of extensive interviews with doctors, families, and others involved in Victoria's law in its first year of operation.

In Section 20, we have added more general comments which we believe should be taken into consideration when devising and implementing VAD legislation.

## Part 1: Preliminary

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### Clause 3. Objectives and principles

We support the principles as laid out in the bill in clause 3.2:

*A person exercising a power or performing a function under this Act must have regard to the following principles:*

*(a) every human life has equal value;*

*(b) a person's autonomy, including autonomy in respect of end of life choices, should be respected;*

*(c) a person has the right to be supported in making informed decisions about the person's medical treatment, and should be given, in a manner the person understands, information about medical treatment options, including comfort and palliative care and treatment;*

*(d) a person approaching the end of life should be provided with high quality care and treatment, including palliative care and treatment, to minimise the person's suffering and maximise the person's quality of life;*

*(e) a therapeutic relationship between a person and the person's registered health practitioner should, wherever possible, be supported and maintained;*

*(f) a person should be encouraged to openly discuss death and dying, and the person's preferences and values regarding their care, treatment and end of life should be encouraged and promoted;*

*(g) a person should be supported in conversations with the person's registered health practitioner, family and carers and community about treatment and care preferences;*

*(h) a person is entitled to genuine choices about the person's care, treatment and end of life, irrespective of where the person lives in Tasmania and having regard to the person's culture and language;*

*(i) a person who is a regional resident is entitled to the same level of access to voluntary assisted dying as a person who lives in a metropolitan region;*

*(j) there is a need to protect persons who may be subject to abuse or coercion;*

*(k) all persons, including registered health practitioners, have the right to be shown respect for their culture, religion, beliefs, values and personal characteristics.*

We note that points (g), (h), (i), (j) and (k) do not appear in the Victorian VAD bill.

In our view, the practical consequence of these principles is that they will speak to, and guide, the medical community, families, institutions, and the general public, in their approach end-of-life care.

## Part 2: Interpretation provisions

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### Clause 6. Relevant medical condition

GGA strongly supports setting a time frame to death. We see this as important because it gives guidance to assessing medical practitioners and ensures consistency. By acting in this way as a fundamental safeguard, this provides confidence to the public and the Parliament.

GGA supports the eligibility requirements contained within this bill, with one, important exception: we would like to see the timeframe to expected death extended to 12 months for all conditions.

Statistically, the majority of people who access these laws overseas, and in the first year of Victoria's law, are 60 and older, and dying of cancer or chronic cardio-respiratory failure. The laws in VIC and WA – which allow for 6 months for those diagnosed with an incurable disease, illness or medical condition that is advanced and progressive and will cause death – will help those people.

The additional reach of the laws – 12 months for those with a neurodegenerative disease, such as motor neurone disease, multiple sclerosis, or Parkinson's disease – helps the next largest category of those who seek access to VAD. Many people with MND are over-represented in Australia's (and Western Australia's) suicide statistics.

The experience in Victoria shows that on average 25 per cent of applicants have progressed between their first and last request within 11 days, and 50 per cent within 19 days.

The VADRB in its last report states that if an applicant has all the required information, the process should only take a few weeks. However, it can take considerably longer if there are delays in gathering evidence, accessing medical practitioners, and completing the paperwork or correcting errors.

Experience from the first year of Victoria's law shows that many people come to VAD late in their illness. In a number of cases, they have died before being able to get through the process. In some, it has ended up being a race between a natural, and an assisted, death. For this reason, rather than there being a 6/12 month timeframe depending upon the nature of your illness, we believe that a 12 month timeframe of life expectancy for all eligible conditions will offer maximum palliative value and is appropriate.

Additionally, as the WA Ministerial Expert Panel noted:

*The Panel finds merit in the incorporation of a 12-month timeframe into the legislation. This timeframe is consistent with existing end of life policy documents including the National Consensus Statement on essential elements for safe and high-quality end-of-life care.*

*The Panel recognises that considering a 12-month timeframe is also consistent with existing practice. During the consultation process many health practitioners commented that they use the 'surprise question' (Would I be surprised if my patient died in the next 12 months?) when planning and discussing the treatment and care of people who are at the end of life. The Panel clarifies that although the surprise question involves consideration of a 12-month timeframe, this question*

*would not be appropriate for assessing the Panel's recommended eligibility criteria.*

While it is generally accepted that prognostication is not an exact science, research shows that physicians more commonly overestimate their patients' prognoses. A review of studies by White et al<sup>1</sup> in 2015 revealed that, across eighteen studies, the *predicted* median survival ranged from 14 to 219 days, while the *actual* median survival ranged from 10 to 126 days.

GGA also recommends legislation clearly and unequivocally state that injury, disability and advanced age are not, on their own, sufficient criteria, however, that none of these factors should rule out eligibility once all other eligibility criteria have been met.

### **VICTORIA: VOICES OF EXPERIENCE**

*"For the VAD, there were three needles, three syringes with stuff in them. So the first one is... a relatively light sedative that puts you... into like a light sleep. The second one knocks you out cold. And the third one is the one that ends the life. So, the doctor administered the first needle. Helen went quiet... And she was already gone."*

- Reg Jebb, whose wife, Helen, dying of MND, was so exhausted after taking more than 6 months to go through the application process that she died before the substance could be administered.

*For mum, it was four months and... every day seemed like a month*

- Lisa Hogg, whose mum, Margaret, took four months to be assessed as eligible for VAD. Margaret had a rare neurological disorder, Corticobasal Syndrome.

