REPORT ON PROCEEDINGS BEFORE

STANDING COMMITTEE ON LAW AND JUSTICE

PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

CORRECTED

At Macquarie Room, Parliament House, Sydney, on Wednesday 8 December 2021

The Committee met at 9:15.

PRESENT

The Hon. Wes Fang (Chair)

The Hon. Anthony D'Adam
The Hon. Greg Donnelly (Deputy Chair)
Ms Cate Faehrmann
The Hon. Scott Farlow
The Hon. Trevor Khan
The Hon. Taylor Martin
The Hon. Rod Roberts
Mr David Shoebridge

The CHAIR: Welcome to the first public hearing of the inquiry into provisions of the Voluntary Assisted Dying Bill 2021. Before I commence I acknowledge the Gadigal people, who are the traditional custodians of the land on which Parliament sits. I pay respect to Elders past, present and emerging of the Eora nation, and extend that respect to other Aboriginal people present. Today we will hear from supporters of the bill. We will hear from Dying With Dignity NSW [DWD NSW], Go Gentle Australia and representatives from other key peak bodies. We will also hear from a number of private individuals with lived experience relating to the bill.

Before we commence I will make some brief comments about procedures. Today's hearing and the hearings on 10 and 13 December are closed to the general public due to the room capacity restrictions under the New South Wales Parliament's COVID-safe arrangements. However, the hearing will be broadcast live on the Parliament's website. While parliamentary privilege applies to witnesses giving evidence today, it does not apply to what witnesses say outside of their evidence at the hearing. Therefore, I urge witnesses to be careful about comments they may make to the media or to others after they complete their evidence.

Committee hearings are not intended to provide a forum for people to make adverse reflections about others under the protection of parliamentary privilege. In that regard, it is important that witnesses focus on the issues raised by the inquiry terms of reference and avoid naming individuals unnecessarily. All witnesses have a right to procedural fairness according to the procedural fairness resolution adopted by the House in 2018. There may be some questions that witnesses could answer only if they had more time or with certain documents to hand. In those circumstances witnesses are advised that they can take a question on notice and provide an answer by 28 January 2022.

Today's proceedings are being live streamed, and a transcript will be placed on the Committee's website when it becomes available. Today's hearing includes witnesses in person and via the videoconference system. I ask Committee members to clearly identify who questions are directed to, and I ask everyone appearing remotely to please state their name when they begin speaking. Will everyone appearing via videoconference please mute their microphones when they are not speaking. Members and witnesses should avoid speaking over each other so that we can all be heard clearly and to assist Hansard. Also to assist Hansard, I remind members to speak directly into their microphones and avoid making comments when their head is turned away.

STEVE OFFNER, Communications Director, Go Gentle Australia, affirmed and examined

PENNY HACKETT, President, Dying With Dignity NSW, affirmed and examined

SHAYNE HIGSON, Vice President, Dying With Dignity NSW, affirmed and examined

JANET COHEN, Advocate, Go Gentle Australia, before the Committee via videoconference, affirmed and examined

IAN WOOD, Spokesperson, Christians Supporting Choice for Voluntary Assisted Dying, before the Committee via videoconference, sworn and examined

The CHAIR: I welcome our first witnesses. We are now providing witnesses the opportunity to make an opening statement. I believe that Dying With Dignity will give their opening statement first.

Ms HACKETT: Thank you, Chair. We welcome the opportunity to participate in this hearing. Dying With Dignity NSW is a registered charity. Our principal aim is to have voluntary assisted dying laws passed in New South Wales, and we have been lobbying for this reform since the 1970s. Numerous independent polls and surveys over many years show overwhelming public support for these laws, ranging between 75 per cent and 85 per cent. This covers all locations, demographics and political persuasions. It also includes a sizeable majority of those with religious faith.

There is a very high level of public awareness of this issue. Death is not theoretical for anyone, and almost every adult will have had some personal experience with death of a family member or friend. We have over 110,000 supporters in New South Wales, and the vast majority have a personal experience of the bad death of a loved one. Some are terminally ill themselves; many are healthcare workers who see terrible deaths in their professional lives, and they know that even the best palliative care cannot always relieve the suffering of some dying people. Some of our supporters have lost loved ones to suicide because they could no longer endure their suffering. You will hear from some of these people later today, but I will just make a personal comment that the mother of one of my own friends jumped in front of a train at Lindfield station several years ago. She had a terrible cancer and saw no other way to end her suffering. She had a loving family and the best possible medical care, but she felt she had to take matters into her own hands.

We have heard thousands of testimonies, and I have personally read over 26,000 messages sent by our supporters to New South Wales MPs over the last four years. Many of these are so shocking and distressing that I have sought professional counselling. We are not medical or legal experts or professional campaigners, and we have no ideology. We are simply advocates giving voice to people who would benefit from voluntary assisted dying [VAD] laws or who have watched loved ones suffer. For us, this is about giving choice to people who are already dying and want some control over how they die.

The bill passed the Legislative Assembly with a resounding majority. It is a bill that was carefully developed over many months and drew on the laws passed in other States, numerous inquiries and independent reviews, plus the detailed reports from the Victorian Voluntary Assisted Dying Review Board. It creates a regime which is substantially the same as those in other States. It is conservative and balances the rights of patients and healthcare workers, with robust safeguards for everyone involved, but it also avoids unnecessary processes and barriers that would simply increase or prolong the suffering of the very people it is designed to help.

There are a few key points I would appreciate the Committee taking note of as you embark on these hearings and the review of submissions. We fully support palliative care, and we welcome the Premier's commitment to greater funding and access in New South Wales. But it is absolutely clear that even the best palliative care cannot relieve symptoms for a small but significant minority of dying people, and it is for these people that VAD is essential. Voluntary assisted dying and palliative care are not mutually exclusive. Evidence from Victoria and other jurisdictions shows that the majority of people who use VAD are also in palliative care. It is also clear that VAD laws are not detrimental to delivery or funding of palliative care. Palliative Care Australia, which is the peak body for palliative care, in 2018 conducted a major review and found that in jurisdictions with VAD laws, the palliative care sector had further advanced.

