

Submission to the

Inquiry into the provisions of the

Voluntary Assisted Dying Bill 2021

NSW Legislative Council's Standing

Committee on Law and Justice

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Go Gentle Australia: prefatory notes

Go Gentle Australia 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 (VAD) laws, appropriate to the circumstances of Australian medical, political and social culture.

Since then, five Australian states have passed VAD laws. NSW is now the only state yet to pass this landmark reform.

Go Gentle has played a key role providing evidence-based information to legislators in every other Australian parliamentary debate; Victoria in 2017, WA in 2019 and then Tasmania, South Australia and Queensland in 2021. This furnishes us with a strong understanding of the political realities – and the challenges – of developing a law acceptable to both politicians and the general public.

In saying this, we emphasise that the first principle of any legislation is that it must be practically useful for the eligible person; while it should contain strict safeguards, these safeguards should not be so onerous that the very people the law was designed to help struggle to access it.

The Victorian, Western Australian 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.

Although among the five states there is now a clearly defined ‘Australian model’, each state has passed slightly different legislation subject to its local requirements. Faced now with this legislative question, we encourage you to consider how NSW will improve upon the laws that have come before.

Any amendment should seek to improve the operation of the bill and facilitate access for terminally ill people in NSW. We caution against last minute pile-on amendments - seemingly small changes - to a carefully developed bill that are not made in good faith and that could have larger, unintended ramifications. As two of Australia’s pre-eminent minds on end-of-life law and policy have written:

*Evaluating a VAD law must be based on how it will work as a whole, and not by considering individual provisions in isolation... Concern about one criterion when considered in isolation may resolve if all criteria are considered as a whole.*¹

PROFESSORS BEN WHITE AND LINDY WILLMOTT, QUT’S AUSTRALIAN CENTRE FOR HEALTH LAW RESEARCH

¹ White and Willmott, ‘Voluntary Assisted Dying research: A Policy Briefing’, Australian Centre for Health Law Research, Faculty of Business and Law, Queensland University of Technology, August 2021 - <https://research.qut.edu.au/voluntary-assisted-dying-regulation/wp-content/uploads/sites/292/2021/08/Voluntary-assisted-dying-research-Policy-briefing-web-version.pdf>

Finally, when framing this legislation we urge you to never lose sight of the aim of VAD itself; to support a person – who is already in the advanced stages of a terminal illness and who is suffering intolerably – to control the manner of their death. This is for whom this law is written, (not medical professionals or institutions), and who it must be designed to serve.

How we have responded

The terms of reference of this inquiry ask that we address the provisions of the Voluntary Assisted Dying Bill 2021, currently before NSW Parliament.

GGA broadly supports the bill as put forward by Alex Greenwich MP.

As such, we have addressed only those parts of the bill that we believe require further comment or discussion. Many clauses are, in our view, unremarkable and form part of the emerging 'Australian model' as adopted by every other state. We restrict our comments to only those clauses or sections that we believe are vital to preserve, or which should - in our view - be amended or given additional attention.

Throughout, we illustrate our responses with examples of how VAD law has operated in Victoria for more than two years drawn from interviews in our ground-breaking podcast [Better Off Dead](#), compiled by Andrew Denton and his production team. These insights were gained from several months of extensive interviews with individuals, families and doctors involved in Victoria's VAD law. They provide insight into how VAD law operates beyond the hypothetical.

In the section titled [Additional notes: Other matters](#), we have added more general comments which we believe should be taken into consideration when devising and implementing VAD legislation.

What has changed since 2017?

The NSW Parliament last debated voluntary assisted dying (VAD) in 2017, when no Australian state had passed such legislation. That bill was defeated by one vote in the Upper House. Since then, Australia's VAD landscape has transformed. Now, NSW is the only state *without* a VAD law.

Reforms in other states have been supported by Ministerial Expert Panels (Victoria and WA), an independent review by the University of Tasmania and a thorough report by the Queensland Law Reform Commission (QLRC). Your inquiry further embodies this commitment to getting the law right.

That 17 million Australians are now legally entitled to VAD reflects a dramatic shift in political sentiment on end-of-life care, and is echoed internationally. In the past 18 months, New Zealand, Portugal, Spain and the US state of New Mexico have all passed laws to allow terminally ill people a choice over how they die. A bill is currently before the House of Lords in Britain.

More than just a political and societal shift, it is a medical one too. In 2017 only two Australian medical bodies openly supported VAD. Today, the majority support or have taken a neutral stance, with only three remaining opposed.



There is also strong community support from those most directly affected by this issue. Members of the NSW VAD Alliance include state branches of the Nurses and Midwives Association, Council on the Ageing, Cancer Voices, Older Women's Network, Council for Civil Liberties, as well as the Australian Paramedics Association.

Public support for VAD now sits around 80 per cent, up from around 70 per cent five years ago. More than 155,000 ABC Vote Compass survey responses collected in the run-up to the 2019 federal election showed overwhelming support for VAD in every NSW electorate, including huge majority support among Coalition voters and those with religious faith. Three quarters of Catholics (75%) and Anglicans (77%) and 80 percent of non-Christian faiths supported VAD. Among voters with no-religion there was 94 percent support.²

Research commissioned by Council on the Ageing NSW recently showed 72 per cent of the NSW over-50 population support the legislation and more than half would consider voluntary assisted dying as an option for themselves.³

The arenas of politics, health and public opinion all tell us there is overwhelming and growing support for voluntary assisted dying.

²https://www.google.com/url?q=https://www.dyingforchoice.com/VoxPop_VAD_NSW/&sa=D&source=docs&ust=1636944264683000&usg=AOvVaw1m8YSct3qkbUR65rFywOQB

³ State of the (Older) Nation, 2021, Council of the Ageing for Older Australians, <https://www.cota.org.au/wp-content/uploads/2021/06/COTA-State-of-the-Older-Nation-2021-Research-Report.pdf> pp49-50

How do the 2017 and 2021 bills compare?

Five years have passed since the NSW Parliament last debated voluntary assisted dying (VAD). In that time, five Australian states have passed VAD laws and a clear 'Australian model' has emerged. Because of this, the 2021 NSW bill is a stronger piece of legislation than that put forward in 2017. Having been informed by other state legislatures, most particularly Victoria and WA where VAD laws are already in operation, there is clear evidence to support its framers' contention that this is a law that works both safely and as intended.

As Justice Peter Applegarth AM wrote in the QLRC's report into Voluntary Assisted Dying, published in May 2021:

It is the notion that the states are 'laboratories of democracy' in which different policies can be enacted and tested in a state, as in a scientific experiment. If the policy is a failure, it does not affect any other state. If, however, the policy is a success, it might be expanded to another state. If improvements are made in that next state, they might be adopted in another.

The result is not necessarily uniform legislation across the states that adopt the policy. A state can identify the strengths and weaknesses of laws that were enacted in another.

The key differences between the 2017 and 2021 bills are:

- **Implementation period:** The 2017 bill had a six-month implementation period from Assent to the Act becoming effective. The 2021 bill has lengthened this to 18 months, in recognition of the time required to train medics, prepare policy and form the Review Board.
- **Minimum age:** The 2017 bill specified a person must be aged 25 or over to be eligible for VAD. However, the age of medical consent in Australia is 18. At 18 years of age, a person can consent to or refuse any medical treatment - even if their parents, legal guardians or medical team disagrees. This includes making decisions with life-ending consequences, such as refusing blood transfusions or deciding when life-sustaining equipment is removed or switched off. It is inconsistent to have a higher age of consent for VAD alone, and every other Australian state has opted for a minimum age of 18. As such, the approach of the 2021 bill is correct in applying the same medical consent standards to VAD law. In reality, it is a tragic and rare circumstance where an 18 year old would be terminally ill and in the final months of life.
- **Waiting period:** In the 2017 bill, a 48 hour cooling-off period commenced on the completion of the request certificate. In the 2021 bill, there is a mandatory five-day period between the first request and the final request. In GGA's view, an additional cooling off period is an unnecessary further delay; there is already an additional waiting period while authority to proceed is received and while the prescription is issued. More importantly, experience from Victoria, WA and overseas shows that nobody chooses VAD on a whim. By this point, the person has already endured a stringent eligibility and application process, generally

preceded by a long period of illness and multiple treatments. Confirmation of the enduring nature of their request continues until the person receives the medication for self-administration or at the moment of practitioner administration.