*"They're often well down the path towards death by the time they get to the stage of seeking the permit. So, we have so many that ... they get to form three and die, get to form four and die. ... Some who are really sick are terrified they're not going to be able to actually get to the stage of taking the medication because it's taken, in their mind, way too long."*

- Betty King, Chair of the Voluntary Assisted Dying Review Board.

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<sup>1</sup> <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0161407#sec025>



## **Clause 9. Authorised medical practitioners**

GGA supports the requirements for authorised medical practitioners in the bill. However, we believe that point (d) - relating to completion of a VAD training within a 5-year period before a person makes a first request – should be amended from five years, to two.

It is very important that VAD law be strictly followed. Doctors have ongoing obligations to upskill throughout their professional life. The details of a VAD course completed 5 years earlier may be difficult to recall in light of later education or training which may, or may not, be related to VAD. We believe a two-year timeframe before a first request is made will better support doctors throughout the VAD application process.

## **Part 3: When a person may access VAD**

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### **Clause 11. When a person meets residency requirements**

We agree with the requirements in both the VIC and WA legislation that the person accessing the legislation be an Australian citizen or permanent resident.

The purpose of the clause regarding residency is to discourage/prevent 'VAD tourism', whereby people with a terminal illness would move to a state solely to access VAD. This in itself is extremely unlikely. Terminally ill patients have support systems, including family, treating physicians and care givers, that are not easily moved.

However, there is a group of residents that do not necessarily require a permanent residency visa or citizenship to remain in the country. This includes:

- a range of [Working and Skilled Visas](#) which allow a person to stay in Australia permanently.
- people from NZ,
- British citizens who made Australia their home before current visa requirements were implemented in 1984. This group would now be advanced in age and therefor more likely to develop a terminal illness.

For this reason, we support the addition of clause 11 (1) (a) (iii) in the Tasmanian bill. BY adding point (iii) those on a different visa where a long-term or permanent stay is permitted, will be allowed access to VAD, without the prospect of encouraging 'VAD tourism'.

## **Clause 12. When a person has decision-making capacity, and;**

## **Clause 13. When a person is acting voluntarily**

The legal principle 'competent (capacity) until proved otherwise' is well-established in Tasmania's medical law.

GGA believes that capacity regarding a request for VAD should be determined by the two assessing medical practitioners in the following way:

A person has decision-making capacity in relation to a decision when they are able to:

- understand the information relevant to the decision and the effect of the decision;
- retain that information to the extent necessary to make the decision;
- use or weigh that information as part of the process of making the decision; and
- communicate the decision and the person's views and needs as to the decision in some way, including by speech, gestures or other means.

### **VICTORIA: VOICES OF EXPERIENCE**

*I proceed exceptionally carefully, you know, ... there's many safeguards, and it's clear. And because they're my patients, I do know exactly the decision-making capacity. we don't give patients treatment if they can't decide on which treatment to have.*

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- **Medical Oncologist, Professor Phillip Parente**

*There's nothing exact in medical science, and in healthcare, but you can be as sure as you can be that a person has decision making capacity. And we make those judgments every day of the week.*

- **Palliative care physician, Greg Mewett**

*People forget that we test competence capacity every single day in professional clinical life, because every time we have a conversation with someone, they make a decision about their health care, we're making an assumption of competence.*

- **GP, Nick Carr**

It is important to keep in mind that, under Australian medical law, decision-making capacity is already protected in other end-of-life decisions by patients.

In Australia, there is no requirement for psychiatric assessment if a patient declines treatment, including life-sustaining treatment. It is entirely the decision of the patient, provided they are an adult. Not respecting someone's refusal for treatment would be assault – it is treatment without consent.

Judicial decisions of the Supreme Courts of NSW (CJ McDougall), WA (Rossiter), and SA (J Kourakis) have all determined the right of competent persons to make these decisions without mandatory psychiatric assessment. All confirmed that such action was not suicide, and that such persons should be considered to be dying, and provided with the same palliation of any suffering and/or distress as any dying person.

GGA believes that Tasmania's current laws – along with existing case law – supply sufficient guidance in the case of assessing capacity for VAD, as they currently do in other end-of-life decisions.

#### **Clause 14. When person is suffering intolerably in relation to relevant medical condition**

GGA supports the position taken by the WA Joint Select Committee – which is also that contained within both the Victorian and Canadian legislation – that the eligibility criteria include that the eligible condition is causing suffering that cannot be relieved in a manner acceptable to the person.

GGA also supports the position taken by the Joint Select Committee which is that suffering be subjectively assessed – that is, from the person's point of view. This is consistent with a person-centred approach, not only to VAD, but to health care in general.

No doctor can measure suffering, but they can determine what suffering is claimed and relate that to the state of the illness to create some objectivity. Suffering can also be measured against treatments that have – or are – being tried (and the impact of those treatments).

## **VICTORIA: VOICES OF EXPERIENCE**

*We examine on a weekly basis every death that occurs here, VAD or otherwise. So, I think that when you have a lot of experience in cancer land, and can see what the trajectory of the patient has been, what types of treatment they've had, and what sort of palliative care they've had or had access to. To be honest, a little bit about who's been looking after them. Because a lot of these people are with clinicians who will have tried every possible means to alter the natural history of their disease. And when those clinicians are saying, 'We've got nothing more to give, there are no other alternatives'. Then we need to take that on board and by and large, most of the people that I have seen at one way or another fulfilled those criteria.*

- Peter MacCallum Cancer Centre, Chief Medical Officer, David Speakman.

