Voluntary Assisted Dying Bill – Discussion Paper

Response from Go Gentle Australia

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Go Gentle Australia / Andrew Denton: 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 euthanasia/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 VE/VAD law in action around the world and is considered to be unique.

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

GGA's extensive experience in South Australia in 2016 as VE 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.

Overseas experience demonstrates that laws need to be clearly written, in language which is unambiguous and easily understood. Local experience demonstrates that uncertainty around key terminology (eg suffering as a subjective concept) can cause confusion amongst 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 practise, is critical.

Access and eligibility

Our view is:

- the access/eligibility point should be defined as 'a terminal disease' or 'terminal illness'
- we note that the term 'unbearable suffering' (or variations of that) have been viewed by some as controversial and/or unclear in jurisdictions such as the Netherlands, Belgium and more recently Canada.
- Evidence shows that the USA practice (eg Oregon and California) of having 'terminal' as the sole entry point, with no explicit mention of 'suffering' in the eligibility criteria, has worked well and non-controversially, for doctors, patients, legislators and the public. (The concept of suffering is implicit in the word 'terminal' as it is the primary - though not sole - criteria that any treating doctor needs to assess when faced with a request for VAD).
- it is essential to have a concrete prognosis of time to death, despite the medical fact that it can be imprecise. The alternative - which is to have formulations such as "death being reasonably foreseeable" or 'days and weeks' or even 'inevitable' – means that doctors are working with vague terms which are too open to debate and confusion.
- We suggest that a time limit also assists the general public and politicians to understand that there is a defined scope and limit to the law.

Time to death prognosis

We strongly recommend that Victorian legislation follow the lead of the USA by setting a time to death.

The 6-month time frame adopted in the USA is because of statutory health insurance and hospice care requirements

We suggest that the 6-month time frame be regarded as a minimum. A longer timeframe (see below) is a more humane solution while still having very effective safeguards.

12 months or 24 months?

In Australia there is established medico-legal precedent for a 12 month prognosis.

- the insurance industry uses this formula when paying out life insurance policies to the terminally ill.

In 2015 the Australian government passed the Tax and Superannuation Laws Amendment (Terminal Medical Conditions) Regulation 2015, extending the certification period for a terminal medical condition from 12 to 24 months.

- This change made it easier for a person with a terminal illness to access their superannuation earlier, though it has no impact on insurance products

In late 2016 Asteron Life announced it was marketing the first retail insurance product to adopt an "unlikely to survive more than 24 months" terminal illness definition for superannuation and non-super policies.
- Asteron said this was aligned to the Superannuation Industry Supervision (SIS) conditions of release for cover structured through super.

The relevant federal acts - the Superannuation Industry (Supervision) Act 1993 and the Tax and Superannuation Laws Amendment (Terminal Medical Conditions) Regulation 2015 - define a terminal medical condition as existing if 'two registered medical practitioners, at least one of whom is a specialist in the relevant medical area, have certified that a person suffers from an illness or injury that it likely to result in their death within the certification period of 24 months or less.'

GGA recommends adopting a 12 months to death prognosis as the entry point for legislation.

- this applies to the insurance industry and is considered an appropriately conservative time frame, as opposed to the 24 month time frame which applies to the superannuation industry but is more speculative
- the period gives a good amount of time for doctors and patients to manage the terminal phase of life together, by taking the emotional heat and associated intensity out of a very late stage decision
- this reflects wide-spread attempts by Australian governments, the legal and medical professions to encourage the community to engage in a more open and frank discussion of end of life options
- the philosophy underpinning the 12 and 24 month periods is that the terminally ill person should have sufficient time to plan their lives. We suggest that this also includes planning their deaths.

A 12 month prognosis followed by permission to access VAD does not mean that people will end their lives earlier. Indeed, research suggests that the opposite is the case. It means they will have more time to manage their end-of-life situation with their doctor and families. GGA has documented hundreds of conversations with terminally ill people and doctors and nurses, which illustrate that a dying person granted access to medical assistance will only carry through on that in the final days or weeks of life.

We note that a 12 month prognosis will provide access to a law for people in the late stages of severely degenerative diseases of the nervous system including Parkinson's, Huntington's and Multiple Sclerosis, some of whom - evidence presented to the Victorian end-of-life inquiry shows, - are currently choosing to end their lives prematurely, often violently and alone.

No need for 'suffering' clause

If there is a time limit to death then it becomes unnecessarily onerous on doctors and patients to also demand that a person be in unbearable or unrelievable suffering.

It also removes the subjective nature of what constitutes suffering or what constitutes 'acceptable' when it comes to medical treatments. Our experience is that some politicians are not comfortable with any legal clause which relies on self assessment or subjective judgement. Indeed our view is that this will be very difficult to prosecute successfully in the political arena and runs the risk of legislation being amended to a point where it is onerous for the dying person to access it.