- **Mandatory psychiatric assessment:** The 2017 bill required that, following assessment by two independent doctors, a psychiatrist or psychologist must assess whether the person has decision-making capacity and whether the person's decision was made freely, voluntarily and after due consideration. This approach has not been taken in any other Australian state, nor in any other legislature in the world, chiefly because it is unnecessary (doctors are more than capable of assessing capacity and do so on a routine basis) and it becomes another barrier to access for people, particularly those in rural and remote areas. In the 2021 NSW bill, it is only where a health practitioner is unable to assess a person's capacity that they must refer a person for psychiatric assessment. This reflects the 'Australian model'. We examine this further in [Clauses 27 & 38 - Referral for opinion—other matters](#).
- **Specialist referral:** The 2017 bill required the first assessing doctor to offer to refer the person to a palliative care specialist. This requirement doesn't exist in any other Australian state law. It is unnecessary, since most patients seeking VAD are also receiving or had received palliative care; in Victoria, 84% of people seeking VAD were in, or had received, palliative care⁴. It is also onerous to mandate an additional step for people under time pressure, particularly as all doctors have a right to conscientiously object. Experience from Victoria shows that it can take weeks, and sometimes months, for a terminally ill person to find a qualified specialist prepared to confirm their eligibility. As such, the 2021 bill only requires referral to a specialist in the event that a second opinion is required in deciding if a person meets the eligibility criteria.
- **Review:** The 2017 bill mandated a review of the Act by the Health Minister after five years of operation. The 2021 bill has shortened this to two years. GGA supports this greater scrutiny.

⁴ Voluntary Assisted Dying Review Board, Report of Operations January-June 2021, Safer Care Victoria, p18. <https://www.bettersafercare.vic.gov.au/sites/default/files/2021-08/VADRB%20August%202021%20report%20FINAL.pdf>

Part 1: Preliminary

Clause 10. Health care worker not to initiate discussion about voluntary assisted dying

GGA supports clause 10 when read with the qualifying subsections (2) and (3) that the prohibition on initiating discussions about VAD (subsection (1)) will not apply where:

- a medical practitioner also informs the person about their treatment options, including palliative care, and its likely outcomes; or
- a health care worker also informs the person they have other treatment and palliative options available and they should discuss these with their medical practitioner.

GGA appreciates concerns that a medical practitioner or health workers' provision of information about VAD in isolation may be interpreted by the patient as endorsement. As such, **we support clause 10 that VAD should be raised alongside *all* available treatment options, including palliative care.**

GGA recommends that the Department of Health make available printed and electronic literature outlining not just the process for VAD but also other possible pathways, such as palliative care. This will assist medical practitioners and ensure balance and consistency in the information provided, in line with current best practice in end-of-life care.

We caution against any revisions to the clause as it is. To place the onus of initiating a conversation about VAD onto the terminally ill person would introduce an avoidable inequity into the draft legislation. In requiring that the person is both well informed about VAD and confident in asking questions of their health team, those patients who lack the health literacy, language skills or confidence to start the conversation themselves are effectively denied an opportunity to apply for a lawful medical treatment.

As the QLRC highlights in its report:

Research suggests that up to 60 per cent of Australians have low levels of individual health literacy. This means that many eligible patients may not know voluntary assisted dying is an option.⁵

What's more, there is a real risk that a blanket prohibition, and the subsequent threat of disciplinary action, will impede and inhibit open conversations between doctors and patients about the end of life. This endangers not just the doctor-patient relationship, but also the level of care dying people receive.

⁵ Queensland Law Reform Commission, Report 79: A legal framework for voluntary assisted dying, May 2021, p. 76 - https://www qlrc.qld.gov.au/_data/assets/pdf_file/0020/681131/qlrc-report-79-a-legal-framework-for-voluntary-assisted-dying.pdf

In Victoria, where there is a blanket prohibition written into legislation, the rules governing these conversations lack clarity and can make doctors overly cautious in discussing end of life with patients. As the QLRC wrote in its report for the Queensland Parliament:

*The Victorian Act does not specify what amounts to initiating a discussion that is ‘in substance about voluntary assisted dying’. However, the use of the words ‘in substance’ would suggest that the health practitioner does not need to use the phrase ‘voluntary assisted dying’ to contravene the prohibition.*⁶

Since health practitioners already adhere to strict professional standards and duties, there is no need to censor conversations about VAD. No other doctor-patient conversations are censored in this way.

It has created this stigma and this fear within the community - medical and nursing and allied health communities - about the issue and about the legislative rights and wrongs of what they can and can’t do.

It’s actually introducing an indirect discrimination against people who are of lower educational status, people of non-English speaking backgrounds and essentially just people within the last six months of their life who aren’t au fait with the current legislative changes of the Victorian State Government, which I wouldn’t expect them to be.

DR CAMERON MCLAREN, MEDICAL ONCOLOGIST, MELBOURNE

Unfortunately there is no way of knowing how many terminally ill Victorians have been denied the chance to apply for VAD because they did not know the option existed - but for the inevitable individuals to whom this has happened, the price they have paid is very high indeed.

Victoria’s VAD Review Board has since recommended the blanket prohibition on initiating conversations about VAD be amended to align with the positions in WA, Tasmania, Queensland and the draft NSW legislation.⁷

It is antithetical for a law premised on patient choice and autonomy to deny dying people the option to know and choose from all the available treatment options, including palliative care and VAD alongside any others.

⁶ ibid p61

⁷ Voluntary Assisted Dying Review Board, Report of Operations January-June 2020, Safer Care Victoria, p16.
https://www.bettersafecare.vic.gov.au/sites/default/files/2020-08/VADRB_Report%20of%20operations%20August%202020%20FINAL_0.pdf

A key principle of the NSW Ministry of Health's End of Life Care and Decision-Making guidelines is the 'right to know and to choose':

Everyone receiving healthcare has a right to be informed about their condition and their care options and have access to good quality health information, in a format and language that is culturally responsive and that they can understand. People have a right to accept and decline life-sustaining treatment. Health practitioners have an ethical and legal obligation to acknowledge and honour these stated choices and preferences.⁸

We urge no amendments to this clause.

VOICES OF EXPERIENCE FROM VICTORIA:

I would prefer that... I could offer people the full range of options. When you talk about any medical care, you're giving people a range of options ... for them to choose. And obviously my job is to help them be educated so they can make an informed decision. And I would like to be able to do that in appropriate cases

DR NOLA MAXFIELD, GP, MELBOURNE

⁸ End of Life Care and Decision-Making, NSW Health, p5.
https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/GL2021_004.pdf

Part 2: Requirements for access to voluntary assisted dying

Clause 16. Eligibility Criteria

Subsection (1)(d)(ii) specifies a **time frame to death** for a person to be eligible for VAD; 12 months for a neurodegenerative disease and six months otherwise.

GGA's view is that VAD should only be an option for people at the end of life. One way to ensure this is to specify a time frame to death in the statutory eligibility criteria, which NSW's bill does alongside all Australian state laws.

The advantage of including a time frame to death in legislation is that it provides clear guidance to medical practitioners, who are accustomed to prognostication; in Australian palliative care, a common screening tool to identify people nearing the end of life is: *"Would you be surprised if your patient was still alive in 12 months' time?"* A time frame to death also provides consistency of the law's application to all NSW citizens.

On the other hand, there is a strong argument to do away with time frames altogether. They can be arbitrary; particularly in the case of degenerative chronic or neurological conditions, decline can happen swiftly, with devastating consequences, in patients whose death was not predicted for many months.

What's more, prognostication is an inexact science. Research shows people often have even less time than they think because physicians commonly overestimate prognoses. A review of studies by White et al⁹ in 2015 revealed that, across eighteen studies, the *predicted* median survival ranged from 14 to 219 days, while the *actual* median survival ranged from 10 to 126 days.

Sometimes, too, time frames can condemn people to greater suffering over a longer period; the suffering of an incurable and irreversible disease can be greatest in those who are not immediately dying. For example, a person with advanced multiple sclerosis, or motor neurone disease, may face many years of extreme pain, loss of autonomy, indignity and mental anguish.

Initially, parliamentary committees in Victoria and WA did not recommend specific timeframes for the assessment of terminal illness (although expert panels later did recommend 12 months). Tasmania's law was introduced to the Upper House without a specific timeframe to death. They considered doctors well-equipped to assess when patients were at the end of life and that arbitrary time limits would be too restrictive for the volatile progressions of terminal disease.

While GGA broadly supports the current bill's provisions, we would prefer to see a single 12 month time frame to death for *all* applicants, irrespective of the nature of their disease or illness. This echoes the approach of Queensland's legislation.

⁹ White N, Reid F, Harris A, Harries P, Stone P (2016) A Systematic Review of Predictions of Survival in Palliative Care: How Accurate Are Clinicians and Who Are the Experts? PLoS ONE 11(8): e0161407. <https://doi.org/10.1371/journal.pone.0161407>

A longer 12-month timeframe offers maximum palliative value.

