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# **Submission to**

# **Queensland Law Reform Commission**

In response to

# A legal framework for voluntary assisted dying

**Consultation Paper WP 79** 

November 2020



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# Go Gentle Australia: prefatory notes

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.



# Chapter 3: principles

# Q-1 What principles should guide the Commission's approach to developing voluntary assisted dying legislation?

We support the principles as set in section 5(1) of the Voluntary Assisted Dying Act 2017 (Vic), with the addition of one point, captured below in point (g):

- (1) A person exercising a power or performing a function or duty under this Act must have regard to the following principles
  - (a) every human life has equal value;
  - (b) a person's autonomy 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;
  - (d) every person approaching the end of life should be provided with quality care 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 health practitioner should, wherever possible, be supported and maintained;
  - (f) individuals should be encouraged to openly discuss death and dying and an individual's preferences and values should be encouraged and promoted;
  - (g) 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 the metropolitan region;
- Q-2 Should the draft legislation include a statement of principles:
- (a) that aids in the interpretation of the legislation? YES
- (b) to which a person must have regard when exercising a power or performing a function under the legislation (as in Victoria and Western Australia)? YES
- Q-3 If yes to Q-2(b), what would be the practical, and possibly unintended, consequences of requiring such persons to have regard to each of the principles?

The practical consequence is that the principles will speak to, and guide, the medical community, families, institutions and the general public in their thinking about – and approach to – end-of-life care.



Q-4 If yes to Q-2(a) or (b) or both, what should the principles be? SEE ANSWER TO Q-1

# Chapter 4: eligibility criteria for access to voluntary assisted dying

Q-5 Should the eligibility criteria for a person to access voluntary assisted dying require that the person must be diagnosed with a disease, illness or medical condition that:

- (a) is incurable, advanced, progressive and will cause death (as in Victoria); or
- (b) is advanced, progressive and will cause death (as in Western Australia)?

GGA believes that the Victorian definition of eligibility is precise language that provides clear guidelines to medical practitioners who will be assessing requests:

GGA supports the eligibility requirements within the Victorian legislation:

You must be diagnosed with an incurable disease, illness or medical condition that is advanced and progressive; and that will cause death within weeks or months, but not longer than 12 months.

We draw to your attention the thinking of the Victorian Expert Panel that led to this formulation:

#### Incurable

The Panel has chosen to retain the word 'incurable' in its recommendation because it considers it is well understood by medical practitioners to mean a medical condition that cannot be cured. Medical treatment for a person suffering from an incurable medical condition, such as those identified above, may have the effect of delaying a person's death; however, it will not cure the person's medical condition. Instead, the medical treatment aims to manage the symptoms of the medical condition to promote the person's quality of life and ensure their comfort. The Panel is firmly of the view that a person should not be prevented from accessing voluntary assisted dying when they exercise their right to refuse lifesustaining medical treatment that is managing the symptoms of their incurable medical condition and they meet all of the eligibility criteria for access to voluntary assisted dying.

Disease, illness or medical condition

The Panel also considers that use of the words 'disease, illness or medical condition' better describes the conditions intended to be captured by voluntary



assisted dying legislation. If a person is suffering from an advanced, progressive condition that will cause death and is causing suffering, they should not be precluded from accessing voluntary assisted dying because it is considered a medical condition, rather than a disease or illness. The Panel recommends the use of the words 'medical condition', rather than just 'condition' to clarify that voluntary assisted dying cannot be accessed for suffering associated with decline as a result of ageing or frailty for example. The Panel is of the view that although a disability may be the result, or a symptom, of a disease, illness or medical condition, the disability itself should not be considered a disease, illness, or medical condition for the purposes of the eligibility criteria.

#### Advanced and progressive and will cause death

The word 'advanced' was suggested on the basis that it is better understood by practitioners and more specific than the word 'serious'. Furthermore, it relates to a point in the trajectory of a disease, illness or medical condition rather than just describing the disease, illness or medical condition more generally. The word 'progressive' was also suggested on the basis that it indicated an active deterioration in a person's disease, illness or medical condition such that the person is not going to recover and instead will continue to decline. The Panel agrees with this feedback and is of the view that the inclusion of these words will provide the clarity necessary for the community and health practitioners in determining eligibility for access to voluntary assisted dying.