Patients and doctors have been successfully managing this process in Oregon for almost two decades without a statutory need for an eligible person to be in 'suffering' of any sort. The evidence is that dying patients do not want to end their lives prematurely and only do so once their situation has become intolerable.

Potential unintended consequence of 'terminal' PLUS 'suffering'

If a person must be in suffering before they can initiate a request then it is very possible that the whole process starts too late to be of any real benefit:

- patients and their doctors will have only a brief period of time to go through a demanding set of procedures, which only add to the burden of those facing death and who are already in great distress.
- it may severely limit the time, and capacity, for doctors and patients to have meaningful and rational discussions
- it may limit or even reduce to zero the palliative impact of being prescribed a lethal medication (see Syme case below)

We therefore recommend that the bill:

- be silent on the question of suffering
- define 'terminal medical illness' as the sole entry point
- should expressly and loudly exclude injury, dementia, disability and minors from the definition 'terminal medical illness'
- sets the projected time to death to 12 months, in line with current well-established medico-legal practice as used by the insurance industry

This allows proponents of the legislation to say that:

"The legislation gives doctors and patients the time to rationally manage the terminal phase of the patient's life, giving patients the choice to take life ending medication after ongoing and meaningful discussion and with the full palliative benefit provision of such medication confers."

Importance of VCAT Syme decision

Further support for the proposition we advance can be found in the decision of the Victorian Civil and Administrative Tribunal (Administrative division) Syme v Medical Board of Australia (Review and Regulation) [2016] VCAT 2150, dated 20 December 2016.

There is abundant evidence from Oregon to demonstrate that providing legal, regulated access to life-ending medication has strong palliative power and likely helps prolong life.

The case of Dr Rodney Syme v the Medical Board of Australia underlines this conclusively in the Australian context.

It is most strongly expressed in the words of Dr Syme's terminally ill patient, Mr Bernard Erica, who saw access to Nembutal in these terms (as quoted in the VCAT decision):

> *"I just want to have complete control over decision making about the future course of my life and the treatment I receive, and certainly don't want to rely on any palliative care or nursing home.*
>
> *This is important because I am in control and will not be leaving it up to someone in palliative care who does not really understand my pain level or psychological state of mind.*
>
> *As a result of the advice and assistance Dr Syme gave me I became far more relaxed knowing that I would have Nembutal if he were able to supply it to me. It gave me more energy knowing that I am not stressed out by trying to source Nembutal from overseas. Feeling better psychologically has also made me feel better physically.*
>
> *At the time of the conditions being placed on Dr Syme's registration, I once again became worried about losing control and knowing that I would have to attempt to source Nembutal overseas with the knowledge that it is illegal and could result in heavy fines or a jail sentence. It meant I may have to resort to some other, ugly form of suicide as I refuse to go into palliative care.*

Bernard Erica's statement (and the experience of others) proves that if access to life-ending medication is to be legalised, then it is better that it be done as early as possible in the dying process. If this can be done with a 12 month prognosis then all the better, because it gives patients more control and more comfort for longer and it allows them to much better manage their stress and anxiety, thereby adding to their quality of life.

The Syme case also underlines that physical suffering is not the only form of suffering which needs to be addressed by a VAD law:

'In his oral evidence Dr Syme confirmed that he had spoken to Mr Erica twice in the previous week. Mr Erica's disease has progressed, but his ***psychological*** *suffering has been significantly palliated by Dr Syme's support.'* (Our emphasis)

Indeed, as data on Orgeon's laws shows year after year, 'pain' is usually only the third ranked reason that terminally ill patients seek to end their lives early. The leading reasons relate to dignity, autonomy and quality of life – none of which is clearly captured by the term 'suffering'.

In finding against the Medical Board of Australia, the VCAT decision supported the following:

1. **The right of any individual of sound mind to seek reassurance that they will be able to, if they wish, control the manner of their dying.**
2. **The palliative effect on a patient, knowing that they are dying; and**
3. **That the reassurance of the promise or actual possession of the drug does not, from the patients' perspective, place them at any risk.**

We therefore see the VCAT decision as a clear demonstration that there are more dimensions to the final stage of life than physical suffering/pain alone. We consider that the legally elegant – and unambiguous - solution is to eliminate any reference at all to suffering.

Making a request

GGA endorses the approach taken by Oregon legislators and since adopted also by California.

This allows for two witnesses, only one of whom can be a relative by blood, marriage or adoption or be entitled to any portion of the person's estate on death or be employed at the place where the person receives medical treatment or lives. The patient's doctor cannot be a witness. Nor can any member of their medical treatment team.