*I've got to know that for whatever the condition they've got, their treating subspecialist has said, you're at the end of the line, I don't have anything else that I can offer you. That's the starting point.*

GP and Rheumatologist, Dr Andrea Bendrups

## **Part 4: Communication in relation to access to VAD**

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### **Clause 15. When person's communication under Act may be made by another person**

The draft legislation should provide that an interpreter who assists a person in requesting or accessing voluntary assisted dying must be accredited and impartial, in similar terms to the legislation in Victoria and Western Australia.

GGA considers it essential that the need to be respectful of cultural differences – as well as sensitivities to VAD that may be present in communities afflicted with high rates of suicide – be taken into account.

It is important to have appropriate resources (such as interpreters and resources in community languages) to properly inform people about voluntary assisted dying. People from culturally and linguistically diverse communities, people with communication or cognitive impairments, people with disabilities and the Deaf community, will each require purpose-built resources.

A person who does not speak English, or requires other types of communication assistance, should be able to seek assistance from an accredited interpreter, including an accredited Auslan interpreter, when accessing voluntary assisted dying.

The use of accredited and impartial interpreters is an important safeguard in ensuring the interpretation is independent and that the person is acting voluntarily.

People who do not communicate orally or in writing should not be prevented from accessing voluntary assisted dying when they meet all of the eligibility criteria.

We support in particular point 5 which allows for the occasion where communication with the person maybe be difficult to understand for an outsider, whereas a family member may be able to understand and assist with the communication.

### **VICTORIA: VOICES OF EXPERIENCE**

*"I've had people that have required an interpreter. I've done a whole assessment via an interpreter. And this lady was very clear. She only ... knew one word in English: legislation. The only English word she ever spoke to me."*

- Professor Phillip Parente, Oncologist, Director of Cancer Services at Eastern Health.

## **Clause 17. Certain persons not to initiate discussions about voluntary assisted dying**

GGA does not support this clause.

We understand concerns that the provision of information about voluntary assisted dying may be taken as a suggestion by a health practitioner that their patient should follow that pathway.

Nonetheless, we note the WA End of Life Choice Committee's observation that:

It is usual practice for health practitioners to have discussions with patients about life and death decisions, and this includes appropriately informing people of the relevant options currently available to them. These may include discussions about treatment initiation and withdrawal, Advance Health Directives and decision making about Cardio Pulmonary Resuscitation (CPR).

To this, we would add discussions about withdrawal of life-sustaining treatment and Voluntary Refusal of Food and Fluids.

On this basis, it is our view that medical practitioners should not be censored on the conversations they can have with their patients, and they should be able to raise the option of VAD with patients without fear of being reported for disciplinary action. As noted by the WA Committee, Victoria is the only jurisdiction in the world with VAD / PAD that prohibits health practitioners from starting such a conversation.

However, we do recommend that, in addition to discussing VAD, in the same consultation it be mandated that all other appropriate treatment options be discussed, including, particularly, palliative care.

To assist medical practitioners in this – and to ensure that balanced and well-thought-through information, consistent with good end-of-life care, is given to each person who enters into such a conversation – GGA recommends that printed /electronic literature be created by the Department of Health, outlining, not just the process for VAD but also other possible pathways including, most particularly, palliative care.

We note that, with the exception of Victoria, no VAD/VE law anywhere else in the world forbids the doctor from initiating such a conversation.

## **VICTORIA: VOICES OF EXPERIENCE**

*"One of the most important things that I think should be changed in legislation is that doctors are not allowed to bring it up in a consultation. You can talk about palliative care, but you're not allowed to tell them about the VAD option, which is a bit mad to me."*

- **Dr Andrea Bendrups, GP and Rheumatologist, Royal Melbourne Hospital**

*"I think the other thing that's had an effect on is not only the doctor-patient interaction but the nurse-patient interaction on the ward, other health care professionals and the patient because no one is really sure about whether that means every time that this needs to be raised they need to talk, they need to wait for the patient to raise it or not."*

- **Dr Cam McLaren, Oncologist, Melbourne**

*"It's like saying to someone with heart disease, I can give you pills but not tell them about the option of surgery. And voluntary assisted dying is one of their legal rights of medical care and for a doctor not to be able to inform some of that is ridiculous. The idea that any doctor is going to foist voluntary assisted dying on people is just an insult. It's not gonna happen."*

- **Dr Nick Carr, GP, Melbourne**

## Part 5: First request

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### **Clause 20. Refusal to accept first request, and;**

### **Clause 21. Medical practitioner not required to give reasons for accepting or refusing request**

GGA considers the right of any medical practitioner to object conscientiously to VAD to be a bedrock of the law. Legislation must specifically permit physicians to 'opt out' without sanctions or criticism. This may be on the grounds of religion. It may be because he/she is unwilling to participate in a process that is unfamiliar to him/her or because they view it as against their Hippocratic oath. Whatever their reason, a doctor has an absolute right not to participate.

While the doctor's rights must be protected, so too must the rights of the dying patient.

GGA recommends that any institution that refuses to allow VAD on its premises must inform potential patients/residents of this policy prior to admission of the person. And that their position should also be part of any published literature (print, digital, or other) where they advertise, or inform people about, their services. This is to avoid a potentially harmful situation if a patient should ever wish to apply for VAD.