The process of applying for VAD takes time. In Victoria, it is expected to take a few weeks. However, it can take considerably longer if there are delays in gathering evidence, accessing medical practitioners, and completing the paperwork or correcting errors.

Helen's doctor wrote numerous letters and made numerous phone calls to, I don't know, it seemed like 30 neurologists - but nobody would do it, and Helen's doctor said: 'I think this is going to be a race between us getting the approval for VAD and you dying.'

REG JEBB, WHOSE WIFE HELEN, IN THE FINAL STAGES OF MOTOR NEURONE DISEASE, TOOK ALMOST SIX MONTHS TO COMPLETE THE VAD PROCESS

This is compounded by the fact that applicants tend to start the process in the late stages of their illness. In Victoria, close to 50 per cent of eligible applications are withdrawn from the portal because the applicant has died before they can complete the process.¹⁰

In the final stages of terminal illness mere days can become the difference between a natural and assisted death if a sudden or cascading deterioration causes a person to lose mental capacity or the ability to act. Almost one third of eligible applicants in Victoria died before using the VAD medication.¹¹

VOICES OF EXPERIENCE FROM VICTORIA:

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

JUSTICE BETTY KING (RETIRED), FORMER CHAIR OF VICTORIA'S VAD REVIEW BOARD

We struggled ... weeks are going past and Dad's like wheelchair bound and major, major deteriorations. And that's what I've heard a lot about people who have tried to go down this path, they get to a certain point and ... they give up. They just physically can't get to these appointments.

DR KRISTIN CORNELL, WHOSE FATHER ALLAN, 74, HAD MND AND CHOSE VAD IN VICTORIA

A time frame of 12 months for all, irrespective of the nature of the illness or disease, allows people to get their medical choices in order earlier, lessening anxiety and giving them the best chance of being able to make decisions about the end of their life, whether or not that is through VAD, in a considered way.

¹⁰ In the period 1 July 2020 - 30 June 2021, of the 211 withdrawn applications, only two were due to the applicant not deciding to proceed, while 30 were withdrawn due to other reasons. All other withdrawals were due to the death of the applicant. Voluntary Assisted Dying Review Board, [Report of Operations](#), Jul-Dec 2020 & Jan-Jun 2021

¹¹ VAD Review Board, Report of Operations August 2021, p.13
<https://www.bettersafercare.vic.gov.au/sites/default/files/2021-08/VADRB%20August%202021%20report%20FINAL.pdf>

This can also be beneficial to a person's loved ones, who are not then faced with a potential medical emergency and the stress of trying to seek help when symptoms are becoming harder and harder to control.

As the QLRC report noted:

The Commission notes the concerns of some that a timeframe is arbitrary and could potentially prolong a person's suffering until the person can satisfy this eligibility criterion. We consider, however, that a timeframe of 12 months is a compassionate and balanced response. It will enable people to begin the voluntary assisted dying process at a time that suits their individual circumstances including the trajectory of their particular condition and level of suffering. At the same time, it ensures that eligibility is limited to people who are at the end of life.

*In those jurisdictions that do not include a specific time frame until death, most people do not access voluntary assisted dying until they are close to death. Allowing people to begin the process during what may well be the last 12 months of their lives does not mean that they will proceed to the administration stage as soon as they become eligible. They are likely to wait until they are closer to death.*¹²

While we do not object to the six month timeframe to death (and 12 months for a neurological condition), which is in-line with a majority of other states' VAD laws, **we support a single eligibility time frame of 12 months as a more compassionate and balanced response.**

VOICES OF EXPERIENCE FROM VICTORIA:

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 IT TOOK HER MORE THAN SIX MONTHS TO COMPLETE THE VAD PROCESS THAT SHE DIED BEFORE THE SUBSTANCE COULD BE ADMINISTERED.

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

LISA HOGG, WHOSE MUM MARGARET TOOK FOUR MONTHS TO BE ASSESSED AS ELIGIBLE FOR VAD. MARGARET HAD A RARE NEUROLOGICAL DISORDER, CORTICOBASAL SYNDROME.

People come to this often, late, and they come late because they really just haven't known about it, haven't been told about it, or are in a situation of ... they don't want to face mortality. And then when they do come and they're very sick, by that stage, it's very hard for them to access the doctors, and they have to travel.

JUSTICE BETTY KING (RETIRED), FORMER CHAIR OF VICTORIA'S VAD REVIEW BOARD

¹² n5 p112

Clause 16. Eligibility Criteria (continued)

Subsection (1)(d)(iii) specifies that a person's disease, illness or medical condition must be causing suffering that cannot be relieved in a way the person considers tolerable.

GGA strongly supports this clause for three key reasons:

First, this clause as written recognises that we must consider suffering holistically; suffering is about more than pain, encompassing both the physical and emotional.

Suffering includes symptoms that cannot be solved by pain medication, for example:

- paralysis, common with motor neurone disease
- distention (accumulation of body fluids in the abdomen), open sores, weight loss, odour, disfigurement, incontinence, unremitting fatigue and systemic inflammation (a persistent flu-like feeling), all common in end-stage cancer
- unresolvable shortness of breath and smothering, as in end-stage emphysema
- uncontrollable seizures, common in conditions affecting the central nervous system
- mobility issues
- choking
- emotional suffering

GGA strongly opposes any amendment that seeks to define suffering as physical suffering. This excludes a large part of the suffering that is beyond pain and often experienced at the end of life, as well as underestimating its profound impacts on the dying person.

Second, the clause's current wording recognises that even if pain were the only suffering, it is not the case that all suffering can be relieved.

Professor Eric Cassell, Emeritus Professor of Public Health at Cornell University, member of the Institute of Medicine of the National Academy of Sciences and a Master of the American College of Physicians has written:

Not all suffering can be relieved, no matter how good the care... and with even the very best treatment, the suffering of some patients is terrible and unremitting. Experienced clinicians know that even if you think you have seen the worst suffering possible, given time you will see someone suffering even more.¹³

¹³ Cassell, Eric, *The Nature of Suffering and the Goals of Medicine*, Oxford University Press, 2004, p.xii. Google Books Edition, viewed 19 July 2017, p289.
https://books.google.com.au/books/about/The_Nature_of_Suffering_and_the_Goals_of.html?id=K1kjFYrliTMC&redir_esc=y

While palliative care accommodates the needs of the majority of dying people, even the best-resourced care cannot relieve the extreme suffering some endure. Palliative Care Australia puts the number of patients truly beyond palliative care's help at around 4 per cent.¹⁴ Other experts put this number higher, at between 5-10 per cent.¹⁵ In Palliative Care Australia's own words:

While pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal palliative care.

The author of those words for Palliative Care Australia was Professor Michael Ashby, who is a Professor of Palliative Care at the University of Tasmania and teaches bioethics, palliative care and grief and loss in the MBBS course. He is a past President of the Australia and New Zealand Society for Palliative Medicine (ANZSPM) and a past Chairman of the Chapter of Palliative Medicine at the Royal Australasian College of Physicians. He told us in an interview for our *Better Off Dead* podcast in early 2021:

Yes, palliative care has limitations. And I think it's incumbent upon our medical specialty to be honest with people that we'll try our best and we don't give up, but that we can't abolish all symptoms. We can't relieve all suffering.

When asked how he feels when he hears doctors claim that palliative care can relieve all suffering Prof Ashby said:

I find any assertions of that nature to be untrue. I think the overselling of the product is also unhelpful and disingenuous.

Third, the clause's current wording recognises that suffering is subjective; no one but the individual can determine if they are suffering, the level they can tolerate and when they have had enough. We can't look at someone else and say 'you haven't got enough physical symptoms to be suffering'. This is consistent with a person-centred approach, not only to VAD, but to health care in general.

[Opponents] seem to focus on pain as the main component of suffering. Increasing breathlessness, fear of suffocation (for example, with MND or COPD) are often awful and difficult to manage. This will not respond to 'stunning advances in pharmaceutical technology' unless you completely obliterate/sedate the person i.e bring about their 'social death'.

DR GREG MEWETT, PALLIATIVE CARE PHYSICIAN, BALLARAT HEALTH VICTORIA

Australia is at the forefront of pain management. I trained under one of the world's best pain management specialists, Professor Michael Cousins, but even with his expertise we struggled to manage the pain of many palliative patients referred to us. For many, we eventually reverted to sedation.

¹⁴ Claire Moodie, 'With his death he made a statement': Clive Deverall's widow speaks out on euthanasia, news report and video, ABC News 20 September 2017 (see quoted content in video at 4.00) - <https://www.abc.net.au/news/2017-09-19/clive-deveralls-widow-speaks-out-on-euthanasia/8882854>

¹⁵ Roger Hunt, "Re P.C. Figures", Email to Andrew Denton, Go Gentle Australia, 23 July 2017.