Reasoning: this is sufficient safeguard for the state to be satisfied that there is no coercion of the patient and that the request is voluntary. It is to be noted that it is only part of a more protracted process also involving two or more independent doctors.

We say this is more than acceptable because of other stringent eligibility requirements, most notably that you need to be terminally ill.

The alternative is to propose that neither witness be a relative by blood, marriage or adoption or be entitled to any portion of the person's estate on death or be employed at the place where the person receives medical treatment or lives.

The risk is that this demand becomes onerous for people who may not wish to air their private affairs with anyone outside close family, or who do not have many people who can be witnesses.

Our view is that other eligibility criteria cancel out any potential risk from having a witness with what could be (even remotely) construed as a conflict of interest, and that is preferable to having a situation where a patient cannot apply under the legislation simply because they cannot find two witnesses who are both said to be (legally) disinterested parties.

Time period:

We see no reason to disagree with adopting the USA standard of 15 days between the initial oral request and the final oral request (with a written request after the initial oral request). Once this is satisfied it is regarded as an enduring request and, if you satisfy the criteria, you are then eligible to receive a prescription.

Properly informed/ Confirming a request

We broadly agree with the detail as suggested by the Committee.

We would draw the Committee's attention to the stipulation in California and Oregon legislation that a doctor advise the person to tell his/her family about the request. It is not mandatory, however in this context it further supports a cultural shift towards more open, inclusive conversations within families about death and dying.

We appreciate the important role of Palliative Care and endorse PC as an important end-of-life choice. We acknowledge that doctors already have a duty of care to their patients to properly inform them of all treatment options and we expect that this would be extended also to advice around voluntary assisted dying.

We recommend that:

- it be mandatory for both the primary and secondary doctor to inform the person of palliative care expertise and options and likely results.
- To assist doctors, health authorities should create resources covering Palliative Care options (on-line or hard copy) which doctors can discuss in detail with patients.
- It may be worth considering the creation a register, divided by region, of Victorian palliative care doctors / nurses / institutions willing to be consulted in the event of a VAD request.

We believe there may be benefit in patients receiving a consultation with a Palliative Care specialist, but this should be the patient's choice, not mandatory. It should be noted that the majority of patients will, when making a request, already be receiving quality palliative care.

In Oregon, for example, 93% of those who apply successfully for assistance in dying are enrolled in hospice care. It would be unusual if this were not the case under Victoria's proposed laws.

We do not believe that any patient can or should be compelled to enter a Palliative Care facility.

Confirming a request

Expertise of medical practitioners.

GGA does not have specific expertise to comment on whether or not doctors should be qualified in specific disease fields in order to participate in a VAD regime.

We note that the insurance industry stipulates that one doctor must be a specialist in the relevant disease area.

We point out however that the legislation should have regard to the circumstances of those living in smaller towns or rural areas where certain medical specialists might not be easily available.

In the event that the panel decides that one of the doctors must be a specialist in the disease, consideration should be given – for those in rural and remote areas – for consultations via teleconference.

Jurisdictions in the USA do not require that either doctor be a specialist.

Conscientious objection

We recommend that any institution which will not allow VAD on its premises must inform potential patients/residents of this policy prior to admission of the patient. 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 hazardous and/or harmful situation if a patient should ever wish to apply for VAD.

An institution which is religiously or philosophically opposed to VAD must respond to any request by a patient for transfer to a suitable facility in a timely and professional manner.

Any institution or doctor with a conscientious objection should be compelled to arrange, at the patient's request, a prompt and orderly transfer of a patient's medical records to parties who operate a VAD regime.

We believe conscience objectors (doctors and institutions) should, in line with duty of care obligations, be compelled to refer patients to those who have no objection to VAD or to a service, approved by the State, which will provide that referral.

These considerations underscore how important it is to have end-of-life discussions as early as possible, to avoid last minute upheavals and/or crises.

In short, no individual or institution must act in a way which impedes, or is harmful to, the proper medical treatment of a patient as competently requested by them.

We believe any publicly funded health care institution must provide for VAD procedures to be carried out on its premises, though individual doctors must have the right to object.

Monitoring the use of a lethal dose of medication

The discussion paper notes:

"While it is important to ensure that the lethal dose of medication is safely stored and properly monitored, it must also be recognised that there are already many prescription medications and other household items that may cause death if they are ingested. People are generally able to responsibly manage this risk, and it is expected that they will also be able to do so if they are prescribed a lethal dose of medication for assisted dying."

We respectfully suggest that storage will need to be addressed in detail given that legislators may not be comforted by existing practice with potentially lethal substances in the home. We observed during the South Australian debate that this became a contentious issue, with concern that lethal drugs might be stolen.