Many opponents of VAD, including those in the palliative care profession, will claim that palliative care can deal with all suffering at end of life. This was asserted by a number of MPs in their second reading contributions last month. Sadly, this is not the case and this is confirmed by Palliative Care Australia itself and acknowledged by all major medical bodies, including the Australian Medical Association [AMA]. I might just take the opportunity to quote from the testimony of Dr Edward Mantle at the Queensland parliamentary inquiry. He is a palliative care specialist in Perth who does not support VAD. He said:

> I think it is disingenuous, and it is probably closer to a bald-faced lie, when palliative physicians say that they can relieve all suffering for all patients. It is simply not true.

You will hear from a number of groups during these hearings and we appreciate and respect the genuinely held beliefs of those who oppose these laws, but Parliament must legislate for everyone and the beliefs of those who hold a religious or ideological objection to VAD laws should not determine the end-of-life rights of people who do not share those beliefs.

The key feature of this law is choice. It is voluntary and no-one is compelled to be involved. Those who oppose VAD laws are not required to use them or to participate in the process. It would be unconscionable to deny the choice of VAD to others in our community due to the objections of a small minority who will not be affected by these laws. Ideally, VAD would be addressed by Federal legislation but it is a matter of State jurisdiction under the Constitution. The Committee will hopefully agree that nationally consistent legislation is desirable. Dying people in this country should have the same rights at the end of their lives regardless of where they live. Equally, practitioners, professional bodies and healthcare organisations should have broadly similar regimes to work with when they are creating guidelines for the care of patients and legal protections for their members and staff.

In the Assembly debate, many opponents expressed concerns about the risk of elder abuse or coercion of vulnerable people, and this is a very serious issue in our community. But we would submit that the safeguards and assessments in the VAD process are more likely to expose abuse than to facilitate it. We ask the Committee to listen to bodies who represent these vulnerable groups, in particular the Council on the Ageing, which is the peak body representing older Australians. They have endorsed the VAD Bill and consider its protections sufficient. Other supportive groups include the Older Persons Advocacy Network and the Older Women's Network. You might also note the submission from the Physical Disability Council of NSW in which they believe the bill strikes the right balance between safeguards and accessibility of the regime.

In closing, we support the VAD Bill as it now stands, without further amendment. There is nothing uniquely special or vulnerable about dying people in New South Wales to warrant adding additional requirements or safeguards above and beyond those which apply to dying people in other States. To amend the substantive provisions of the bill to add more onerous criteria or processes, particularly in relation to medical assessments, would significantly reduce the ability of dying people to access the regime. This is especially relevant for people in regional and remote areas. It would simply increase the suffering of people who are already struggling with a significant burden of illness, without adding any meaningful protections against abuse. Thank you for your time.

The CHAIR: Thank you very much. I will now invite a representative from Go Gentle to provide an opening statement.

Mr OFFNER: Thank you for the invitation to address the Committee. First off, I would like to acknowledge and thank you for the task that you are undertaking. Not only is the scope of this inquiry wide, it is also one where emotions can run high and, as we know, the subject matter is difficult. By way of some background on the organisation that I represent, Go Gentle Australia is an expert advisory and health promotion charity founded by Andrew Denton. Some years ago Andrew began a journey to explore why at that time we did not have a voluntary assisted dying law in Australia and by contrast why some other countries did. For more than a year he travelled across the globe to speak with those for and against assisted dying, doctors and nurses, legislators, palliative care specialists, disability patient and elderly advocacy groups and the terminally ill. The result was an initial, and now two, comprehensive documentary podcast series called *Better Off Dead* that provide a compelling insight into why these laws are so necessary. The evidence Andrew collected galvanised his resolve that Australia had to have a better conversation about end-of-life choice and he and others established Go Gentle in 2016 to do this.

By way of our credentials, Go Gentle has played a key role providing evidence-based information to legislators in every Australian parliamentary VAD debate. 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 all our work we emphasise three basic principles. The first principle is that any legislation must be practically useful for that eligible terminally ill 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. A second principle is that we believe it is important that VAD laws are made on the basis of careful analysis, peer-reviewed evidence and establish facts. In any debate, if no evidence can be provided to support statements and other claims, we believe those claims should be set aside. Just as importantly, if evidence is provided, it is essential to ask how reliable is it, who provided it and are there any undeclared allegiances that are influencing conclusions. And underscoring everything is a simple, third principle: that Australians should have the right to choose what happens at the end of their lives and not be coerced, because of someone else's beliefs, into cruel, pointless and avoidable suffering.

We have produced many resources in the last five years. The most recent is the booklet the *State of Suffering*, which we produced in collaboration with Dying with Dignity. It collates more than 150 testimonies of cruel suffering in New South Wales in the absence of a voluntary assisted dying law. These accounts were drawn from more than 26,000 we received from all corners of the State. It is not an easy read but I urge members to do it. These are the people this law is designed to help and who are currently denied the choice of a legal and compassionate alternative. In contrast to these testimonies, the implementation of Victoria's landmark VAD law in 2019 is a significant step forward for Australians who want choice at the end of life. More than 300 people have made use of the law in its first two years. Some of their stories are told in the second series of the podcast *Better Off Dead* and also in our submission to this Committee. The difference between their peaceful, empowered deaths and the cruel, often gruesome deaths recounted in *State of Suffering* is stark. Also—and this is a point already emphasised—VAD is just one option at the end of life. We also strongly support the need for good, well-resourced palliative care. Palliative care's aims to alleviate suffering and to make possible a good death, both for the dying person and their families, are also Go Gentle's aims.