After billions of dollars of research and drug development, our go-to drugs, the opioids, are centuries old. This is because the pain system is so hard to corrupt, and almost impossible to hack in some pain states. We doubt we will ever eliminate pain. That's why we call it pain management.

Many of my patients are disappointed when I tell them we can't cure their pain.

The so-called 'new' therapies mentioned by some members in the Lower House debate - ketamine, methadone, coeliac plexus blocks - have all been around for decades and have very limited applicability.

DR GAVIN PATTULLO, ANAESTHETIST AND PAIN MEDICINE PHYSICIAN, SYDNEY

No amount of psychiatry or psychological support was going to alleviate the suffering, you know. Mum had got to a stage where she was virtually unable to do anything for herself. She was hoisted up in a sling, with no pants on, being transferred from her chair into the toilet, in front of staff. She had some movement in one arm and poorly controlled movement in the other. She was finding it increasingly difficult to swallow and to eat and she was starting to choke on her food, and particularly on drinks. She got to the stage, she couldn't even turn herself over in bed, so she couldn't make herself comfortable at any point. There was no drug, there was no treatment, there was no surgery that would make her condition go away. There was nothing they could give her even to postpone the progression of her condition.

LISA HOGG, WHOSE MOTHER MARGARET, 81, HAD CORTICO-BASAL DEGENERATION AND CHOSE VAD IN VICTORIA

Even right towards the end, when my brother and I were trained and we had to syringe different medicines in, and there were days when, you know, it wasn't working. It wasn't killing his pain. I mean, sometimes it would space him out, sometimes it would make him sick. It was fentanyl that they ended up having Dad on. There were so many different things going into him. And it wasn't keeping him comfortable. No increases of any of the pain meds was doing anything different.

KATIE HARLEY, WHOSE FATHER PHIL, 70, HAD METASTATIC BLADDER CANCER AND CHOSE VAD IN VICTORIA

My lung physician. ... said, 'Well ... you don't need to do any more lung tests, because there's nothing there to test'. It's like walking around with a straw in your mouth trying to suck in enough air. There's no cure for it. Your lungs don't regenerate. I would be bedridden the whole time. ... massive amounts of morphine. Anti-psychotics. It's not a life I find attractive at all.

PETER JONES, 66, CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD). DIED, USING VICTORIA'S VAD LAW, MARCH 2021

Part 3: Requesting access to voluntary assisted dying and assessment of eligibility

Clause 18. Eligibility to act as coordinating practitioner or consulting practitioner

Clause 18 sets out the eligibility criteria medical practitioners must meet to act as coordinating and/or consulting practitioners in the VAD process.

GGA agrees that only experienced medical practitioners should be able to assess a person's eligibility for VAD.

However, the levels of qualification and experience must not be set so high that too few doctors meet the standard and this becomes a barrier to access for terminally ill people.

With this in mind, **GGA recommends that the subsection (a)(ii) requirement that a medical practitioner of general registration must have practised for 10 years is reduced to five years.**

This is consistent with clause 55 which requires an administering practitioner to have practised for at least five years.

All medical practitioners who undertake VAD assessments must also undergo specialised training. What's more, the eligibility criteria state only the *minimum* qualifications and experience a practitioner must have. As the QLRC wrote in its report:

*If experience in Victoria is a guide, the practitioners who qualify and who are prepared to undertake the specific training to participate in the voluntary assisted dying process are likely to have **experience well in excess of the minimum required**. They may be specialists in general practice or other fields where the scope of their practice brings them into contact with people who are dying. They may be experienced doctors who have been working for years in hospitals in areas like oncology, acute care of patients with chronic obstructive pulmonary disease, or in palliative care.¹⁶*

A proportionate approach must be taken. While the most highly qualified and experienced medics may seem desirable, their ability to achieve positive outcomes for patients will diminish if there are so few practising that many patients cannot access a doctor at all. This will be magnified by a doctors' right to conscientiously object which, as experience from Victoria has shown, means that some terminally ill people have to make multiple requests before finding a doctor who is both qualified and willing to assess them for VAD.

GGA recommends that GPs must have practised for five years to be eligible to take part in the NSW VAD scheme.

¹⁶ n5 p382

Clause 21. Medical practitioner to accept or refuse first request

Subsection 5 specifies that where a medical practitioner refuses a request for VAD on the basis of their conscientious objection, the medical practitioner must provide the person making the request with information approved by the Health Secretary. **We strongly support the inclusion of this provision.**

A medical practitioner's right to conscientiously object to participating in VAD should not override a patient's right to access information about VAD.

As the QLRC wrote:

The rights and interests of different participants must be balanced. Participation must be entirely voluntary, including for medical practitioners. The right of a practitioner not to participate must be recognised, including because of a conscientious objection. A person must also be able to access information about their end of life choices and take steps to access lawful options, including voluntary assisted dying.

Requiring a medical practitioner who refuses a first request to give the person certain information appropriately balances these different rights and interests.¹⁷

This is consistent with the AMA's Position Statement on conscientious objection:

A doctor's refusal to provide, or participate in, a treatment or procedure based on a conscientious objection directly affects patients. Doctors have an ethical obligation to minimise disruption to patient care and must never use a conscientious objection to intentionally impede patients' access to care.¹⁸

The people for whom this law is written may well not be in a position to do their own research. Beyond their terminal illness, they will likely be of an older generation with less access to the internet. People from a CALD background may lack the linguistic skills to find information alone.

The inclusion of a clause to this effect in Victoria's law, alongside a gag clause prohibiting medical practitioners from initiating conversations about VAD with patients, is considered a major barrier to access and has been remedied in the WA, Tasmanian and Queensland laws.

We note that a clause to the effect that a conscientiously objecting medical practitioner must provide information to ensure a patient's access to legal medical treatment is not blocked is also included in the Abortion Law Reform Act 2019, showing it is an accepted part of medical practice.

We strongly recommend retaining this clause in the NSW VAD bill.

We also strongly recommend the inclusion of a complaints mechanism in the event that a person is unhappy with a medical practitioner's conduct; for example, blocking or otherwise obstructing a person's access to information about VAD.

¹⁷ ibid p202

¹⁸ Australian Medical Association, Position Statement: Conscientious Objection (2019) [1.5].
<https://www.ama.com.au/position-statement/conscientious-objection-2019#:~:text=1.5%20A%20doctor's%20refusal%20to,impede%20patients'%20access%20to%20care.>

Clauses 26 & 37 - Referral to another medical practitioner for opinion - disease, illness or medical condition

In both the first and consulting assessment processes, there is provision for a referral to someone with appropriate skills and training if the medical practitioner is not able to determine that a person's disease, illness or medical condition makes them eligible for VAD. **GGA strongly supports these clauses in their current form.**

However, in other debates amendments have been attempted to include specialist referrals for every person applying for VAD. **We reject any changes to this clause's current wording.**

We urge against the inclusion of mandatory specialist referrals in the NSW bill.

The existing provisions in clauses 26 and 37 already provide for the situation where a specialist referral is necessary. This is consistent with good medical practice. However, to make referral mandatory would be to add an additional step to an already lengthy process for terminally ill people, and an additional barrier to access for those living in rural and remote areas where there are fewer health practitioners.

VOICES OF EXPERIENCE FROM VICTORIA:

If I wasn't sure about, say, a respiratory problem, I have the opportunity to say, 'Look, 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 an independent respiratory assessment so that he or she can look at 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 useful for your condition.'

DR ANDREA BENDRUPS, GENERAL PHYSICIAN AND RHEUMATOLOGIST, ROYAL MELBOURNE HOSPITAL

If they have a cognitive impairment, the provisions within the legislation allow me to have a geriatrician who can assess the patient to get a cognitive assessment.

DR PHILLIP PARENTE, MEDICAL ONCOLOGIST, DIRECTOR OF CANCER SERVICES, EASTERN HEALTH

The neurologist had to ask her a lot of very specific questions and the concentration for her was pushed to the max, basically. We thought, 'Oh my goodness, can't he see that she's old? Can't he see that she's tired?' But actually, despite all of that, he went through his process and he did very rigorous testing.

LISA HOGG, DESCRIBING THE ASSESSMENT PROCESS FOR HER MOTHER MARGARET, 82, WHO HAD CORTICOBASAL SYNDROME, AND WHO WAS REFERRED TO A SECOND NEUROLOGIST

Clauses 27 & 38 - Referral for opinion—other matters

In both the first and consulting assessment processes, there is provision for a referral to someone with appropriate skills and training if the medical practitioner is not able to determine a person's decision-making capacity. **GGA strongly supports these clauses in their current form.**

However, in other debates amendments have been attempted to include mandatory psychiatric assessments for every person applying for VAD. **We reject any changes to this clause's current wording.**

We strongly oppose the inclusion of mandatory psychiatric assessments in the NSW bill.