During the consultation process the Panel received considerable feedback that a 'serious and incurable condition' will not always cause death. For example, people with osteoarthritis may describe this medical condition as 'serious and incurable' but it will not cause death. The majority of feedback supported the inclusion of only diseases, illnesses and medical conditions that will cause death.

Q-6 Should the eligibility criteria for a person to access voluntary assisted dying expressly state that a person is not eligible only because they:

- (a) have a disability; or
- (b) are diagnosed with a mental illness? YES

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



Q-7 Should the eligibility criteria for a person to access voluntary assisted dying require that the person must be diagnosed with a disease, illness or medical condition that is expected to cause death within a specific timeframe? YES

Q-8 If yes to Q-7, what should the timeframe be? Should there be a specific timeframe that applies if a person is diagnosed with a disease, illness or medical condition that is neurodegenerative?

For example, should the relevant timeframe be within six months, or within 12 months in the case of a disease, illness or medical condition that is neurodegenerative (as in Victoria and Western Australia)?

GGA recommends that Queensland's legislation follows the lead of Victoria and WA and sets a time to death.

We see this as essential for two reasons:

Firstly, 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.

Secondly, any law – and particularly this law – must be written with regard to the society for which it is framed.

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 – are designed to 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 much longer if there are delays in gathering evidence, accessing medical practitioners, and completing the paperwork or correcting errors.



Research shows that physicians generally overestimate their patients' prognoses. A review of studies by White et al<sup>1</sup> in 2015 revealed that in five of the studies the median difference showed an underestimate, while thirteen showed an overestimate: the predicted median survival ranged from 14 to 219 days while the actual median survival ranged from 10 to 126 days.

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.

"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.

"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

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



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.

Q-9 Should the eligibility criteria for a person to access voluntary assisted dying require that the person must be diagnosed with a disease, illness or medical condition that is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable (as in Victoria and Western Australia)? YES

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.

By way of example, the eligibility criteria in Victoria's law are clear: The disease, illness or medical condition must be incurable, advanced and progressive and likely to cause death within 6/12 months. This objectivity can ensure that trivial claims to suffering are screened.

Proposal 1 - The draft legislation should provide that, for a person to be eligible for access to voluntary assisted dying, the person must be aged 18 years or more. YES

Q-10 Should the eligibility criteria for a person to access voluntary assisted dying require that the person must be:

- (a) an Australian citizen or permanent resident; and YES
- (b) ordinarily resident in Queensland? YES

Q-11 If yes to Q-10(b), should that requirement also specify that, at the time of making the first request to access voluntary assisted dying, the person must have been ordinarily resident in Queensland for a minimum period? If so, what period should that be?

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.



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 <u>Working and Skilled Visas</u> 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.

We suggest to amend this clause as per the <u>Tasmanian End-Of-Life Choices</u> (Voluntary Assisted Dying) Bill 2020, Clause 10:

For the purposes of this Act, a person meets the residency requirements if –

- (a) the person
  - (i) is an Australian citizen; or
  - (ii) is a permanent resident of Australia; or
  - (iii) has been resident in Australia for at least 3 continuous years immediately before the person makes the relevant first request; and
- (b) the person has been ordinarily resident in [Queensland] for at least 12 continuous months immediately before the person makes the relevant first request.

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, adding point (iii) allows for those on a different visa where a long-term or permanent stay is permitted, without encouraging 'VAD tourism'.

Proposal 2 - The draft legislation should provide that, for a person to be eligible for access to voluntary assisted dying, the person must be acting voluntarily and without coercion. YES

Proposal 3 - The draft legislation should provide that, for a person to be eligible for access to voluntary assisted dying, the person must have decision-making capacity in relation to voluntary assisted dying. YES



Q-12 Should 'decision-making capacity' be defined in the same terms as the definition of 'capacity' in the Guardianship and Administration Act 2000 and the Powers of Attorney Act 1998, or in similar terms to the definitions of 'decision-making capacity' in the voluntary assisted dying legislation in Victoria and Western Australia? Why or why not?

The legal principle 'competent (capacity) until proved otherwise' is well-established in Queensland'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.

According to this definition, assisted dying should be made available to people who have decision-making capacity about their own medical treatment. This means that a request for voluntary assisted dying must be made by a person who fully understands: their condition and its consequences; the treatment options available to them; and the nature and consequences of their request, and who is able to retain and use that information to make a decision about voluntary assisted dying.

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. This happens very regularly and 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 Queensland'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.