An institution that is religiously or philosophically opposed to VAD, if requested by a person in their care to provide VAD, must immediately respond, informing them they cannot support that request. They must then facilitate transfer to a suitable facility in a timely and professional manner. Until such transfer can be arranged, no institution should be allowed to block access to the person making the request of: either the co-ordinating or consulting practitioner; the care navigators; the pharmacist; or anyone else involved in that person's legal right to access VAD. Any efforts to do so should be punishable by a fine.

We believe conscientious objectors (doctors and institutions) should, in line with duty of care obligations, be compelled to refer people in their care to a place where they can find information, such as the Care Navigators or a body similar to Safer Care Victoria or the DHSS, which can also provide a referral. In addition, they must also – in a timely manner – give access to, or transfer, the patient's medical file, in order to provide the full known patient history.

## VICTORIA: VOICES OF EXPERIENCE

*"Our only request of any of our staff who objects to the process that if a patient does bring it up, they explain to them where they can access information about the program or how to explore it. And that they're also welcome to explain why they don't particularly participate. But yeah, and that that's what the law requires. I think that's important."*

- Dr David Speakman, Chief Medical Officer, Peter MacCallum Cancer Centre

*"I feel really disappointed. Especially since they knew him and they'd seen his decline, and were intimately aware of how difficult it was for him. And the impact that it had on his mental health and general state of being in the world, and to not have any compassion in regard to that. I couldn't understand why it is better for someone to suffer and have a horrible death ... It just seemed to make no sense to me at all."*

- Deb M whose brother, Colin, was dying of metastatic bowel cancer. The ethics committee of the Catholic nursing home in which he was resident, took nine days to inform Colin that they had denied permission for the pharmacist to deliver his medication to him. He was eventually transferred to a hospital after considerable distress to both himself, and his family.

## Part 6: Second request

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### Clause 30. Person may make second request

The current draft bill stipulates the second request as well as the final request must be in writing. It seems unnecessary to have BOTH requests in writing.

Of course there needs to be a formal request in writing, but we feel it is more appropriate after two independent medical practitioners have determined eligibility.

This allows for ample discussion with the assessing practitioners to explore other treatment options as well as time for further reflection on the part of the person. At this stage, the patient cannot be more informed about their decision.



We note that in both the Victorian legislation (Clause 34) as well as the WA legislation (Clause 42) the written declaration comes after assessment by two independent practitioners. However, the FINAL request (VIC Clause 37; WA Clause 47) may be made verbally.

### **Clause 31. Certain persons may not witness a second request**

We do NOT support excluding a family member as a witness to a second request. Family is often closely involved. Given that a potential witness must already NOT benefit (financially or otherwise) we feel that is a sufficient safeguard. Many patients will opt to discuss this within their family and may want family support.

**We do support that the legislation provide that not more than one witness may be a family member of the person making the declaration (as in Victoria).**

To avoid doubt about questions of possible family coercion, we believe it is appropriate for only one family member to act as a witness.

However, the current draft legislation requires a written request, witnessed by two independent witnesses, be submitted twice: as a second request and then again as a final request. We feel this is not necessary and feel one written request should be sufficient. See also our answers to [Clause 30. Person may make second request](#) and [Part 10: Final requests](#).

We note the value of witnesses to be able to ask questions of the coordinating practitioner to ensure they are comfortable with providing their signature.

#### **VICTORIA: VOICES OF EXPERIENCE**

*"I make it very clear to the witnesses that your role is not just to witness the signature, it's to witness the person does have the mental capacity, that's their own free will. They know exactly what will happen when they take the medication and so on. And once they get the medication, they don't have to take it. So the witness needs to be reassured that all that's the case before they can sign."*

- Dr John Stanton, GP, West Brunswick

*And they ask all those questions you know. I think we were asked it every time, was it? How we felt about it? Obviously, for Robert, that none of us were forcing him to do any of this. At no stage we could take Paul to anything of it, because Paul was in Robert's will so everything had been left to Paul so Paul couldn't be involved in any of that.*

- Jean Caliste, whose son, Rob, died of MND.

## Part 7: Referral to medical practitioner for second opinion

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### **Clause 37. PMP who determines person eligible must refer person to medical practitioner for second opinion .**

We support the provision that two medical practitioners must each assess the person's eligibility, and that they 'must be independent of each other'. This means that one medical practitioner must not be employed by or working under the supervision of the other medical practitioner, and that the medical practitioners must not be family members.

While the assessment must be made independently, both practitioners will still be able to rely on existing medical records, which should be made available on request. We note that in this context, a practitioner who exercises their right to conscientiously object, should still be required to make relevant medical records available.

We also note that the establishment of an independent referral service for practitioners who are trained to assess for VAD, would provide an additional safeguard to ensure practitioners are truly independent of each other. It would also greatly assist the process of finding a second practitioner and ensure equitable access, particularly in rural areas. In Victoria, the VAD Care Navigators have, to a certain extent, fulfilled this role.

## Part 8: Requirements where referral accepted

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If a practitioner is not able to determine that the person has decision-making capacity in relation to voluntary assisted dying, or that they are unclear about diagnosis or prognosis – they must refer the person to a health practitioner with appropriate skills and training to make a determination in relation to the matter (as in Victoria and Western Australia).