To conclude, New South Wales must join other Australian States to allow a kinder, more compassionate option for people who are dying and who want to alleviate their suffering. We commend the bill in the form that passed the Legislative Assembly with its strong endorsement and we urge no major changes. Any changes, should they arise, should seek to improve the operation of the bill and facilitate access for eligible terminally ill people in New South Wales. We caution against last-minute pile-on amendments—those seemingly small changes to a carefully developed bill that could have larger, unintended ramifications. Especially, it is crucial to avoid any changes they would have a negative impact on the people the law is intended to help. As a society we must do better by our terminally ill, who are among our most vulnerable. These are the people for obvious reasons that you will not see marching in the street advocating for their rights, but it is to their voices that we must listen. I welcome any questions. Thank you.

The CHAIR: Thank you very much. Mr Wood, do you have an opening statement?

Mr WOOD: Yes, thank you for this opportunity to give evidence. My background is that I was a community pharmacist in Port Pirie, South Australia, for 40 years, which involved caring for people. My wife and I raised two children and we enjoyed community involvement in heritage conservation, classical music and entertaining at aged-care facilities with music and singing. I had long supported assisted dying choice but became public in support in 2009 when Reverend Trevor Bensch, a retired minister and hospital chaplain at the church I attended, decided that Christians who supported VAD needed a voice, and we formed our group. Our vision essentially is "Do unto others" and "Love thy neighbour". That leads to: "How is love best served?" Conservative Christians in the past opposed the abolition of slavery, opposed pain relief in childbirth for women and opposed women becoming doctors, lawyers and politicians. We believe those Christians were wrong. Conservative Christians oppose marriage equality and discussion on sexual orientation. With regards to sexual orientation, we find that, to its eternal shame, many of the church hierarchy indulged in a massive cover-up of paedophile clergy, in many cases leading to the tragic suicide of the innocent victims, is a cruel irony with the church opposition to VAD. Clearly, those Christians were very wrong.

So how is love best served for a person who is about to die but has suffering that they find unbearable? A very vocal minority of Christians say hold that person's hand, say that we are with you, but let the suffering continue. Where is their Christian empathy, we might well ask? Curiously, the religious opposition generally now does not give religious reasons for opposing VAD. So this is an issue in our society whose time has come for the reasons outlined in our submission and numerous other reports. The vast majority of voters, including a significant majority of Christians, trust that this inquiry and the New South Wales Parliament will conclude that Christian love is best served by putting the dying patient at the centre of this debate and in control, providing choice and compassion under the provisions of this bill. I have also requested four additional documents be tabled for the inquiry to consider and I hope they will be circulated. Thank you.

The CHAIR: Thank you very much. My apologies, I will also give the other witnesses an opportunity to make a short opening statement if they would look to as well. Ms Higson?

Ms HIGSON: Thank you. My name is Shayne Higson and I am the Vice President of Dying with Dignity NSW. Thank you for the opportunity to speak today. As some of you know, I have been an advocate for voluntary assisted dying law reform for nine years, following the death of my beautiful mother, Jan, from an aggressive brain cancer. When mum died in late 2012 there was no law to provide her with a more compassionate end-of- life option, so she was forced to endure the terrible end stages of that dreadful disease and we, her loved ones, were forced to watch on, powerless and traumatised.

My mother loved life and she had a loving family supporting her and caring for her through the entire seven-month journey from diagnosis to death. We were also supported by a caring community palliative care team from one of Sydney's top hospices: Sacred Heart in Darlinghurst. Despite all that support, mum did not die peacefully and the last 15 days of her life were cruel and harrowing. Just two weeks before her death, mum started to ask for some form of medication that would knock her out, but nothing the doctors prescribed eased her suffering or distress. Each day it just got worse and mum could not take it anymore; she kept asking, "Why are they doing this to me? Why are they torturing me?"

Over the nine years that I have been advocating for assisted dying through organisations including the Voluntary Euthanasia Party, Dying with Dignity, and Go Gentle Australia, I have heard literally hundreds, if not thousands, of similar testimonies. So mum's experience is far from unique. Later today the Committee will hear from six other family members. If you had more time you could take evidence from hundreds more, but there will not be time. So, instead, I wish to table two documents, if I can. The first is a book that was published in 2016 when I worked for Go Gentle Australia, called *The Damage Done*. The second is a booklet that Go Gentle and Dying with Dignity published together this year called *The State of Suffering*, which Mr Offner referred to earlier. These publications contain testimonies from terminally ill people and their families, doctors and nurses, and they expose the suffering, the trauma and the suicides that take place in the absence of assisted dying laws. The contents are explicit and emotionally powerful; they can be challenging and disturbing, but we believe it is vital for all members on this Committee and all members of the Legislative Council to read these personal accounts to understand why people like me and the wider community want to see voluntary assisted dying legalised in New South Wales.

I would like to stress three critical points. Firstly, and most importantly, despite the very best efforts of palliative care, there are some terminally ill people, like my mother, who will be forced to endure the unbearable end stage of their illness with suffering that many describe as torture. The second point is that others who are facing unbearable end-of-life suffering decide to take matters into their own hands to avoid the end stage of their illness. These suicides are lonely and often horrific, and devastating for families and first responders. As data released earlier this year showed, over 20 per cent of suicides of people over 40 in New South Wales in 2019 were by people with a terminal or debilitating medical condition or had experienced a significant decline in physical health. The third point is that under the current law our society already allows someone with end-of-life suffering to hasten their death by refusing all treatment, including food and water to basically starve and dehydrate themselves to death.

In New South Wales, in the absence of an assisted dying law, family members, carers, doctors and nurses, have to accept the person's decision to begin this long and psychologically cruel process. It is legal for someone to choose to hasten their death in this way or by suicide, but it can be devastating for all involved, based on the testimonies sent to MPs and the examples documented in the publication that I have tabled. A voluntary assisted dying law, in contrast, would give the dying individual the option to die quickly and peacefully at a time and place of their choosing. I would like to finish my opening statement with one sincere request: please always consider the effect on the dying individual. No matter what amendments are suggested throughout this inquiry or during the debate in the upper House, just ask yourselves, "How will this affect the dying individual and will it add to their suffering?" The voluntary assisted dying law must be workable so that unnecessary and prolonged suffering can be avoided. I sincerely hope that New South Wales will soon join every other State and pass voluntary assisted dying legislation, which would give terminally ill people in New South Wales the same rights as other Australians. Thank you.