Q-13 What should be the position if a person who has started the process of accessing voluntary assisted dying loses, or is at risk of losing, their decision-making capacity in relation to voluntary assisted dying before they complete the process?

#### For example:

- (a) Should a person who loses their decision-making capacity become ineligible to access voluntary assisted dying?
- (b) Should there be any provisions to deal with the circumstance where a person is at risk of losing their decision-making capacity, other than allowing for a reduction of any waiting periods? If so, what should they be?

Note: see also [6.16] ff and Q-20 and Q-21 below as to waiting periods.

(c) Should a person be able, at the time of their first request, to give an advance directive as to specific circumstances in which their request should be acted on by a practitioner administering a voluntary assisted dying substance, despite the person having lost capacity in the meantime?

GGA believes there is merit in allowing waiting times to be reduced in some circumstances where loss of capacity may be imminent; however, this should only be considered in tandem with the most important entry-points to the process – diagnosis of a terminal illness and a prognosis of death within 12 months.

We do not recommend consideration be given in the law to people who lose capacity after they commence the VAD process. As noted, decision-making capacity and enduring consent, including the ability to change one's mind and withdraw from the process at any stage, are key safeguards that ensure the VAD process remains transparent and self-determined throughout.

For this same reason, GGA does not support providing VAD to people solely on the basis of a request made in an Advance Care Directive. It should also be noted that, for some doctors in Victoria, administering a life-ending drug to someone who is conscious and capable of verbally consenting is — nonetheless — a confronting and emotional experience. We believe asking doctors to do the same with people who are unconscious, and incapable of verbalising consent, is to ask too much. It will also most likely have a chilling effect on the number of doctors wishing to qualify for VAD.



"I was surprised, I think, by the strength of the real prohibition, the instinctive prohibition, I'd like to hope most people share, against taking human life even in that circumstance where intellectually I understood it was very much the right thing to do. The experience was quite difficult and it was that experience that really led me to understand why people may or may not wish to step forward."

- Dr Peter Lange, Head of Acute Medicine, Royal Melbourne Hospital.

# Q-14 Should the eligibility criteria for a person to access voluntary assisted dying require that the person's request for voluntary assisted dying be enduring? YES

In speaking to doctors, and family members of people who have opted for VAD, it became clear that, without fail, a decision to apply for the option of VAD was never taken lightly and only ever came after great reflection. While this may be the case in practice, a workable test should be defined in the law.

A request repeated three times in various forms over a defined period of time makes it more likely that it will be both enduring and carefully considered by the person themselves and the medical practitioners who are responsible for assessing the person's eligibility to access voluntary assisted dying.

Distinguishing between informal discussion and a formal request represents an important safeguard because it would address the issue of people requesting voluntary assisted dying when they are feeling depressed or vulnerable.

This rigorous process needs to balanced with recognising that adults with decision-making capacity can make decisions about their own lives.

GGA supports multiple checks with the person making the application to confirm that they do wish to proceed. We see this not only as a strong safeguard against coercion but also as a moment for the patient to possibly express doubt and perhaps to consider other options. It removes any possibly perception of being "locked into the process" and removes any pressure, allowing a change of heart at any step of the way. Equally, they should be continually reminded by all medical professionals in the process that they can opt out at any time.

"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, to do any of this."

- Michelle Caliste, whose son, Robbie, died of MND.



# Chapter 5: initiating a discussion about voluntary assisted dying

Q-15 Should the draft legislation provide that a health practitioner is prohibited from initiating a discussion about voluntary assisted dying as an end of life option? NO

Q-16 If yes to Q-15, should there be an exception to the prohibition if, at the same time, the practitioner informs the person about the treatment options available to the person and the likely outcomes of that treatment, and the palliative care and treatment options available to the person and the likely outcomes of that care and treatment (as in Western Australia)?

GGA understands concerns that the provision of information about voluntary assisted dying may be taken as a suggestion by a health practitioner that their patient should request and access voluntary assisted dying.

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.



"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

# Chapter 6: the voluntary assisted dying process

Requesting access to voluntary assisted dying

# Witnessing requirements for the written declaration

Q-17 Should the draft legislation provide that the person who makes a written declaration must sign the written declaration in the presence of:

- (a) two witnesses (as in Western Australia); or
- (b) two witnesses and the coordinating practitioner (as in Victoria)? YES

We support option (b). We feel it is important for the witnesses to be able to ask questions of the coordinating practitioner to ensure they are comfortable with providing their signature.