If a practitioner is not able to determine if the person has a disease, illness or medical condition that meets the eligibility criteria – they must refer the person to a specialist medical practitioner with appropriate skills and training in that disease, illness or medical condition (as in Victoria);

If a practitioner is not able to determine if the person is acting voluntarily and without coercion – they must refer the person to another person who has appropriate skills and training to make a determination in relation to the matter (as in Western Australia).

## VICTORIA: VOICES OF EXPERIENCE

*"The legislation allows us to make a referral. So for example, if I wasn't sure about, say, a respiratory problem. And I didn't think that the management had been adequate. I have the opportunity to say, look, and I'm not prepared to make a call based on this assessment. I'd like you to go and see Dr Bloggs, who's a respiratory specialist for independent respiratory assessment so that he can he or she can look at everything you've had done all of the treatment options for the condition that you've got and to reassure me that you've had all of the things that are potentially useful for your condition."*

- Dr Andrea Bendrups, GP and Rheumatologist, Royal Melbourne Hospital

*"When it comes to complex malignancy, I would defer mostly to an oncologist and their opinion would, in my view, outweigh mine because some of these malignancies are fairly uncommon and as a general practice, we don't deal with them all that often."*

- Dr Nick Carr, GP, Melbourne

## Part 9: Second opinion as to eligibility to access VAD

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We note reference to meeting the person 'by way of audio-visual link'.

GGA supports the use of audio-visual consultation for VAD in the event that the CMP considers it too onerous, or too painful, for the person to travel. However, we also note that there will be times where only a face-to-face consultation, particularly in the case of complex neurological disorders, will be sufficient. We therefore believe that audio-visual consultation should only be used in exceptional circumstances, at the direction of the PMP, who must document their reasons why.

### **Clause 52. Where process ends under Section 51 former PMP may not accept first request for 12 months.**

We strongly disagree with this clause as it is potentially highly prejudicial to the needs of the patient. While the law may place a 12 months' time limit on the PMP's right to hear a

new first request from a patient, the illness the patient is suffering from knows no such timeframes.

A very-likely scenario which could result from this clause, is of a person, who may have lung cancer, being ruled ineligible by 2 CMPs. Within 3 months the cancer has metastasised into the liver or the brain but, due to this clause, they are unable to approach the PMP who may have been their family GP or their treating oncologist. This unnecessarily penalises the patient, who will have no option but to seek out an unfamiliar doctor.

The first principle of VAD law should be that it protects the interest and needs of the terminally ill.

We recommend that, should the scenario outlined in Clause 52 arise, that the PMP, when facing a new request from the same patient, must inform the CMP at the time of their assessment that the previous application had been ruled ineligible by 2 CMPs.

## **VICTORIA: VOICES OF EXPERIENCE**

*There was one lady who had a neurodegenerative disease, but she was certainly more than 12 months out from the way her disease was going. And we had this discussion about she didn't fulfil the criteria. I think she was really annoyed that I just couldn't do it for her then and there at that stage.*

- GP, Dr Nola Maxfield

*I've denied people access to the legislation who failed that criteria. And I said, I'm saying no, today. That doesn't mean no, later on. So please ask again.*

- Medical Oncologist, Professor Phillip Parente

*I spoke to a woman just a few weeks back. When I first met her, we weren't sure how well she was going to go. Two months later, things have gotten a bit better. I haven't completed her first assessment because I don't believe her prognosis is less than six months. So, we'll just keep in touch. And then if things don't go well, then we'll move on.*

- GP, Nick Carr.

*Yes, I did decline a request that came for a referral from a GP and it was purely on prognosis, there was no doubt. I had a good talk with and one of our haematologists has done the training, just as a consulting and he said no, clearly this man, he may have two years given where his trajectory is. But I've always said to him, we'll revisit this if things change.*

- Palliative care physician, Greg Mewett.

## VICTORIA: VOICES OF EXPERIENCE

*I have had patients ... who have just said all right we are going to treat this for as long as we can and then I want VAD ... and then we talk about that a bit more and ... I say okay well you are not eligible yet because you know we are doing chemotherapy and I expect that this will last for a good deal more than that but I am really glad that ... you've seen me now. I can talk to you about the paperwork that you will need when the time comes. So, all of that's in order, it's ready to go.*

- Medical Oncologist, Cam MacLaren

## Part 10: Final requests

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We refer to our answers in [Part 6: Second request](#)

It seems unnecessary to have two requests in writing. There are many check points along the way to determine whether a person wishes to proceed. Experience from Victoria shows that many people are desperately ill by the time it gets to writing their final request. To make them write two seems unnecessarily onerous.

Of course there needs to be a formal request in writing, but we feel it is more appropriate after two independent medical practitioners have determined eligibility.

This allows for ample discussion with the assessing practitioners to explore other treatment options as well as time for further reflection on the part of the person. At this stage, the patient cannot be more informed about their decision.

We note that in both the Victorian legislation (Clause 34) as well as the WA legislation (Clause 42) the written declaration comes after assessment by two independent practitioners. However, the FINAL request (VIC Clause 37; WA Clause 47) may be made verbally.

### Waiting period

For a person who is terminally ill and experiencing enduring and unbearable suffering, even 24 hours is a very long time to wait to end that suffering.

GGA endorses the inclusion of a minimum timeframe between first and last requests to enable reflection by the person about the decision to access VAD. This time period should be as short as reasonably possible (and no more than ten days).