The CHAIR: Thank you very much. Ms Cohen, I invite you to make an opening statement if you so wish.

Ms COHEN: Yes, thank you. Actually, I am one of the people who will be the beneficiaries of this law if and when it is passed. On the surface I just look like any other sixties-plus retiree, living the good life in the Port Macquarie area, but you probably would not guess that I am terminally ill. In 2013, just before my sixtieth birthday, lung cancer uprooted my life like a gale-force storm. In the 8½ years since, it has been very challenging for my partner Glenn and me to stay afloat in very unpredictable weather. We are lucky, we have had many periods of smooth sailing between some pretty major squalls—the pretty major squalls of lung surgery and brain surgery when the cancer metastasised. But we have not capsized yet, and I am grateful for that. I am very grateful to have had my life extended time and time again by lung and brain surgery, targeted medications, augmented by the inherent nature of my cancer, which was described by an oncologist as "indolent". Whoever thought that being lazy would be a positive attribute?

But, again, the weather has changed and recently a new mutation has surfaced like a monster from the deep. Targeted treatment options have run out and we feel like we are on the edge of a very major tempest. Last week I finished a course of radiation and we feel like we are now drifting in a fog of uncertainty. Of course I will cling to life, but I will probably die within a few years. These mornings I am wide awake before the birds sing; my thoughts go round and round in a familiar course: Am I going to live long enough to access VAD in New

South Wales? How will I get to Switzerland in the midst of a pandemic if this law does not pass? From the very beginning of this end-of-life journey I have had two very clear aims and these have never wavered: one is to live well and the other is to die well, which, to me, means having the choice to plan a dignified exit if the impact of my illness becomes unbearable and cannot be relieved by the best that palliative care can offer.

I knew from the very outset that only the choice of a voluntary assisted death would give me the degree of control I needed over the kind of death that I want. I want to be supported by this law to take proactive steps to prepare for this major life transition, as anyone would for any important major life event. I want to die in a way that is consistent with my values and ethical compass, not dictated to by someone else's beliefs about what they think is right for me. As far as I am concerned, I have already completed a master's degree in suffering over the last 8½ years and I have no need to gain a PhD in the subject when I die, as opponents of voluntary assisted dying would have me do. As a voluntary assisted death was not and still is not available to me in my home State, I took two pathways. Firstly, in 2015 I became an advocate, volunteering with DWD NSW and Go Gentle Australia. In 2018 I applied for and received the green light, which has given me provisional approval for an assisted death in Basel with an organisation called lifecircle, run by the incredible Dr Erika Preisig in Switzerland. It goes without saying almost that I should not have to travel halfway across the world for an assisted death or contemplate moving to another State, as I have also done, but I might have to take this course if VAD legislation is not passed and enacted as soon as possible.

Like many people with a terminal illness, I do not fear death but I am under no illusions about what a bad death could look like, and the very real prospect disrupts the peace I try to find in each day. I just cannot overstate the positive effect that having approval for an assisted death, albeit overseas, has had on me and my family. It has been deeply reassuring to know that if my pain and suffering become unbearable and cannot be relieved by palliative care, I have a choice to say, "Enough is enough", and to enact my exit plan. A voluntary assisted dying option has actually put me back in the driver's seat, giving me a sense of control at a time when my life feels increasingly out of control. Applying for an assisted death has also been a surprisingly empowering process. It has provided a legal framework for me to think deeply about death and life and what I value and the kind of death that I want. It has enabled me to discuss the confronting subject of death with loved ones and medical professionals, normalising these conversations in the context of a society which has incredibly low levels of death literacy.

Opponents of VAD emphasise the need to protect vulnerable people. Well, I could not agree more. One does not need to imagine coercive family scenarios to identify who these vulnerable people really are. They are the people who, like me, without VAD legislation, may die in fear and unbearable suffering. Another concept frequently cast about is that of the slippery slope, inciting unfounded fears that the passing of the VAD Bill will herald an inevitable decline in society's moral and ethical standards. From where I am standing, I can report that the real slippery slope, arguably the slipperiest of slopes, is the dying process itself. I know there are some sturdy grab rails at hand in the form of palliative care and the best that medical treatment can offer, but what I really want and need as well is a safety net at the bottom of that slope in the form of this legal framework.

Finally, I do not want you to feel sorry for me and then do absolutely nothing to help. Sympathy without action just feels like callous indifference. I want you to act to protect me and others in my situation at the most vulnerable time in our lives. I want you to help us achieve what we deserve: the right to a choice for a humane, empowered and peaceful death. I want you to help us die the way we want to die, protected by a legal framework and a robust and closely monitored management process. Above all, I want you to help families achieve greater peace and to save them from distress and uncertainty at the time of their loved one's death. I also want you to act in accordance with the wishes of the majority of the people of New South Wales, who have waited far too long for this legislation. In closing, I would like to add that the bill as passed in the lower House is more than adequate, provides more than adequate protection for the vulnerable, and I hope that the upper House will respect the wishes of the people's House and just pass this bill in its current form. Thank you for your attention. I apologise for the emotion, but for me it is a very personal issue.

The CHAIR: Thank you, Ms Cohen. There is no apology necessary.

Ms COHEN: Thank you.

The CHAIR: We will now move to questioning. I invite Mr Khan to commence questioning.

The Hon. TREVOR KHAN: I think my question is directed to Ms Hackett and Mr Offner, but that does not prevent anyone else from making a contribution. I am interested in the Victorian experience because that is the scheme that has operated the longest in Australia and whether the number of people taking up access to the scheme has been consistent with what the expectation was or whether it has been different.