"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

Q-18 Should the draft legislation provide that a person is not eligible to witness a written declaration if they:

- (a) are under 18 years (as in Victoria and Western Australia); YES
- (b) know or believe that they:
  - (i) are a beneficiary under a will of the person making the declaration (as in Victoria and Western Australia); YES
  - (ii) may otherwise benefit financially or in any other material way from the death of the person making the declaration (as in Victoria and Western Australia); YES
- (c) are an owner of, or are responsible for the day-to-day operation of, any health facility at which the person making the declaration is being treated or resides (as in Victoria); YES
- (d) are directly involved in providing health services or professional care services to the person making the declaration (as in Victoria); YES
- (e) are the coordinating practitioner or consulting practitioner for the person making the declaration (as in Western Australia); YES
- (f) are a family member of the person making the declaration (as in Western Australia)? NO

We agree with all of the above, except point (f) and recommend this be removed. 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.

Q-19 Alternatively to Q-18(f), should the draft legislation provide that not more than one witness may be a family member of the person making the declaration (as in Victoria)? YES

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



## Waiting periods

Q-20 Should the draft legislation include provisions about the prescribed period that must elapse between a person's first request and final request for access to voluntary assisted dying, in similar terms to the legislation in Victoria and Western Australia? YES

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 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>

Q-21 If yes to Q-20, should the draft legislation provide that the final request can be made before the end of the prescribed period if:

- (a) the person is likely to die within that period; or YES
- (b) the person is likely to lose decision-making capacity for voluntary assisted dying within that period? YES

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.

"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.

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



"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"

Katie Harley

# Eligibility assessments

Requirement for the eligibility assessments to be independent

Q-22 Should the draft legislation provide that the coordinating practitioner and the consulting practitioner must each assess whether the person is eligible for access to voluntary assisted dying and that:

- (a) the consulting assessment must be independent from the coordinating assessment (as in Victoria and Western Australia); YES and
- [b] the coordinating practitioner and the consulting practitioner who conduct the assessments must be independent of each other? YES

We agree with the W&W provision, which requires two medical practitioners to each assess the person's eligibility. The two medical practitioners who undertake the assessments '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 would provide an additional safeguard to ensure practitioners are independent of each other. It would also greatly assist the process of finding a second practitioner and ensure equitable access.



Requirements for referral of certain matters to a specialist or another person

Q-23 Should the draft legislation provide that, if the coordinating practitioner or consulting practitioner:

- a) is not able to determine if the person has decision-making capacity in relation to voluntary assisted dying—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); YES
- b) 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:
  - (i) a specialist medical practitioner with appropriate skills and training in that disease, illness or medical condition (as in Victoria); or YES
  - (ii) a health practitioner with appropriate skills and training (as in Western Australia);
- c) 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)?

We agree that 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).

We agree that 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).

While physicians routinely screen for signs of coercion, if there is doubt in the mind of a practitioner, this is an appropriate safeguard.

"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

### Other requirements

Q-24 Should the draft legislation provide (as in Western Australia) that the coordinating practitioner, the consulting practitioner, any health practitioner (or other person) to whom the person is referred for a determination of whether the person meets particular eligibility requirements, or the administering practitioner must not:

- a) be a family member of the person; YES or
- b) know or believe that they are a beneficiary under a will of the person or may otherwise benefit financially or in any other material way from the person's death? YES

Please note that "benefitting financially" should not exclude a practitioner from charging any normally applicable fees.

# Review of certain decisions by Tribunal

Q-25 Should the draft legislation provide for an eligible applicant to apply to the Queensland Civil and Administrative Tribunal for review of a decision of a coordinating practitioner or a consulting practitioner that the person who is the subject of the decision:

- a) is or is not ordinarily resident in the State (as in Victoria); YES
- at the time of making the first request, was or was not ordinarily resident in the State for a specified minimum period (as in Victoria and Western Australia);
   YES
- c) has or does not have decision-making capacity in relation to voluntary assisted dying (as in Victoria and Western Australia); YES



d) is or is not acting voluntarily and without coercion (as in Western Australia)?NO

Q-26 If yes to Q-25, should an application for review be able to be made by:

- a) the person who is the subject of the decision; YES
- b) an agent of the person who is the subject of the decision; or YES
- c) another person who the tribunal is satisfied has a special interest in the medical care and treatment of the person? NO

We agree a review of a decision should be allowed to go before a Tribunal; however, we do NOT support:

Q25 (d) — as there have already been assessments by two independent doctors and Q26(c) — as we feel this leaves the door open to allow frustration of the process by people who may disagree with the option of VAD, such as family members, or even health professionals, who may not share the same world view as the patient.