First, it would contradict a cornerstone of the law of consent and decision-making capacity, which has been incorporated into the NSW legislation: a person is assumed to have decision-making capacity unless there is evidence to the contrary.

Australian courts have confirmed the right of competent persons to make decisions about their medical treatment without psychiatric assessment - even if these decisions hasten death.

Judicial decisions of the Supreme Courts of NSW (CJ McDougall), WA in the case of Rossiter, and SA (J Kourakis) have all determined the right of competent persons to make these decisions without mandatory psychiatric assessment, and 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.

To reverse the capacity assumption in the case of terminally ill people seeking VAD is inconsistent and unjust; there is no 'special case' for VAD and the NSW bill recognises that VAD is distinct from suicide.

This difference was underlined by the WA parliamentary inquiry into end-of-life care, which wrote:

It is possible to distinguish temporary suicidal ideation from an enduring, considered and rational decision to end one's life in the face of unbearable suffering.

Associate Professor Steve Ellen, who has decades of experience in General Hospital Consultation Liaison Psychiatry before being appointed as Head of Psycho-oncology at the Peter MacCallum Cancer Centre, explained in correspondence to GGA that psychiatric assessment is only mandatory in relation to refusal of care (a decision which has the likely foreseeable consequence, in someone who is terminally ill, of death) if there is evidence of mental illness:

*I'm not aware of any mandatory psychiatric assessments for people refusing care... The only time a patient has a **mandatory** assessment (excluding court ordered assessments) is if a patient has evidence of a mental illness, plus ideas of self-harm (such as suicidal plans), and is refusing mental health care. They must meet ALL three criteria. Only then must they have a compulsory psychiatric assessment, as required by state mental health legislation. This would not be the case for refusing treatment, unless they appeared to be mentally ill. So, the psych assessment is only compulsory if there is evidence of mental illness.*

The Victorian Ministerial Expert Panel noted that a person's prior history of mental illness (for example, a mental illness that occurred 20 years ago) does not necessarily warrant a referral to a psychiatrist either. As Justice (retired) Betty King, former Chair of Victoria's VAD Review Board notes:

A lot of people think that depression equals an inability to make a competent decision. It's not surprising if you have a terminal illness that you have a degree of depression. Most doctors are good at determining that, and the coordinating doctors, rather than necessarily referring off to a psychiatric report, say 'I note a history of depression six months ago, person was treated, et cetera', and they talk about the steps that have been taken in relation to whether or not it affects their cognitive impairment.

Second, mandatory psychiatric assessment ignores the reality that experienced medical practitioners routinely assess for capacity, including for decisions with life-ending potential such as ceasing chemotherapy.

Dr Andrea Bendrups, a GP and rheumatologist based at Royal Melbourne Hospital with more than 30 years experience, says in the *Better Off Dead* podcast:

In the first assessment, what you're really doing is checking competency, decision making capacity, and looking for coercion... Those are things that as a treating doctor, I've been doing for years. This is not new. This is not a VAD skill. This is something that, to get consent to swallow a tablet, or to prescribe, we've all had to ensure patient comprehension and engagement with the process of therapeutics. That's called doctoring.

Palliative care specialist at Ballarat Health, Dr Greg Mewett, explained:

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

And, as Doctors for VAD Choice pointed out in their submission to the WA Joint Select Committee, general practitioners can often be:

...best placed to assess the patient's mental state and decision-making capacity due to their longitudinal relationship with the patient and the routine use of this assessment in all health care decisions that patients make. There should be no need for a mandated psychiatrist review.

Third, doctors carrying out VAD assessments are already obliged by the current bill to refer to a specialist if there is any doubt around capacity or coercion. Moreover, people seeking VAD must express their intention multiple times throughout the assessment process – and even at the point they are delivered life-ending medication - to show that they know what it is they are asking for, and that this is their enduring wish.

That VAD law requires persistent proof of capacity is evident when listening to families whose loved one has made use of the law in Victoria. Reg Jebb, whose wife Helen, 75, had motor neurone disease, told us:

Helen, must have - and I'm not exaggerating her - Helen would have been asked, and confirmed, in this whole process at least 50 times She understood [why] but because it happened so often, she was, like, how many times do you have to bloody say it? How many times is enough?

Justice Betty King (retired), inaugural chair of Victoria's VAD Review Board, explained:

The most common feedback we get, in terms of a complaint, is how often they have to tell people they want to use VAD.

Fourth, for NSW to do this would be an unprecedented step. Proposals for mandatory psychiatric assessment have been rejected by every state parliament in Australia and do not exist in VAD/Voluntary Euthanasia law anywhere in the world. There is no evidence to suggest that people in NSW are uniquely incapable of competently making important medical decisions. In truth, they regularly do so; deciding to have, or to decline, major operations, chemotherapy, radiotherapy and other potentially life-shortening procedures, without the need for mandatory psychiatric examination.

Fifth, mandatory psychiatric assessment would lengthen the waiting time before eligibility is granted, not only prolonging a terminally ill person's suffering but also risking the onset of unconsciousness or mental impairment that could render them ineligible for VAD. It will also impose an unreasonable burden on some people, particularly in remote rural areas, with limited access to mental health specialists, as some (and possibly many) psychiatrists would invoke their right to conscientiously object to VAD. Making psychiatric examination mandatory would only add another layer of difficulty for terminally ill people seeking to establish eligibility.

Finally, mandating that referrals can only be made to a psychiatrist is unnecessarily restrictive. The Victorian Ministerial Advisory Panel identified in its report that geriatricians, psycho-geriatricians, neurologists, neuropsychologists, psycho-oncologists, psychologists and palliative care specialists were all specialists who could potentially make assessments about a person's decision-making capacity, depending on the nature of the concern.¹⁹ For example, when an assessing medical practitioner suspects an elderly person may have a degree of cognitive impairment that may be impacting on their decision-making capacity in relation to voluntary assisted dying the assessing medical practitioner may refer them to a geriatrician for assessment. Where an assessing medical practitioner suspects a person's brain tumour or previous cerebrovascular accident may be impacting on their decision-making capacity they may refer them to a neuropsychologist for assessment.

¹⁹ Ministerial Advisory Panel on Voluntary Assisted Dying Final Report, State of Victoria, Department of Health and Human Services, July 2017, p64 - <https://content.health.vic.gov.au/sites/default/files/migrated/files/collections/research-and-reports/m/ministerial-advisory-panel-on-voluntary-assisted-dying-final-report-pdf.pdf>

Clause 28. Information to be provided if patient assessed as meeting eligibility criteria

Clause 28 subsection(1)(k) states that if the person is a resident of a residential facility, whether permanently or not, the person should inform the residential facility manager about their request for access to VAD.

We do not support this provision. No person should be forced to disclose private medical treatment decisions, in line with the established principles of patient confidentiality. The fact that the person resides in a facility does not alter their right to privacy. The only instance where this would be a reasonable requirement is where active involvement of the facility is required, and even then we recommend this information is shared on a strict need-to-know basis.

We suggest that the VAD training modules should include guidance that the assessing practitioner should give to an eligible person, including advice that it may be in their best interests (and that of the institution) for them to advise the institution that they are pursuing VAD, if they are comfortable to do so.

See also Part 5 which addresses institutional participation, and Appendix A: What it can mean to be forced out of your home at the end of your life. Case studies from Victoria and Western Australia.

Clause 44. Witness to signing of written declaration

Clause 44 subsection (2)(b) stipulates the witness must not be a family member of the person making the declaration.

We do not support this provision. A person's family is often closely involved. A safeguard already exists that a potential witness must not benefit (financially or otherwise) from a person's death. Many people will opt to discuss their VAD application within their family and may want family support. Requiring people to ask outside their family can mean forcing them to share intimate information that they may not wish to share. Dr Kristin Cornell recounts what it was like to find witnesses for her father Allan, who was dying of Motor Neurone Disease, and who had applied for VAD:

And you need these witnesses, which can't be a family and can't be the doctor. And so you've then got to find two people who you are okay to tell about, you know, this is gonna happen. And so you've secretly got to find out their motives for whether or not they approve of this or not... anyway, we ended up asking some neighbours, and thankfully, even though it may not have been their preference to things that they would like to do that day, they signed the paperwork.

It can also be difficult to ask people who are not family to perform such a task, as Katie Harley, whose father Phil was dying of metastatic cancer and who used VAD, recounts.