Mr OFFNER: I might answer that. The Victorian experience shows that only a very small number of people seek to access a voluntary assisted dying law. In the first two years of the law's operation in that State, less than half of 1 per cent of all deaths in that State were through voluntary assisted dying, which is a spectacularly small number. In the first two years I think that number was somewhere in the vicinity of 330 people. Really, at the beginning of that law, there were no real expectations of the number of people who would take up that option. We had some guidance from countries that had already passed these laws, but their models of VAD were very different. I think, broadly speaking, it was in the basic expectation, those figures, in the first two years.

The Hon. TREVOR KHAN: That is the number of people who have accessed the scheme and, in a sense, gone through the process. What is the number of people who have accessed the scheme but have not then used the facility that they have been provided, assuming that they have been successful?

Mr OFFNER: According to the statistics from the Voluntary Assisted Dying Review Board, which collects some of this data, somewhere in the vicinity of 50 per cent of people who apply or initiate the process end up not going through for various reasons, either because they have died already or—a smaller number—they have felt that voluntary assisted dying was not necessary for them.

The Hon. TREVOR KHAN: My next question is to Ms Cohen because I think it flows on from some of her evidence. Ms Cohen, in regard to that group that accessed the scheme but then did not go through with it, were you saying towards the end of your evidence that there is an assurance given to you by being able to access the scheme but not necessarily using it? Is that one of the points that you are making?

Ms COHEN: Yes, very definitely. It feels to me like an insurance policy. As with most people with a terminal illness, I am expecting that I will be in active palliative care by the time I need to make that decision. Yes, I may not need to access that option, but it is very reassuring to know that the exit door is open. It is a choice. It gives me greater choice. I would like to add also that I think the Victorian scheme has seen greater integration between palliative care and voluntary assisted dying, and I think that is one of the things that is really needed. It is not an either-or choice.

The Hon. TREVOR KHAN: Ms Cohen, in that regard, do you think the existence of a voluntary assisted dying law actually allows at least some people to have the discussion about death that perhaps they sometimes avoid and doctors avoid?

Ms COHEN: Most definitely, yes. I have had the same GP for over 15, 20 years. The existence of a VAD law in Switzerland and my intention to use it, of course I have had to discuss that with him and with my medical oncologist. I would say that we have both been greatly educated in the process. It has enabled and allowed those conversations to be had within a legal framework.

The Hon. TREVOR KHAN: My final question is this: Again taking into account the Victorian legislation, what, if any, evidence has been gathered since the passing of its law of elder abuse in the operation of the scheme?

Mr OFFNER: Again, according to the Voluntary Assisted Dying Review Board—which is the independent body tasked with overseeing the operation of that law—absolutely none.

The Hon. GREG DONNELLY: I understand there are two representatives from both the key organisations, Dying with Dignity and Go Gentle Australia. It would facilitate things if there were one spokesperson for each so we can get through questions. Who that is I do not mind. I will go to the current bill that has passed the Legislative Assembly. Do you have a copy of the bill with you?

Ms HACKETT: Yes.

The Hon. GREG DONNELLY: We can provide a copy if you need one. Do you have a copy of the second print of the bill that passed the Legislative Assembly?

Ms HACKETT: I have only got the first print but we have got a copy of the amendments that were passed.

The CHAIR: We are arranging some copies for you.

Mr DAVID SHOEBRIDGE: I think Mr Offner has a copy. Is that the second print, Mr Offner?

Mr OFFNER: I have the amendments that were agreed to.

The Hon. GREG DONNELLY: I will pause because [disorder].

The CHAIR: We are getting some other copies.

The Hon. TAYLOR MARTIN: Here is a copy.

The Hon. TREVOR KHAN: I have a copy.

The Hon. TAYLOR MARTIN: I have a spare one. If we need a second one, I have a spare.

Mr DAVID SHOEBRIDGE: I only have the digital one.

The Hon. GREG DONNELLY: The digital one—as long as it is the second print. Do you have a copy there?

Ms HACKETT: Yes.

The Hon. GREG DONNELLY: Can I take you to clause 6 of the bill, which deals with decision-making capacity? It is on page 3 on my copy, I think you will find. Have you got that?

Ms HACKETT: Yes.

The Hon. GREG DONNELLY: Can I take you to subclause 6 (2), which states:

> (2) For the purposes of this Act—

obviously it is still a bill—

> a patient is—
>
> (a) presumed to have the capacity to understand information or advice about voluntary assisted dying if it reasonably appears the patient is able to understand an explanation of the consequences of making the decision, and
>
> (b) presumed to have decision-making capacity in relation to voluntary assisted dying unless the patient is shown not to have the capacity.

In terms of this issue of presuming they have the capacity—that is, in terms of the decision-making process with respect to proceeding with wanting to access the legislation—do you believe that it is a satisfactory bar to just have the presumption of them having the capacity compared to examining to see whether they have the capacity, for example, by involving medical specialists who may assist in diagnosing, for example, depression that that person might be going through that could be affecting their decision-making?

Ms HACKETT: Obviously I am not a doctor, but I understand that these clauses are consistent not only with the other VAD legislation in other States but also other laws relating to health care and legal matters such as making wills and enduring guardianship. It is accepted that the onus is to prove lack of capacity rather than to prove that someone has decision-making capacity. I think it is legislatively consistent with the arrangements that apply to a whole manner of other decisions that people make in their lives.

The Hon. GREG DONNELLY: It is a reverse onus, is that what you are saying? It is a reverse onus of what normally applies?

Ms HACKETT: Yes, it is exactly that.

Mr DAVID SHOEBRIDGE: Sorry, I think the Deputy Chair is putting words in the witness's mouth.

The Hon. TAYLOR MARTIN: Jeez, that is rich, David.

Mr DAVID SHOEBRIDGE: The witness said exactly the opposite, that it is consistent with the balance of medical treatment.

The Hon. SCOTT FARLOW: Yes, but then he put the proposition and it was confirmed.