"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.

"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, discussing anecdotal evidence of medical professionals seeking to change people's minds about accessing VAD.



#### Reporting requirements for health practitioners

Q-27 At what points during the request and assessment process should the coordinating practitioner or consulting practitioner be required to report to an independent oversight body? For example, should it be required to report to an independent oversight body:

- a) after each eligibility assessment is completed (as in Victoria and Western Australia): YES
- b) after the person has made a written declaration (as in Western Australia); NO
- c) after the person has made their final request (as in Victoria and Western Australia); YES
- d) at some other time (and, if so, when)? NO

There should be a comprehensive system of checks throughout the process, and review after it.

We recommend a body akin to Victoria's Voluntary Assisted Dying Review Board and Secretariat that will provide a comprehensive system of reporting at each step of the assessment process and will identify any breaches. The review board has the power to refer breaches to the police, to AHPRA, to the coroner or to the medical board.

Medical practitioners, and others involved in the process, must report in real time. This has the twin effect of reminding them of all their responsibilities under the law – and of the high likelihood that any breaches will be detected and may be investigated.

"The process is so intricate that there's many places for it to be reviewed and challenged. It is a very intricate process. ... I think I'm more scrutinised when I do an assessment by all my documentation going up to the Board, than any of my other procedures"

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

"They can't cut corners, they just can't. Because they, have to complete all of the requirements, or it's not compliant. End of story. You can't go, Oh, well, I won't bother about doing form one because if you don't do form one you won't be able to do form two. And if you don't do that correctly, you will be stopped. You'll get to the Secretary and they'll go No."

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



#### Additional approval process

Q-28 Is it necessary or desirable for the draft legislation to require the coordinating practitioner to apply for a voluntary assisted dying permit before the voluntary assisted dying substance can be prescribed and administered (as in Victoria)? YES

We support the process as outlined in the law in Victoria and note that we feel it should be in line with existing Queensland legislation, such as the <u>Health (Drugs and Poisons)</u> Regulation 1996.

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.

Administration of the voluntary assisted dying substance

Self-administration or practitioner administration

Q-29 Should the draft legislation provide that practitioner administration is only permitted if the person is physically incapable of self-administering or digesting the voluntary assisted dying substance (as in Victoria)? NO

Q-30 Alternatively to Q-29, should the draft legislation provide (as in Western Australia) that:

- a) the person can decide, in consultation with and on the advice of the coordinating practitioner, whether the voluntary assisted dying substance will be self-administered or practitioner administered; and
- b) practitioner administration is only permitted if the coordinating practitioner advises the person that self-administration is inappropriate, having regard to one or more of the following:
  - I. the ability of the person to self-administer the substance;
  - II. the person's concerns about self-administering the substance; or
  - III. the method for administering the substance that is suitable for the person? YES

We agree with WA model; however, we also note that no practitioner should be required to administer and that they should be allowed to conscientiously object to this particular step. It should be a requirement in that case to hand-over their role to a practitioner who does not have an objection. However, this practitioner then must also independently form the view that this patient meets all eligibility criteria. To avoid delays that may extend the



suffering of a person who is dying, it is important that the regulations / implementation establish a protocol that can expedite the transfer of authority from one qualified doctor to another, in order to provide practitioner administration.

And she was a little bit frightened about the actual doing of it. You know, the actual taking the substance and i and i know when she first did it that her preference had been that it was a physician administered assistance. But in Victoria because mum had some sort of gross motor movement and some ability to swallow and take the substance itself by Victorian law, she was not eligible to have a physician assisted.

Lisa Hogg whose mother, Margaret, was dying of a neurological illness.

#### Requirements for self-administration

Q-31 Should the draft legislation provide that the coordinating practitioner or another health practitioner must be present when the person self-administers the voluntary assisted dying substance? NO

There should be no requirement; however, we believe it is important that the health practitioner is allowed to be present, if the patient desires.

For some, this will be the culmination of months and years of an intense doctor/patient relationship and must be respected in legislation.

Doctors who have legally assisted terminally ill patients to die in other jurisdictions report it as a profound experience to be with their patient as they cross into death.

The health practitioner should have no obligation to assist with preparing the drug. In Victoria, the Statewide 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 Queensland.