It should be noted that, in Oregon, where there is a 15-day waiting period between first and final request, 20 per cent of people die before they are able to complete the process. In July 2019 an amendment was passed which allows Oregonians expected to die within 15 days to bypass the waiting period<sup>2</sup>

If a mandatory waiting period is instituted in the law, GGA endorses the provision for a timeframe to be reduced to as little as 1 day if, in the opinion of both participating medical practitioners, death or loss of capacity is imminent, and the person's suffering has become intolerable. It would be unreasonable to require them to wait, as delay may effectively preclude them from accessing voluntary assisted dying and will impose further days of intolerable suffering.

### **VICTORIA: VOICES OF EXPERIENCE**

*"10 days for someone who is in agony with every breath that they take is, you know, it's a long time. ... I could see Dad was very deflated about that ... so, we had to see another doctor. She had to then come in and ascertain that Dad was in his right mind again, ask him the same set of questions."*

- Katie Harley, whose father, Phil, died of multiple metastatic cancers. He applied successfully to have the 10-day cooling off period shortened. Nonetheless, it was a stressful time for Phil and his family.

*"I was emailing ... basically, at every step to keep them updated so that they knew how much this was necessary"*

- Dr Cam McLaren, Phil's co-ordinating practitioner.

*"Even with the application, there was no guarantee it was going to be approved because they had to assess that this man was you know, they had to rely on both Cam's and the other doctor's medical opinion that Dad was progressed to this situation"*

*It needs to be that the person is expected to die within that nine-day period or they're very close to the end. First and foremost, you need to have a really clear understanding from the VAD doctor and any other treating doctors of how quickly that person is deteriorating.*

- Representative, VAD Care Navigator Service

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<sup>2</sup> <https://gov.oregonlive.com/bill/2019/SB579/>

## Part 11: Health practitioner who is to supply VAD substance to person

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### Clause 63. Requirements for appointment of AHP.

To ensure there is appropriate access to VAD, a suitably qualified nurse practitioner may be authorised to administer the VAD substance, but only in circumstances where, geographical distance and/or imminent death require, and only when the body overseeing VAD has confirmed that the person is eligible and that the nurse practitioner is qualified to administer the substance.

We note that the training requirements for a nurse practitioner in Tasmania<sup>3</sup> far exceeds the training of a registered nurse<sup>4</sup>. Given the seriousness of VAD, we feel it is imperative that administering should be limited to suitably trained nurse practitioners only.

We refer to our answer regarding **Clause 9. Authorised medical practitioners** . We believe that the VAD training should have taken place within two years, not five.

The relevant experience as mentioned in subclause (iv) should also apply to nurse practitioners.

## Part 12: Authorisations and prescriptions in relation to VAD substances

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We support the process as outlined in the law in Victoria and note that we feel it should be in line with existing Tasmanian legislation.

The issue of the permit is the final sign-off that the process has been completed in accordance with the law. It also provides protection to the doctor under the law.

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<sup>3</sup> [https://www.dhhs.tas.gov.au/\\_data/assets/pdf\\_file/0004/64084/NP\\_Frequently\\_Asked\\_Questions\\_-\\_2008-03-12.pdf](https://www.dhhs.tas.gov.au/_data/assets/pdf_file/0004/64084/NP_Frequently_Asked_Questions_-_2008-03-12.pdf)

<sup>4</sup> <https://www.acnp.org.au/classification>

## Part 13: Final administrative requirements

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### Clause 71. What pharmacist may do on receiving VAD substance prescription.

We strongly recommend that the Victorian model be adopted, whereby all prescriptions for the VAD substance are written, and delivered to the person by, a central, state-wide pharmacy service.

This has multiple advantages:

- It means that all doses have been centrally created, to the same quality control specifications, which will minimise the risk of complications.
- It will remove possible delays, at a most critical time, should a PMP discover that the pharmacist they have approached conscientiously objects to VAD
- As in Victoria, the role of the pharmacists in delivering the medication acts as a final safeguard. Independently of the PMP or CMP they can make an assessment of the person's capacity and of the voluntary nature of their request.
- The contact person is required only to return unused medication to the pharmacy service.
- Pharmacists also play an important educational role by training those who will be present when the substance is self-administered how to prepare the substance, and by answering any questions about that may arise.
- Finally, the pharmacists supply advice and support to medical practitioners, particularly those who are administering a VAD substance to a patient.

We also recommend that the pharmacy supply the substance in a standardised locked box. This will avoid the necessity for PMPs or AHPs to have to find the same.

#### **VICTORIA: VOICES OF EXPERIENCE**

*Very early on, we decided that it was really important that there was a centralised approach. This wasn't a type of scenario where you could just go to any pharmacy or go to any GP and get a prescription. This is very different circumstances. That was really important for patients and their families to make sure you really had the ability to deliver consistent and quality service. So we decided to have a State-wide Victorian pharmacy service. It is very different to just doing a prescription. The service is very different in how it supports medical staff and nursing staff. How we have to go into patients' homes and have conversations with them and assess patients to do all the things we do isn't something that could just be done all over the place by different people.*

- Professor Michael Dooley, Head of the State-wide Pharmacy Service



## **VICTORIA: VOICES OF EXPERIENCE**

*There may be a difference between the time that we see them and the time that the doctors had seen them. We speak to all the medical staff. But it's been a small number where they haven't been able to demonstrate either competency or haven't been able to demonstrate they're able to take it and those instances, we've had to make a difficult decision to say no.*

- Professor Michael Dooley, Head of the State-wide Pharmacy Service

## **Clause 78. Final determination by AHP of decision-making capacity and voluntariness.**

We support that the AHP must determine whether the person still has decision-making capacity and is acting voluntarily

## **Part 14: Provision of assistance to die**

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### **Division 1 – Supply and administration of VAD substance where no private self-administration certificate**

We recommend the legislation provide that a witness, who is independent of the administering practitioner, must be present when the practitioner administers the voluntary assisted dying substance.