Dad asked a couple of his best friends to come ... and sign a waiver to say that they agree that Phil's in his right mind that they don't stand to benefit ... financially from his death. That was a hard one, you know, asking friends to come in and ... Dad... he was joking at the time and he said, You got to sign my death warrant. ... but I could tell that it was very hard for them because, you know, it was going to be one of the last times that they saw Dad as well.

Part 4: Requesting access to voluntary assisted dying and assessment of eligibility

Clause 55. Eligibility to act as administering practitioner

Clause 55 subsections (a)(iv) and (a)(v) state that a nurse practitioner or a registered nurse who has practised the nursing profession for at least five years can act as the administering practitioner in the VAD scheme. **GGA strongly supports the inclusion of suitably trained nurse practitioners in the bill but counsels against the inclusion of less qualified registered nurses.**

NSW Health defines a nurse practitioner as

A registered nurse educated and authorised to function autonomously and collaboratively in an advanced and extended clinical role. The nurse practitioner role includes comprehensive clinical assessment, requesting diagnostic investigations, management of care for patients/clients, prescribing medicines/therapies and includes direct referral of patients to and from other health care professionals, including Aboriginal Health Workers.

Nurse practitioners undergo extensive clinical training and supervision and must complete a certified master's degree course. In NSW, all nurses undertaking a Nursing and Midwifery Board of Australia-approved program of study (including transitional nurse practitioners) are required to undertake integrated professional practice as part of their nurse practitioner master's program.²⁰

The inclusion of suitably qualified nurse practitioners as administering practitioners ensures people in rural and regional areas, whose coordinating practitioner does not live locally, do not face additional hurdles to accessing VAD.

As the QLRC wrote:

Nurse practitioners are highly qualified, skilled and experienced. They are authorised to autonomously manage complete episodes of care for people with a variety of health needs, in a range of healthcare settings.

As nurse practitioners already undertake these advanced practice roles, authorising them to act as an administering practitioner may facilitate access to voluntary assisted dying, particularly for those Queenslanders residing in rural and remote areas where there are fewer medical practitioners.²¹

The inclusion of suitably qualified nurse practitioners in the administration of VAD in NSW mirrors the VAD legislation in WA, Tasmania, Queensland and New Zealand.

²⁰ NSW Health Nurse Practitioners, Policy Directive, p7.

https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2020_034.pdf#:~:text=Transitional%20nurse%20practitioner%20clinical%20training%20is%20to%20be,to%20satisfy%20the%20authority%20to%20prescribe%20in%20NSW

²¹ n5 p407

We note that the WA Ministerial Expert panel were adamant nurse practitioners possessed the qualifications and necessary experience to take a pivotal role in the VAD process, arguing nurse practitioners registered in Australia on an ongoing basis should also be permitted to act as consulting medical practitioners in the VAD assessment process:

... having regard to the scarcity of medical practitioners in many country districts and towns of Western Australia, the Panel has recommended that the second (consulting) practitioner may be a qualified nurse practitioner.²²

The WA expert panel argued the policy intent was to ensure that there was appropriate access to voluntary assisted dying across the geographically diverse state of Western Australia. We note this recommendation was not taken up by the WA parliament.

Tasmania and Queensland do permit registered nurses to administer the VAD medication. Again, this was justified on the grounds of ensuring no geographically isolated resident of those states were disadvantaged in access to VAD. **However, GGA counsels against this inclusion in the NSW bill.**

While registered nurses are experienced in the technicalities of administering medications, the role of administering practitioner can be emotionally taxing. It also requires a final assessment of the patient's capacity. As such, we believe nurses involved should be at the highest level of training and experience.

Clauses 73-76. Prescribing and supplying of voluntary assisted dying substance

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

This has multiple advantages:

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

²² Malcolm McCusker AC QC, Ministerial Expert Panel on Voluntary Assisted Dying Final Report, page vi 2019. https://ww2.health.wa.gov.au/~/_media/Files/Corporate/general-documents/Voluntary-assisted-dying/PDF/voluntary-assisted-dying-final-report.pdf

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

Professor Michael Dooley, Head of Victoria's Statewide Pharmacy Service

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

Professor Michael Dooley, Head of Victoria's Statewide Pharmacy Service

Clause 71. Board must decide application

Subsection (1) indicates the Board must make a decision "as soon as practicable". However, no indication of time is given.

GGA recommends stipulating a reasonable amount of time the Board may take, for example "as soon as practicable but not in excess of two business days".

The law must keep the suffering, terminally ill person at the centre of its focus. By not including a timeframe, the Board may deem it "practicable" to only convene once a week for example, thus further delaying what is already a long process.

We note a similar time frame is included in clause 72 which deals with refusal of an application.

Part 5: Participation

Divisions 2 & 3: Residential facilities and healthcare establishments

While the religious freedoms of individuals to conscientiously object are protected in the NSW bill, the ability of institutions to do the same are, rightly, curtailed.

Division 2 of the NSW Bill specifies that although residential facilities (retirement villages and residential aged care facilities (RACFs) can elect to not actively participate in VAD, they cannot block residents' access to VAD services if that is the resident's choice. This is because retirement villages and RACFs are people's permanent homes and the State has no right to dictate to people what legal medical treatments they can access in the privacy of their own homes. **This is an important protection within the NSW Bill that must not be dismantled.**

Within the bill, NSW hospitals, however, do have a right to refuse to participate in VAD (hospitals are not permanent residences). This right is granted with one proviso – they must facilitate a person's transfer to another facility to access VAD.

While supporting these provisions at a minimum, GGA would prefer the NSW Bill to follow the example of Queensland to best ensure that the rights of the people for whom this law has been written – the terminally ill – are in no way compromised by the moral objections of an institution.

In Queensland, if a person cannot be safely or practically transferred to another institution (i.e. if transferring would cause them serious harm, such as significant pain or deterioration in their condition, or loss in decision-making capacity) the hospital must allow access to external VAD doctors for both the assessment and administration of the VAD substance. **There is no such provision in the NSW bill, and GGA strongly recommends a provision to this effect be added.**

Division 2 (residential facilities) and Division 3 (health care establishments) of the NSW bill both state regard must be had as to:

- a) whether the transfer would be likely to cause serious harm to the person
- b) whether the transfer would be likely to adversely affect the person's access to voluntary assisted dying
- c) whether the transfer would cause undue delay and prolonged suffering in accessing voluntary assisted dying
- d) whether the place to which the person is proposed to be transferred is available to receive the person
- e) whether the person would incur financial loss or costs because of the transfer.

However, there is no explanation of what happens to the applicant if any of the above are deemed to be the case. Are they to be denied access to VAD and condemned to experience the very death they wished to avoid?

The Queensland law draws a line that the NSW bill does not; it weighs up the competing harms of moral distress caused to an institution that objects to VAD against the actual harm done by forcing a terminally ill person to move, when doing so would cause them greater harm or lead to them losing mental competency.

In that instance, Queensland's law seeks to protect the person from that greater harm, recognising that **people suffer in ways that institutions do not.**

The Queensland model is preferable because it acknowledges that:

1. An unfettered right to institutional objection cruelly privileges the rights of the institution over the rights of the terminally ill person.
2. Experience from Victoria shows that the numbers of NSW residents who will seek, and be found eligible for, VAD – and who are also in a faith-based facility and unable to be transferred – will be very small. But for those few the prospect of transfer can be devastating.
3. Case studies from the first two years of Victoria's VAD law show how extreme end-of-life suffering can be. For some people in NSW – even in the State's most populous regions - finding a public hospital that will support VAD is not necessarily straightforward. Away from cities and regional hubs, that prospect becomes more difficult.
4. Case studies from Victoria, WA, and also Canada, show how institutional objection in faith-based facilities can lead to distress, desperation, and loss of dignity, for people at the end of their lives. SEE APPENDIX A; What it can mean to be forced out of your home at the end of your life. Case studies from Victoria and Western Australia.

Faith-based health services and VAD can work together: The example from Western Australia.

GGA urges the Committee to look to Western Australia when assessing claims made in NSW about the need for an absolute right to institutional objection.

The Catholic Church of Western Australia – which shares the same operating ethos as Catholic Health in NSW – has taken a practical, yet compassionate, approach when considering its obligations to the terminally ill.

Western Australia's VAD law, which came into operation in July 2021, allows all individuals to conscientiously object, but is silent on institutional objection.

In August, the Catholic Archdiocese of Western Australia announced that – even though it would not provide or facilitate VAD, or authorise its caregivers to be in any way involved – it would '**not impede a client or resident who wishes to make private arrangements to receive and use VAD substances**'.

Speaking for the Catholic Archdiocese of Perth, LJ Goody Bioethics Director, Rev. Joe Parkinson, confirmed 'Our services have agreed that we will not provide or facilitate VAD.'