#### 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.



#### Requirements for practitioner administration

Q-32 Should the draft legislation provide that a witness, who is independent of the administering practitioner, must be present when the practitioner administers the voluntary assisted dying substance? YES

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

#### Requirements for interpreters to be accredited and impartial

Q-33 Should the draft legislation 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? YES

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.

"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.



## Procedural requirements

Q-34 Are there any other issues relating to these or other procedural matters that you wish to comment on?

We strongly recommend using a practitioner portal for the process, as was set up in Victoria. However, we also note there is much frustration among practitioners as the portal is clumsy, not user-friendly and slow. We highly recommend investing in creating a portal that is user-friendly, fast and relatively low in data-consumption to ensure practitioners in remote areas do not require a fast internet connection to operate the portal effectively. Any barriers to doctor participation in VAD, such as the onerous task of navigating a poorly designed system, are best avoided.

# Chapter 7: qualifications and training of health practitioners

Minimum qualification and experience requirements of coordinating and consulting practitioners

Q-35 Should the draft legislation provide that only a medical practitioner can act as a coordinating practitioner or a consulting practitioner and **assess the person's eligibility** for access to voluntary assisted dying? YES

Q-36 Should the draft legislation set out minimum qualification and experience requirements that a medical practitioner must meet in order to act as a coordinating practitioner or a consulting practitioner? YES

Q-37 If yes to Q-36, what should the minimum qualification and experience requirements be? For example, should it be a requirement that either the coordinating practitioner or the consulting practitioner must:

- a) have practised as a medical specialist for at least five years (as in Victoria); and
- b) have relevant expertise and experience in the disease, illness or medical condition expected to cause the death of the person being assessed (as in Victoria)?

We agree that only medical practitioners should be able to act as a coordinating practitioner or a consulting practitioner and assess the person's eligibility for access to voluntary assisted dying.



We agree that a medical practitioner is eligible to act as a coordinating practitioner or a consulting practitioner for a person if they hold specialist registration and have practised as a registered specialist for at least five years. We feel the 5-year experience is important to allow for additional experience in the field. We also feel it would be a big ask for someone who has had only 1 year in their vocation to be asked to participate.

Before assessing a patient, both doctors are required to complete approved training in assessing the eligibility criteria for voluntary assisted dying; assessing decision-making capacity of the patient; and identifying risk factors for abuse.

#### Role of other health practitioners

Q-38 Should the draft legislation provide that the voluntary assisted dying substance can be administered by:

- (a) the coordinating practitioner (as in Victoria and Western Australia); YES
- (b) a medical practitioner who is eligible to act as a coordinating practitioner for the person (as in Western Australia); YES or
- (c) a suitably qualified nurse practitioner (as in Western Australia)? YES

In option (b), the practitioner must meet all eligibility criteria as mentioned in our answer to Q37 AND then must also independently form the view that this patient meets all eligibility criteria.

To ensure there is appropriate access to VAD across such a large state as Queensland, 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.

# Mandatory assessment training

Q-39 Should the draft legislation require health practitioners to complete approved training before they can assess a person's eligibility for access to voluntary assisted dying? YES

We recommend that approved training be mandatory:

• To ensure that medical practitioners are equipped and confident to navigate the various stages of the VAD process and that they have access to all information and support.



• To ensure the process is undertaken appropriately and safely, and that both the person seeking VAD and participating medical practitioners are adequately safeguarded.

# Chapter 8: conscientious objection

Q-40 Should the draft legislation provide that a registered health practitioner who has a conscientious objection to voluntary assisted dying has the right to refuse to do any of the following:

- a. provide information about voluntary assisted dying; NO
- b. participate in the request and assessment process; YES
- c. if applicable, apply for a voluntary assisted dying permit; YES
- d. prescribe, supply, dispense or administer a voluntary assisted dying substance; YES
- e. be present at the time of the administration of a voluntary assisted dying substance: YES or
- f. some other thing (and, if so, what)?

Q-41 Should a registered medical practitioner who has a conscientious objection to voluntary assisted dying be required to refer a person elsewhere or to transfer their care? YES

Q-42 Should the draft legislation make provision for an entity (other than a natural person) to refuse access to voluntary assisted dying within its facility? YES If so, should the entity be required to:

- a. refer the person to another entity or a medical practitioner who may be expected to provide information and advice about voluntary assisted dying; and YES
- b. facilitate any subsequent transfer of care? YES

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.