As the patient is no longer fully in control, we feel this is an important safeguard that protects both the patient and the doctor.

### **Division 2 – Self-administration in private**

We note that the bill requires the AHP to demonstrate how to self-administer. However, this is not the case in Victoria.

In Victoria, the State-wide Pharmacy Service provides clear instructions to the nominated person (often the contact person) about how to prepare the medications. We believe this is appropriate, also, for Tasmania. Please refer to our notes on Clause 71.

## VICTORIA: VOICES OF EXPERIENCE

Nicole

*"They walked us through step by step, making sure mum was well aware at every stage, exactly what happens with the medication. We did a mock mixing of the medication."*

Jacqui

*"They bring a dummy kit with them."*

Nicole

*"To practice, to make sure that there is no room for error."*

- Nicole Robertson and Jacqui Hicks - whose mother, Kerry, was the first to use Victoria's law – describing the role of the pharmacists.

## Part 15: Review of decisions

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### Clause 94. Interpretation of Part 15

We do not support an eligible applicant (who may apply to review a decision) to be defined as in Clause 94 (c):

- *any other person who the Commission is satisfied has a special interest in the medical treatment and care of a person who is the subject of a decision referred to in section 95(1).*
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We feel clause 94 (c) leaves the door open to allow frustration of the process by family members, or even health professionals, who may disagree – for reasons of personal belief, or for other reasons - with VAD.

## VICTORIA: VOICES OF EXPERIENCE

*"That's why... we didn't tell any of the nursing staff that she was planning to do this because Mum was absolutely terrified that somebody would stop her because she knew she was in a Catholic nursing home. She was worried that someone would stop her going through the process or stop her, would stop us taking her out on the day that it was to happen. And it was very stressful for her."*

- Lisa Hogg whose mother, Margaret, was dying of a neurological illness. Margaret, herself a former nurse, had fears that staff of the Catholic nursing home would block her from leaving once they realised her choice to access VAD.

## **VICTORIA: VOICES OF EXPERIENCE**

*Anecdotally, we've had feedback from contact people about the person being told that it would take too long, you'd be dead before this, palliative care is infinitely better, this is a painful process. By far the majority, their GP does not support them. Not that they're opposed to it. A lot of them aren't opposed, they just say I haven't got time, I can't. ... you go and find someone. But there's a few that actively try to dissuade. And that's a complete reversal of conscientious right to object to it. You don't have the conscientious right to change someone's mind.*

- Betty King, Chair of the Voluntary Assisted Dying Review Board.

## **Part 17: VAD Commission**

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GGA strongly supports the creation of a Commission. Transparency will be important to guarantee public confidence in the legislation. Indeed, we consider the review process to be the final safeguard.

We believe a Commission is best served by members with a wide range of experience in public health, consumer advocacy, palliative care, and legal services.

For example, Victoria's Voluntary Assisted Dying Review Board is chaired by a retired Supreme Court judge and includes amongst its members: a neurologist, an oncologist, a palliative care specialist, a professor of nursing, and a consumer representative.

Each member of the board carries expertise and long experience in their field. We believe Tasmanians will draw comfort from a similar approach to a board of review. GGA specifically recommends a representative from the disability communities, in recognition of their particular concerns about how they are regarded by the medical community.

We recommend the board also be involved in community engagement and the promotion of compliance and continuous improvement. To this end, we recommend the Commission collects and publishes more extensive data than is currently happening in Victoria.

Additional to that which is being reported in Victoria, we would like to see data published about:

- number of people also receiving palliative care;
- numbers of people who apply but do not continue with VAD and their reasons;

- numbers of people who die before completing the VAD process;
- the location of the death – eg, at home, in hospice, or hospital;
- the end of life concerns, eg being a burden, pain, control, etc.

We would be happy to provide a more extensive list to bring reporting more in line with overseas jurisdictions, such as Oregon or the Netherlands.

As part of its reporting to the Parliament, the Commission may recommend changes to the legislation to improve its operation.

We suggest, however, that the Commission's functions do not include sections (1) (b) (c) (d) (e), or section (3). In our view, these are operational parts of the law which would be best served by a service such as the VAD Care Navigators Service in Victoria.

We feel that it is not appropriate that the Commission, as is proposed, is both actively involved in the operation of the law, yet also reviewing its operation.

#### **VICTORIA: VOICES OF EXPERIENCE**

*"And then ... over the top of all that is the Board ... an independent group set up by the government, who, who are watching every one of these cases, as they roll through... and so, again, an additional safeguard that people aren't practising outside the realms of what's expected. And I totally accept that this program needs to be completely transparent. And we need to be crystal clear that it is impossible for anyone to be coerced into this, for people to be able to access it outside the rules or outside the process that's been set up."*

- Dr David Speakman, Chief Medical Officer, Peter MacCallum Cancer Centre

## **Part 18: Offences**

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We support all offences listed however, we note the following are not included in the Tasmanian bill but do appear in the VIC and/or WA bill.