However, unlike Catholic Health in NSW, which is claiming a blanket right to object to all steps of the VAD process, Dr Parkinson recognised that this was neither feasible, nor fair.

To begin with, we recognise that wherever we deliver aged care or disability care services, it will usually be in the client or resident's own home setting and they have a right (under Federal legislation) to make any other care arrangements they like.

So, we cannot impede their right to seek VAD privately, and we will comply with the VAD Act in providing statutory information about VAD...

If a resident or client wishes to consult a VAD Navigator they will be able to do so privately, even on our premises, but our staff will not be authorised to assist, other than to put the resident or client in touch with the Navigator Service for the purposes of obtaining information.

Crucially, Dr Parkinson added that the Catholic sector would not impede a resident's or client's right to pursue VAD eligibility – even if that meant external doctors being called in to assist. He emphasised:

If a resident or client wishes to make private arrangements to receive and use VAD substances they will not be impeded, but again our staff will not be authorised to assist in any way.

Dr Parkinson also noted that the Catholic sector did not want to see patients, residents or clients transfer out of their facilities for the purposes of obtaining VAD.

Although of course we will not impede any who wish and are assessed as clinically safe to do so.

Likewise, if a hospital asks to return a resident or client to our care we will accept them, even if they intend to pursue VAD, but our staff will not be authorised to assist with the VAD process itself.

This would not mean – as Catholic Health claims – that those who work for Catholic Health in WA will be denied the choice not to participate in VAD. As Dr Parkinson made clear:

We will not authorise any of our caregivers to be involved in any of the steps required for the client to access VAD, including facilitating assessments for eligibility and helping them to obtain and use the VAD substances.

The person-centred approach of WA's Catholic sector – recognising the rights of individuals in their homes to pursue VAD; putting people in touch with the VAD Care Navigator service; allowing external doctors access to clients for the purposes of VAD, accepting clients who do not wish to be transferred but who have made a private decision to pursue VAD; and recognising that in some cases it may not be clinically safe to do so – stands in stark contrast to the institution-centred approach of NSW faith-based providers who claim the right of refusal in all these things.

That WA's Catholic sector will accommodate VAD, while making it clear their staff will not be authorised to assist in any way, gives lie to the claim by others that VAD will dismantle the operating ethos of faith-based health providers.

As Western Australia's Catholic archdiocese shows, VAD and faith-based care can co-exist.

What will the reality be if terminally ill people in NSW are forced to transfer to another hospital?

The following three case studies from Victoria show what the last 24 hours can look like for a person seeking VAD.

CASE STUDY ONE: Allan Cornell, 74, Motor Neurone Disease, described by his daughter, Dr Kristin Cornell:

He was in pain and desperately short of breath. He was dying. He was suffering. He was exhausted. He was begging me the entire day prior to finish it.

Such was Allan's distress, he took the VAD medication minutes after receiving it.

CASE STUDY TWO: Patient of Dr Peter Lange, Head of Acute Medical Unit, Royal Melbourne Hospital, who was administered VAD medication by him:

She had a very severe neurological disorder. She was bed bound and had barely any volitional movement at all. Just a spoonful of jelly would be enough to cause her to cough terribly for ten to fifteen minutes. She was in a really terrible situation.

CASE STUDY THREE: Phil Ferrarotto, 70, metastatic bladder cancer, described by his daughter, Katie Harley:

Towards the end it was fentanyl they had Dad on. There were so many things going into him. No increase of any of the pain meds was doing anything. This was complete agony. And it was with every breath. To breathe hurt, to swallow hurt.

So extreme was Phil's suffering he begged for it to be ended more quickly. Under Victorian law, the time between his first and last request was shortened, following an application supported by both assessing doctors.

We strongly recommend there be no watering down of the existing provisions in the bill regarding access to VAD in retirement villages and residential aged care facilities (RACFs).

We also strongly recommend a strengthening of provisions in the bill requiring NSW hospitals to allow access to external VAD providers if transferring the patient proves impracticable or likely to cause harm.

Part 12: General

Clause 182. Communication between patient and practitioner

Clause 182 of the NSW bill says that where in-person VAD assessment is not possible, then audiovisual and electronic communication may be used:

- by a person to make a first request, final request or administration decision; and
- by a medical practitioner to provide information or advice in response to the request or decision.

This provision is particularly important for people living in remote and rural areas who may not be able to travel long distances to visit a health practitioner, and where it is not practical for a medical practitioner to travel to them to deliver what may be general information about VAD and other end of life care options. The use of audiovisual and electronic communications, such as email, helps to ensure VAD is accessible to all, irrespective of a person's postcode.

Subsection (3), however, explicitly rules out any communication method that is contrary or inconsistent with Commonwealth law. **GGA calls for urgent clarification from the Federal government as to how Commonwealth 'carriage service' laws apply to state VAD laws, and support any necessary amendment to the Criminal Code (Cth) to ensure their safe and equitable operation.**

Sections 474.29A and 474.29B of the Commonwealth Criminal Code 1995 as amended by the Criminal Code Amendment (Suicide Related Material Offences) Act 2005, state that it is an offence to use a carriage service (such as telephone or telehealth) for suicide-related material. It is unclear if this prohibition applies to lawful conduct under state VAD laws.

Although every state law recognises that VAD is distinct from suicide, including in Clause 12 of the NSW bill, this has no bearing on the statutory interpretation of Commonwealth law. As the QLRC explained in its report, in the case of conflict Commonwealth law takes precedence:

... there is a potential inconsistency between the Commonwealth law and the relevant state law. The state law expressly authorises intentional self-killing if the requirements of the law are met and allows health practitioners and others to communicate via telephone and other electronic means. If those communications fall within a prohibition in the Criminal Code (Cth), then any authorisation given by state law to undertake those communications will be inoperative due to a direct inconsistency between the Commonwealth law and the state law.²³

²³ n5 pp640-1

This uncertainty is highly undesirable. Many health practitioners may avoid using electronic communications altogether, for fear of falling foul of the Criminal Code (Cth), thus severely limiting access for those in rural and remote communities. At the time of Victoria's law passing, the Health Minister instructed that every element of the VAD assessment take place face-to-face to avoid any potential breach. This has posed particular challenges during the COVID-19 pandemic, as highlighted by the Victorian VAD Review Board's January-June 2020 report which called for the Commonwealth to make an exemption so Telehealth could be used in the VAD assessment process.

The governments of WA and Queensland have since written to the federal Attorney-General to seek clarification that 'suicide' does not include VAD when carried out in line with a state or territory law, and to ask the Commonwealth to amend its law to reflect this. We encourage the NSW government to do the same

We also recommend as an interim measure that the Commonwealth Director of Public Prosecutions issue charging prosecutorial guidelines, as posited by the QLRC:

The risk of prosecution would be removed by a guideline that the Commonwealth offences will not be prosecuted where a health practitioner or other person is acting in accordance with a procedure that is authorised under state voluntary assisted dying laws.²⁴

Clause 188. Interpreters

GGA supports the provision that an interpreter who assists a person in requesting or accessing VAD must be accredited and impartial. This is also reflected in Victorian and WA legislation.

However, we would suggest including a provision which allows for the Board to grant an exemption for the use of an accredited interpreter, if there are reasonable grounds to do so. This would allow for the occasion where communication with the person may be difficult to understand for an outsider, whereas a family member may be able to understand and assist.

We also note that accredited interpreters should be able to accept payment for their services under the Act, consistent with what they ordinarily charge for their services.

²⁴ ibid p646.

Additional notes: Other matters

Reporting requirements

GGA notes there are some gaps in the data collected by other states on VAD that would be useful to measure the scheme's efficacy.

Beyond what is stipulated in Clause 176, GGA recommends NSW collect data on the following:

- **Patient characteristics:** Underlying diagnosis, estimated prognosis, age, ethnicity, gender, religion, marital status, education level, geographic region, have or is receiving palliative care/hospice support, preferred language
- **Requests:** Number of approved and ineligible applications, why and by whom ineligibility opinion was reached (including requests prior to the first formal assessment who were ineligible), number of applications where the person withdrew or died prior, duration of each stage and process as a whole: first request, second opinion, approval, registrar review, prescription and death.
- **Administration:** Method of administration, self, doctor or nurse practitioner administered, time from medication administered till death, any unexpected/adverse events, place of administration.
- **Providers:** Total number of medical practitioners involved (and number of cases where they provide), referral to other specialist /type of specialist, and location of trained providers.²⁵

Witnesses to all administration

The NSW bill allows for both self-administration (Clause 59) and practitioner administration (Clause 60). **GGA supports both these clauses in their current form.**

However, in other debates it has been suggested that it should be mandatory for a doctor to be present at every administration of VAD - even in the case of self administration.