In terms of monitoring, our view is that the California model offers good guidance to the Victorian government on how to track the lethal substance. We understand the reasoning for a patient being required to sign a form giving 48 hours notice of intention to ingest medication, but we point out that a patient must know they can change their mind at any moment without fear of generating onerous paperwork.

In our view the guiding principles should include:

- no patient should be in possession of a prescription. That should be relayed by the doctor to the participating pharmacist and remain on file until the doctor, the patient or the patient's authorised agent collects the medication.

- the doctor has the responsibility for monitoring the use of the lethal dose and its disposal in the event death occurs without the patient ingesting the medication.
- The pharmacists' records should be included as part of the the medical records presented to the Board of review (see below)
- While it is important for authorities to be able to track whether or not the medication has been used, we believe the most important thing is to think of this from the patient's perspective.

Attendance

We believe it is important that the health practitioner be 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 the event a doctor administers the drug to an eligible person who is physically incapable of self-administering, then the law should state that the doctor is to remain with the person until death.

After a person has died

We have a view on these selected questions:

Cause of death?

Should be recorded on the death certificate as the underlying illness/disease – because this underscores the reality that this law is for people who are dying from a particular illness anyway.

For the purposes of full oversight, the Coroner should keep a detailed record which lists both the underlying illness and the person's use of VAD medication. This is for parliamentary reporting as well as a clear understanding of who is accessing these laws. Individuals who access VAD are not to be identified for the public record. Even though we do not consider VAD to be 'suicide' – the person is already dying – the two are often deliberately conflated, with all the negative connotations that brings. We believe that it is owed to the memory of the person who has died, as well as to their families, that they are treated with the same respect in death as they commanded in life.

Role for coroner?

We believe the primary doctor should report the death to the coroner and provide a copy of the death certificate and relevant medical records to the coroner.

The coroner may or may not choose to open an investigation using existing powers. However there should be no delay for the grieving family in terms of funeral arrangements.

Oversight

We strongly support and recommend 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.

The primary doctor should be required to submit all relevant medical documentation: a record of the oral request(s), written request, documentation from the second medical practitioner, any psychiatric report(s) and all medical files relating to the terminal nature of the condition. In the event that an earlier, unsuccessful request was initiated, the documentation be regarded as relevant and is to be submitted to the review board.

Reporting to the board should occur as soon as practicable after the death and no later than 14 days.

The board should review the actions of medical practitioners following assisted death and assess whether the medical practitioners have acted in accordance with the statutory requirements.

The board should have powers to call on medical practitioners and others to give evidence. In the event that the board finds a breach of the legislation has occurred it should be required to pass on the information to the appropriate authority.

Additional safeguards

The Parliamentary Committee's framework provides for a moderate law which protects vulnerable people. Our experience shows there is real benefit in explicitly ruling out categories of patients to further avoid any confusion as to who can access assisted dying law.

We would recommend the legislation clearly and unequivocally state that injury, disability and age are not, on their own, sufficient criteria.

Further issues

Is 'Voluntary Assisted Dying' the best term?

There are several possible formulations:
- Voluntary Euthanasia
- Voluntary Assisted Dying
- Physician Assisted Dying
- Medical Aid in Dying/Medically assisted dying

The Upper House Committee has referred to the practice as Voluntary Assisted Dying. This formulation has been carried over into references by the Minister for Health and also the Owler committee.

The question is whether or not there is a strong argument to change the terminology. We believe not.

The American term 'Physician Assisted Dying' does not work in Australia because 'physician' is commonly understood in Australia to refer to a member of the RACP: in other words, a specialist. In the United States, 'physician' equates to a GP.

Medical Aid in Dying/Medically Assisted Dying has the advantage of reflecting the fact that there are several medical workers involved in the process: doctors, nurses, psychiatrists and pharmacists. The disadvantage is that it does not convey the key fundamental concept that the law is voluntary. It also lends itself to the unfortunate acronym: MAD.

Voluntary Euthanasia v Voluntary Assisted Dying:

The focus of euthanasia laws is typically on a doctor-administered lethal injection. Assisted Dying laws typically focus on the patient self-administering a lethal medication.

However the technical difference has become blurred in the public mind and the terms are often used interchangeably.

GGA research shows that 'Euthanasia' has the advantage of being a clearly understood term, evoking 'safe' images of a medically supervised process. For some, however it is sometimes seen as a confronting term, with echoes of eugenics.

'Assisted dying', on the other hand, is sometimes seen as a slightly imprecise term: what does it really mean? On the other hand it is a less confronting term.

On balance, GGA recommends remaining with the term Voluntary Assisted Dying:
- the most powerful reason is that it keeps the word 'Voluntary'. This is a bedrock concept.
- Though lacking the clarity of 'euthanasia' it is sufficiently descriptive to be understood by the public.

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