- Administering the substance when not authorised to do so. In Victoria, this includes administering a substance dispensed under a self-administration permit to another person. (VIC ss 83, 84; WA s 99)
- Advertising a Schedule 4 poison or Schedule 8 poison as a voluntary assisted dying substance (WA s 103)

We believe these, too, should be listed as offences.

## Part 20: Miscellaneous

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### Clause 143. Review of Act

Legislation should mandate a parliamentary review, initially in three years after commencement of operation, and after that every five years, to see that the Act is operating properly and to make recommendations for legislative amendments that will improve the operation of the Act.

In addition, GGA strongly recommends the following:

- **The establishment of an Implementation Taskforce** to coordinate the work that will need to be completed to prepare for the commencement of the legislation. The Taskforce must engage with, and involve, key stakeholders to develop effective implementation strategies and resources. Consistency in implementation and governance arrangements and staff support may best be facilitated in partnership with professional colleges and bodies such as the Australian Medical Association, Australian Nursing and Midwifery Federation, relevant professional colleges, pharmacy bodies, and consumer, carer and service representatives.
- **GGA recommends an implementation period of no more than 12 months** between the passing of the law and its activation so that Tasmania's medical system, and medical practitioners, can be made ready for the necessary changes in practice that such a law will bring. While both Victoria and WA mandated 18-month implementation periods, Tasmania will have the advantage of being able to build on the combined knowledge and experience of both States when setting up its system. This should make possible a shorter implementation period with the clear benefit of making VAD available more quickly to those in need.
- **The establishment of a Secretariat on Palliative and End-of-Life Care** to emphasise the interlocked nature of full spectrum EOL care by developing a flexible, integrated model of palliative care, including VAD. This will be done by implementing a state-wide end-of-life strategy with dedicated funding, and developing a public awareness campaign on the topic.
- **The establishment of a VAD Care Navigator service** that can assist with any or all queries regarding the correct process of the law. This team should also have access to doctors who have completed the VAD training and have indicated they are willing to participate so that referral to a participating doctor after refusal from a treating physician can be facilitated without delay.

- **We feel the role of tele-health should be carefully considered** . While we support use of this for follow-up consults, we feel it is also crucial to have in-person consultations.
- **Reporting forms for doctors should be in plain English and as uncomplicated as possible** (just as the portal should be efficient, clear and fast). Almost every doctor we have spoken with in Victoria has complained about the difficulty in navigating the forms they are required to submit. The practical effect of this is that clerical mistakes can lead to processes having to be repeated and dying people being put under greater stress. It also discourages doctors, who may otherwise consider doing so, from taking on VAD training.
- **Penalties should be included in the Act for doctors who do not give a timely response** – either yes or no – to patients who approach them with a VAD request. Anecdotal evidence from Victoria is that some doctors are either unaware of, or unconstrained by, the requirement that they must reply with seven days.
- **Increasing anecdotal evidence has come to us of doctors actively trying to dissuade patients from pursuing their legal right to VAD** . This, too, is coercion and should not be permissible. We suggest consideration be given in the Act for penalties against doctors who engage in any form of coercive behaviour in regards to VAD – either for or against.
- **The law should recognise that there is a difference between conscientious objection and conscientious obstruction** . We suggest that consideration be given to an Ombudsman's role sitting within the functions of the Commission. At present, in Victoria, there is no clear pathway to complain for those who may have felt impeded, or in other ways obstructed, by doctors and institutions in regards to VAD. As there is no place to register such complaints, there is no record kept of obstructive behaviour. Consideration should be given to the Ombudsman having the power to inform AHPRA , or another relevant governing body, of efforts by doctors or institutions to obstruct , dissuade, or otherwise coerce, people seeking to access VAD.
- **Consider making it mandatory for both the co-ordinating and consulting physicians to have a one-on-one conversation with the person applying for VAD** as part of their assessments.

## VICTORIA: VOICES OF EXPERIENCE

*"It just takes a lot of time. I mean, it is a lot of paperwork. It is complicated. The written declaration, One form is eight pages, the other's four, I think it is, and you don't have to fill them all in because some of them are about interpreters and stuff like that. But as you would know, for the written declaration, you need two independent adult witnesses. So there's a lot of paperwork, a lot of signing."*

- Dr Nick Carr, GP, Melbourne

*"The most onerous thing is that at the end, you got to do a summary which asks you for all of the dates. Now, I've got all the friggin dates you know, they're all there ... in the things that you've already put in. But ... the thing is the dates. The most frustrating thing is getting all the dates right."*

- Dr Andrea Bendrups, GP and Rheumatologist, Royal Melbourne Hospital

*"Some of the detail, the bureaucratic detail, drives me and other VAD doctors nuts. The detail that's required and then they send it back for more information. You know, you spell the name of the street incorrectly and they send it back to you. It can be quite tiresome. And we've had an issue recently with a patient, right up in the country, who died the other week in a very isolated country hospital. It took a long time to get her assessed, to get the medication there. And you know, it is really, it does discriminate against people often who are far flung. So there are, there are a number of things that I think hamper the accessibility."*

- Dr Greg Mewett, Palliative Care Physician, Ballarat Health.

*"I would say, out of all the forms that I do the ... application for VAD is the hardest to get correct."*

- Professor Phillip Parente, Oncologist, Director of Cancer Services at Eastern Health

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