"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.



# Chapter 9: oversight, reporting and compliance

Q-43 Should the draft legislation provide for an independent oversight body with responsibility for monitoring compliance with the legislation? YES

Q-44 If yes to Q-43, should the oversight body have some or all of the functions and powers conferred on:

- a) the Voluntary Assisted Dying Review Board under the Voluntary Assisted Dying Act 2017 (Vic); or
- b) the Voluntary Assisted Dying Board under the Voluntary Assisted Dying Act 2019 (WA)? YES all the functions and powers of the VADRB WA VAD act– in addition to the following powers under the Victorian VAD act: s87

GGA strongly supports and recommends the creation of a review board. 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 board 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 Queenslanders 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 review board collects and publishes more extensive data than is currently happening in Victoria.

We would like to see data published around

- 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.

"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

Q-45 Should notifications to the Health Ombudsman of concerns about health **practitioners' professional conduct relating to voluntary assisted** dying:

- a) be dealt with by specific provisions in the draft legislation, as in Victoria, which provide for mandatory and voluntary notification in particular circumstances; or
- b) as in Western Australia, be governed by existing law under the Health Practitioner Regulation National Law (Queensland) which states when mandatory notification is required and voluntary notification is permitted?

We support this to be in concert with Queensland's existing mandatory reporting requirements, as per the W&W model.

Q-46 Should the draft legislation include specific criminal offences related to non-compliance with the legislation, similar to those in the Voluntary Assisted Dying Act 2017 (Vic) or the Voluntary Assisted Dying Act 2019 (WA)?

We support the inclusion of offences as outlined in the WA legislation but note we would also include "Falsifying a form or record required to be made under the legislation" (s 87 in the VIC legislation).

Q-47 Should the draft legislation include protections for health practitioners and others who act in good faith and without negligence in accordance with the legislation, in similar terms to those in the Voluntary Assisted Dying Act 2017 (Vic)? YES

Q-48 Should there be a statutory requirement for review of the operation and effectiveness of the legislation?



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.

# Chapter 10: other matters

Q-49 How should the death of a person who has accessed voluntary assisted dying be treated for the purposes of the Births, Deaths and Marriages Registration Act 2003 and the Coroners Act 2003?

GGA supports the requirement that VAD be listed as a contributing cause of death only on the Medical Certificate Cause of Death, and only if this information remains publicly unavailable.

Death certificates are used for a range of purposes, and there is no reason to include information about voluntary assisted dying on such a public document. This is to preserve the privacy of the person, their family, and health practitioners.

Proposed legislation provides access to voluntary assisted dying under limited circumstances for those people at the end of their life. They would die from that condition even if they did not choose voluntary assisted dying. Other medical treatments or actions taken that may hasten death – such as stopping dialysis or withdrawing life sustaining treatment – are not included on death certificates.

In our view, it is sufficient to list VAD as a contributing cause of death ONLY on the Medical Certificate of Death. This allows information to be collected on VAD, but also protects the privacy and confidentiality of the person involved and avoids potential conflicts with extended families or cultural groups.



Q-50 What key issues or considerations should be taken into account in the implementation of voluntary assisted dying legislation in Queensland?

GGA strongly recommends the following:

- The legislation should be drafted in plain and unambiguous English. This will be
  crucial in terms of the parliamentary debate and to avoid differing interpretations
  of the law. As a guide, we recommend the <u>Oregon Death With Dignity Act</u>, or the
  <u>California End of Life Option Act</u>, be consulted. Unlike the legislation in WA and
  Victoria, these Acts have been drafted in such a way that they can be read and
  understood by a layperson.
- To include as per WA law that voluntary assisted dying is <u>not</u> suicide. For the purposes of the law of the State, a person who dies as the result of the administration of a prescribed substance in accordance with this Act does not die by suicide. This is to ensure the <u>Federal Criminal Code Amendment (Suicide Related Material Offences) Act 2005</u> does not apply to any discussions relating to VAD, as it is currently interpreted to be the case in Victoria.
- 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 Queensland'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, Queensland 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 team 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
  form a treating physician can be facilitated without delay.
- We feel the role of tele-heath 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.
- We strongly support the establishment of a central pharmacy service, as implemented in Victoria. To allow sufficient coverage of the state, perhaps authorised branches of this service could be located at key rural locations in Central and Northern Queensland.
- 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.
- 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.
- 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.

"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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