The CHAIR: Order!

The Hon. GREG DONNELLY: I do not want my time—I want the clock stopped.

Mr DAVID SHOEBRIDGE: You cannot put words—

The Hon. GREG DONNELLY: If he is going to cut in on my—

The CHAIR: Order!

Mr DAVID SHOEBRIDGE: You cannot put words in the witness's mouth.

The Hon. GREG DONNELLY: If he is going to cut into my time—

The CHAIR: Order!

Ms HACKETT: Perhaps Greg could ask the question again.

Mr DAVID SHOEBRIDGE: Correct.

The CHAIR: Sorry, Ms Hackett, I need to rule on a few things. The first is that Hansard cannot record when we are talking over each other. It is also impolite to the witnesses. The Hon. Greg Donnelly, we do not have a clock running on you. I am prepared to provide you with as much time as you need to get through questioning, provided that we give some opportunities to other members as well. Mr Shoebridge, I accept your point. I do not believe he was putting words in the mouth of the witness. He was putting a proposition forward that the witness was clearly more than capable of addressing. I will allow the Hon. Greg Donnelly to continue his questioning. Please can only one member speak at a time.

The Hon. GREG DONNELLY: My question was about the presumption that is contained in subclause 6 (2): The proposition that instead of just having a presumption, it is ensured that the individual is fully able and cognisant of being able to make the decision through ensuring that, for example, they are not suffering from depression. In other words, a specialist would examine the individual and establish that they were not depressed, medically speaking, and that would impact, potentially, on their decision-making. The proposition is putting a position of presumption. I am putting it to you that it is to ensure that when the individual is clearly in their mind making a decision, which is a significant decision about ending their life through assisted suicide or euthanasia, that there be quite a high bar set to ensure that the person is not making a serious misstep.

Ms HACKETT: Similar provisions apply to other various serious decisions, including decisions made in medical treatment, all the time, including treatments or refusal of treatments that may end a person's life. Doctors are accustomed to determining whether someone has the capacity to consent to decisions of a minor nature and of a major nature—so embarking on surgery that may potentially kill them, deciding to refuse treatment, and deciding to refuse food and water and hasten their death that way.

The Hon. GREG DONNELLY: I am talking about this bill because this is an inquiry into the provisions of this bill.

Ms HACKETT: I think it should be consistent with the laws applicable in other circumstances that deal with important issues, including those which also relate to life and death.

The Hon. GREG DONNELLY: That being the case, I presume you have read carefully the New South Wales Bar Association's submission dealing with this issue of capacity?

Ms HACKETT: I have skimmed through it but I have not examined it in great detail.

The Hon. GREG DONNELLY: Perhaps I will direct you to paragraph 67.

Ms HACKETT: I do not have it in front of me.

The Hon. GREG DONNELLY: I will not pursue that. I will draw your attention to the reference at page 13, paragraph 67, which leads on to a discussion specifically around—this is what I am trying to establish from you, if this is what you are getting at—what is called the—

The Hon. ANTHONY D'ADAM: It is available for the witness to take this question on notice and provide a considered response. I want the witnesses to understand that that option is available, that they can go away, they can look at the submission—

The Hon. GREG DONNELLY: I am not asking a question, I am taking them through—

Mr DAVID SHOEBRIDGE: You should get to a question.

The Hon. GREG DONNELLY: David, if you have a problem with the questions—

The CHAIR: Order!

Mr DAVID SHOEBRIDGE: It is a question and answer process.

The CHAIR: Order! We are not going to do this today. We are going to be very respectful. The Hon. Greg Donnelly, we can provide the witnesses the submission, if required, if you want to continue questioning on this.

The Hon. GREG DONNELLY: No, I am clarifying her evidence about these provisions in other laws. In the Bar Association's submission, there is reference to the New South Wales Attorney General's online publication called *Capacity Toolkit*, which deals with matters of capacity and decision-making. Is that what you are referring to in terms of what is recommended in New South Wales?

Ms HACKETT: I am not familiar in detail with that toolkit, but my understanding is that in a whole range of legal and medical circumstances, the capacity is presumed.

Mr OFFNER: Mr Donnelly, it is a cornerstone of the law of consent, this assumption of capacity. I would say to reverse that assumption in the case of terminally ill people seeking VAD is inconsistent and unjust. There is no special case. If there is a special case, I would say the onus is on others to point to why there should be a special case that that assumption should be reversed.

The Hon. GREG DONNELLY: Some may—

The CHAIR: Mr Donnelly, we have got Mr Shoebridge, Mr D'Adam and Mr Martin who want to ask some questions, so I will pass to Mr Shoebridge and I will come back to you if that is okay.

Mr DAVID SHOEBRIDGE: Thanks to all of you for your time today. Particularly Ms Cohen, thank you for giving up your precious time to come and be with us today. My question was actually to Mr Wood. Mr Wood, I think it was you who gave reference to the most recent study of the experience of the Canadian medically assisted dying laws and the review of a series of practitioners and their experience of medically assisted dying laws. I thought that was your most recent submission. Did you want to just give a brief summary of what the conclusions of that study were?

Mr WOOD: To sum up, the conclusions were that there were very many positive aspects of their Medical Assistance in Dying law and it had led to further discussion with the doctors and patients involved. The overall experiences of dying were positive. We get people in an obituary congratulating and thanking the Canadian Government for passing the legislation that gave them the peace of mind when they were approaching death. Overall, it is positive.

Mr DAVID SHOEBRIDGE: Ms Cohen, in many ways what people in your situation are asking for is a sense of empowerment at this time in their life. Do you want to talk about, if we passed the laws and it was applicable for you, how important that sense of empowerment is?