²⁵ Jessica E Young, Janine Winters, Jeanne Snelling, Ben P White, Colin Gavaghan, Andrew Geddis, Richard Egan, The End of Life Choice Act: a proposed implementation and research agenda (2021) <https://journal.nzma.org.nz/journal-articles/the-end-of-life-choice-act-a-proposed-implementation-and-research-agenda> p154.

GGA does not support any amendments to this effect. An important part of VAD laws is that the dying person can have choice and control at the end, including who is present. Making it mandatory that a medical practitioner be present at self-administration goes against self-determination. It also puts pressure on patients to proceed on a daytime scheduled with the doctor. It's much easier for them to change their minds if they feel they don't have to reschedule. The unintended consequence of potential coercion created by a physician's mandatory presence is to be avoided at all costs.

Further Recommendations

In addition, GGA strongly recommends the following:

- The establishment of an Implementation Taskforce to coordinate the work that will need to be completed to prepare for the commencement of the legislation. The Taskforce must engage with, and involve, key stakeholders to develop effective implementation strategies and resources. Consistency in implementation and governance arrangements and staff support may best be facilitated in partnership with professional colleges and bodies such as the Australian Medical Association, Australian Nursing and Midwifery Federation, relevant professional colleges, pharmacy bodies, and consumer, carer and service representatives, as well as equivalent bodies interstate.
- The establishment of a Secretariat on Palliative and End-of-Life Care to emphasise the interlocked nature of full spectrum EOL care by developing a flexible, integrated model of palliative care, including VAD. This will be done by implementing a state-wide end-of-life strategy with dedicated funding, and developing a public awareness campaign on the topic.
- The establishment of a VAD Care Navigator service, similar to that in Victoria and WA, and consisting of experienced nurses or social workers, that can assist people applying for VAD throughout the application process. This team should also have access to doctors who have completed the VAD training and have indicated they are willing to participate so that referral to a participating doctor after refusal from a treating physician can be facilitated without delay.
- Reporting forms for doctors should be in plain English and as uncomplicated as possible (just as the portal should be efficient, clear and fast). Almost every doctor we have spoken with in Victoria has complained about the difficulty in navigating the forms they are required to submit. The practical effect of this is that clerical mistakes can lead to processes having to be repeated and dying people being put under greater stress. It also discourages doctors, who may otherwise consider doing so, from taking on VAD training.
- Penalties should be included in the Act for doctors who do not give a timely response – either yes or no – to patients who approach them with a VAD request. Anecdotal evidence from Victoria is that some doctors are either unaware of, or unconstrained by, the requirement that they must reply within the set timeframe.
- Increasing anecdotal evidence has come to us of doctors actively trying to dissuade patients from pursuing their legal right to VAD. This, too, is coercion and should not be permissible. We suggest consideration be given in the Act for penalties against doctors who engage in any form of coercive behaviour in regards to VAD – either for or against.

- The law should recognise that there is a difference between conscientious objection and conscientious obstruction. We suggest that consideration be given to an Ombudsman's role sitting within the functions of the Commission. At present, in Victoria, there is no clear pathway to complain for those who may have felt impeded, or in other ways obstructed, by doctors and institutions in regards to VAD. As there is no place to register such complaints, there is no record kept of obstructive behaviour. Consideration should be given to the Ombudsman having the power to inform AHPRA , or another relevant governing body, of efforts by doctors or institutions to obstruct , dissuade, or otherwise coerce, people seeking to access VAD.

Appendix A

What it can mean to be forced out of your home at the end of your life. Case studies from Victoria and WA.

CASE STUDY ONE

Colin M, a 79-year-old Melbourne man dying of metastatic bowel cancer. Despite having been assessed by two doctors and found eligible for VAD in 2020, the Catholic aged care institution in which he lived refused to let the Statewide Pharmacy Service into the facility to deliver the medication.

To make matters worse, they left Colin, whose every day was filled with fear that he would die painfully of a bowel obstruction before the medication arrived, waiting for nine days before informing him of their refusal.

They were forcing him down the pathway of a painful terminal phase.

RHEUMATOLOGIST AND VAD ASSESSOR, DR ANDREA BENDRUPS

He would have had severe pain. He wouldn't have been able to pass any bowel motions. He would have eventually started vomiting because everything in his bowel couldn't get out except by vomiting it up.

GP AND VAD ASSESSOR, DR JOHN STANTON

A man at the end of his life, experiencing very difficult symptoms. I think he certainly felt abandoned.

ASSOCIATE PROFESSOR, PETER LANGE, HEAD OF ACUTE MEDICAL UNIT, ROYAL MELBOURNE HOSPITAL, WHERE COLIN WAS EVENTUALLY ADMITTED FOR VAD

Having been instructed that he couldn't talk to anyone at the home in which he lived about his VAD choice, Colin was forced to leave his friends there without saying goodbye and be transferred to Royal Melbourne where he knew no-one. Once there, it was arranged for the Statewide Pharmacy Service to visit within 24 hours, and Colin took the medication two hours after receiving it.

I don't understand how people can think that that's a good or an ethical thing to do to someone. Physically and emotionally, to put people through that suffering. They'd seen his decline, and were intimately aware of how difficult it was for him, and the impact that it had had on his mental health. 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, COLIN'S SISTER

You can hear Colin's story, and of the distress this refusal caused him and his family in [Episode 8 of Better off Dead, titled The Good Samaritan](#).

CASE STUDY TWO

Margaret, was an 82-year-old Melbourne woman dying of the rare neurodegenerative disease, cortico-basal syndrome. A former nurse, she ended up increasingly unable to do anything for herself and living in full-time Catholic care.

Mum's illness was very insidious – slowly progressing, loss of muscle control and ability to move. Your body just starts to seize up, one limb at a time. She was starting to choke on her food, and particularly on drinks. She would be hoisted up in a sling with no pants on being transferred from her chair into the toilet, in front of staff. There was no drug, there was no treatment that would make her condition go away ... [or] postpone the progression of her condition.

LISA HOGG, MARGARET'S DAUGHTER

After an exhausting assessment process, taking almost four months and involving two neurological assessments, Margaret was found eligible for VAD. Because she was losing control over her ability to communicate, her great fear was that she would not be able to demonstrate to the Statewide Pharmacy Service that she was mentally competent. Had she not been able to do so, the pharmacists would not have given her the VAD medication.

Entirely debilitated by her illness, it would have been far kinder for Margaret to take the medication in the Catholic aged care facility, which was her home. She feared the consequences if she tried, however.

We didn't tell any of the nursing staff that she was planning to do this because mum was absolutely terrified, because she was in a Catholic nursing home, that someone would stop her going through the process or would stop us taking her out on the day that it was to happen. And it was very stressful for her.

LISA HOGG

Instead, in secret, the family located a facility which would support VAD choice. There, Margaret would meet the pharmacists and take the medication. On the morning that news came that the pharmacists were on their way the last day of her life Margaret left her home without saying goodbye to her friends, in a state of anxiety and distress.

It was just this rush to get mum out of there before anybody asked too many questions. My sister had to pop her into the shower and get her into the car and then transfer her to someone else. Get her admitted and all that stuff before they could start the process with the pharmacist. ... it was very stressful, and it would have been much easier to have done it just at the nursing home.

LISA HOGG

You can hear Margaret's story, and the distress this situation caused her and her family, in [Episode 10 of Better off Dead, titled We Who Walk Towards Death](#).

CASE STUDY THREE

Tony was a 75-year-old Perth man dying of brain cancer. He had about 30 days to live and had elected Sunday 6 September as the date he wanted to take the VAD draught.

Even though he had completed the application process for VAD and satisfied all requirements, when it came to exercising his right, institutions blocked him.

Tony was a patient of Charlie Gairdner Hospital in Perth, which transferred him to South Perth hospital. He was a public patient in a public hospital, but just taking up a bed in South Perth Hospital. This facility had informed him they would refuse to allow him access to progress through VAD at the hospital .

He was subsequently transferred to Meath Care, which initially had indicated they would support him and then changed its mind.

A doctor at Meath Care has told Tony's daughter May that around a third of the facility's residents die each year. Yet Meath Care informed May that it needed more time to prepare its staff.

They were under the impression that when taking Tony in, he would have 6-12 months to live, despite the fact that May states the family was very explicit that Tony wanted to use VAD as soon as possible.

In the last days of Tony's life, the family was left organising a last-minute transfer to a major Perth hospital. May summarised:

What was meant to be an experience for dad and for us that made his death easier, you know, less suffering, more peaceful has just become very distressing and difficult.

You can listen to May's interview with Liam Bartlett from 6PR Radio [here](#).

*_*_*