Ms COHEN: This is one of the most confronting transitions we will ever make—all of us will ever make in our lives. I think the culture around death and dying is changing in our society from being a subject that we shy away from, that we fear, to being a subject that we embrace and that offers us an opportunity to think really deeply about the things that we value in our lives. That in itself is a very empowering experience. Not being afraid is an empowering experience. Not having the background to your days filled with anxiety and uncertainty is an empowering experience. Being able to talk openly to medical professionals about one's wishes is incredibly empowering. I think that whole scenario is changing for the better as well where patients are being seen more as equals with their medical professionals, and a patient knows just as much about what they want as their medical professional does.

We are going from a situation of, well, control by others to self-control and independence. For me, personally, it has been a very supportive experience. Dr Erika Preisig in Basel—I have been in communication with her since 2018—is an advocate for voluntary assisted dying programs all over the world. But, surprisingly, she has encouraged and empowered me to live a better life since being diagnosed with a terminal illness. The emails that we shoot back and forth are very supportive. I thought I was going to die in 2018. There was no treatment available—I was on the edge of a cliff—and she emailed me back saying, "Don't give up right now. I understand why you need this reassurance, but I don't actually want to see you in Switzerland. I'd prefer that you didn't come here," and absolutely so would I. I hope that has answered your question.

Mr DAVID SHOEBRIDGE: No, it has. I suppose, Ms Higson, reflecting back upon your family's experience, how different do you think it would have been if there had been that ability to have control?

Ms HIGSON: It would have made an enormous difference. My mother was told at the very first appointment after her seizure—they did an MRI and she was told that there was nothing they could do to save her life and that she had less than 12 months to live. She actually only lived seven months, but her condition deteriorated rapidly. When they told her that there was nothing more that could be done or nothing that could be done, she asked the doctor, the neurologist, "You will help me at the end, won't you?" I was in the room at the time in St Vincent's Private Hospital and, of course, he did not answer that question because we were never going to see him again. Mum was referred to palliative care at that point and obviously he knew that he would not be there for the full journey. But I know that my mother was—she loved life. She had five beautiful grandchildren that she just adored. She wanted to live for as long as possible. She withstood so much suffering through those seven months, but it was only in the last sort of three weeks or so that the suffering, all the symptoms were so bad that she started asking for something, as I said, to just be knocked out. She had had terminal sedation described to her, but the fear—when that was not possible, it was just terrible. She was under the very best of palliative care, a top palliative care specialist, but under the current laws they are not allowed to hasten the death, and so Mum was not able to—she wanted to avoid just that last few weeks, which is what so many people want.

When Mr Khan asked earlier about the peace of mind that it gives people with terminal illness to know that that is an option, not only is it giving people like Ms Cohen a peace of mind but it is also preventing the suicides that we know occur. I believe that there will be a witness later this afternoon whose husband, Lawrie Daniel, was in *The Damage Done*. I knew Lawrie—he had multiple sclerosis. His symptoms were very severe, he was in a wheelchair—and I am sure you could get more information later—but he ended up having to take his life earlier than he otherwise would have because he would have lost the ability to end his own life if he waited for the multiple sclerosis to progress. If he had had, if we had had, if New South Wales had had voluntary assisted dying laws then, he would have had more time to spend with his wife and his two young children. I think that should be remembered as well.

I am confident that my mother would have been one of the people who would have wanted to have this option, and I would picture that she would have chosen to end her life just two weeks earlier. She would have been able to say thank you to me and my sisters and her partner for taking care of her, but instead my mum died angry and so disappointed that we could not help her. At one point in those last few weeks when she was struggling to talk, because brain cancer affects that, and she was paralysed down one side, she actually—my sister and I and her partner were in the bedroom around her bed—and she looked at her partner and she just put her hand up to her throat, the one hand, to indicate, "Please kill me," like strangle; she was so desperate. No family would want to do—I know it would have made a huge difference to my mum to be able to die peacefully.

Mr DAVID SHOEBRIDGE: Thanks, Ms Higson.

The Hon. TAYLOR MARTIN: I will begin with a question to Mr Offner from Go Gentle Australia. In your submission, it states:

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

What aspects of the bill lead you to use the wording "broadly" as opposed to, for example, "completely support" in regard to the bill?

Mr OFFNER: In the general sense of the word, we express broad support for the detail and the intention of the bill.

The Hon. TAYLOR MARTIN: I will be more specific because this is an inquiry into the provisions of the bill. Which provisions would you like to see written differently?

Mr OFFNER: If you have our submission, there are certain recommendations we made that we felt would strengthen the bill. However, that submission was written before the lower House debate, and we are completely comfortable with the bill as it emerged from the lower House after that scrutiny.

The Hon. TAYLOR MARTIN: Okay.

Mr OFFNER: The lower House was comfortable with the bill and they voted strongly in favour of that bill. We are very comfortable with that outcome.

The Hon. TAYLOR MARTIN: So lowering the length of time practiced by a GP from 10 years down to five years was in your submission?

Mr OFFNER: That was one of the points where we thought there was an inconsistency in the bill.

The Hon. TAYLOR MARTIN: Okay. Extending the time frame to 12 months for all diagnoses?

Mr OFFNER: We would broadly support that notion, yes.

The Hon. TAYLOR MARTIN: I guess the point of my questioning and the reason why the wording "broadly" has led me to ask these questions is that if this bill passes the upper House, will your organisation then seek to have those amendments made to what will then be the law of the State?

Mr OFFNER: No, we will abide by the decision of the Parliament of New South Wales.

The Hon. TAYLOR MARTIN: Will your organisation cease to operate because you will have effectively achieved your end goal of having euthanasia in New South Wales?

Mr OFFNER: That is one of our goals but it is not every goal of our organisation.

The Hon. TAYLOR MARTIN: Okay. Could I ask the same of Dying with Dignity? Will your organisation continue—

Mr DAVID SHOEBRIDGE: I am going to take an objection to this line of questioning. The inquiry is in relation to the bill, not the future campaigning of the organisations before us. We have limited terms of reference and we have a limited amount of time. I ask that questioning be restrained to the bill and not the future campaigning of these organisations.

The Hon. TAYLOR MARTIN: To the point of order—

The Hon. GREG DONNELLY: To the point of order: It is another example of cutting into people's time.

The CHAIR: I am prepared to rule on the point of order. Whilst I accept Mr Shoebridge's position, I note that we have witnesses providing evidence that has examples of other jurisdictions, so I will allow Mr Martin a bit of latitude with his questioning. I remind him that it is an inquiry into the bill. There is a reasonable amount of latitude but there will have to be a point where we draw a line. At the moment, I permit him to continue his questioning.

The Hon. TAYLOR MARTIN: The heart of my questions is that is there consensus around the provisions in the bill introduced by Alex Greenwich and passed in the lower House, and those few examples that Mr Offner and I went over a moment ago—that that bill will become law if it is passed by the upper House and it will basically stay as is—or does it need to be widened?

Mr OFFNER: The simple answer is yes, we are happy with the bill in its current form. I understand that there is a review process built into the legislation, which is right and proper. If there are things that need to be considered at that time then of course that would be entirely appropriate.

The Hon. TAYLOR MARTIN: Okay, thank you. Do you have anything to add?

Ms HACKETT: I am happy to answer your question about what we do should the bill pass. The experience of particularly Dying with Dignity Victoria and now Dying with Dignity Western Australia is that they have had to play a very big role in the implementation process by making sure that it is implemented expeditiously and that all of the intent of the law is followed through in terms of guidelines and things. We also feel that we have a strong process of education for not just the public but also practitioners, and we have already started engaging with groups like the college of regional and remote doctors and other groups. We would expect that we would be presenting to them to give them an understanding about how the law works. There is a very low level of literacy on this issue in the medical profession because they are busy being doctors. There are also other groups that provide support and counselling to people who are dying—for example, Violet, which used to be LifeCircle—and healthcare institutions. It will be a big burden on a lot of organisations in getting themselves set up. Whether they are prepared to permit VAD on their premises or not, they will need to be prepared to answer questions. So we will educate and participate in the process and also monitor the implementation to make sure that it is in accordance with Parliament's intentions.

The Hon. TAYLOR MARTIN: Ms Higson, did you want to add to that?

Ms HIGSON: I would like to point out that Dying with Dignity, as the name reflects, is not just about voluntary assisted dying legislation. For many years we have been providing advanced care directives. Not everyone who is reaching the end of their life will be able to access voluntary assisted dying; we know it is less than half of 1 per cent. Our organisation does care and deals with other end-of-life care and advice and that sort of thing, so I cannot see our organisation folding.

The Hon. TAYLOR MARTIN: Okay, thank you. Mr Wood?

Mr WOOD: Our organisation would certainly be supporting legislation in the two Territories, and then I would suspect that the main reason for our group would perhaps cease to exist, except that some members would be encouraged or be willing to put themselves forward to act as witnesses in some of the applications and so on.

The Hon. TAYLOR MARTIN: Thank you for that particularly informative answer. Mr Shoebridge has left but he need not run interference because it was very helpful.

The Hon. ANTHONY D'ADAM: Thank you for your appearance today and your submissions, which were very helpful. I want to turn to the issue around terminal sedation. My question is why is terminal sedation not an adequate approach to dealing with end-of-life care? To elaborate on that, what are the current regulatory arrangements that exist for terminal sedation? Perhaps you could elucidate on that.

Ms HACKETT: If I can start with somewhat technical things, and then Ms Higson can give you the actual experience of her mother having had terminal sedation. Under the palliative care guidelines, terminal sedation is really only available when it is assessed that the person has only two or so days to live. As I am sure everyone who has watched someone dying from cancer understands, the suffering is not just in the last two or three days. It is the case that you can effectively be made unconscious in an induced coma by terminal sedation and you might have no suffering during that short period. But you may well have had months and months of terrible suffering prior to that, for which terminal sedation is, firstly, not available and, secondly, people do not want to be unconscious for very long periods of time.

We would like to see terminal sedation used more widely, but it is an arbitrary choice about two days or a week. There are stories of people who have been put in terminal sedation who have lived for weeks, if not months, and the point of that is the person will starve or dehydrate to death during that period, or their symptoms over the course of their disease will lead to their death, which could involve massive tumours growing, suffocation—those types of things. As we understand it, the intention is that the person is not conscious or aware of that suffering. I think you can ask these questions of the doctors who will be appearing, but it is not always the case that the person has relief of symptoms. There is also an issue within the palliative care specialty about whether or not terminal sedation is actually slow euthanasia, so there are some who will not administer it.

Mr OFFNER: I would just add that terminal sedation is one of the tools in the toolbox and it is used as a last resort. It does not prevent suffering; in fact, it is a response to suffering that is already happening and that cannot be managed. As Ms Hackett said, there can be many weeks, if not months, of intolerable suffering leading up to the point where the patient is put into terminal sedation. So it is a last resort and I would also add that, from our research, many people who have a terminal illness do not want to be sedated into a coma at the end of their life: That is just something they do not want. So it is a last resort, but it is one that most people—many people—do not wish to have.

The Hon. ANTHONY D'ADAM: Can you perhaps explain the decision? How does the decision about electing for terminal sedation occur?

Ms HACKETT: It is often administered without the patient knowing. They are in such a desperate circumstances that the decision is made by the doctor, or the doctor in consultation with the family. We would actually prefer that it be formally discussed and offered to people as an option. I think that does happen sometimes but other times it is a response to a desperate set of circumstances where they have tried everything and the solution to the distressed person is to fill them up with—I am not sure what the drugs are but it is intended to render the person unconscious to various degrees. They, what they call, titrate it to the level they consider is going to be sufficient to relieve the person's suffering. Our view is that if someone is suffering that badly they should have had treatment or whatever drugs are necessary to relieve that suffering at the time rather than having to wait until they reach a sufficient level of suffering that the doctors decide, based on guidelines or their judgement, that the person then qualifies for terminal sedation. The person generally does not put their hand up and say, "I would like to have some terminal sedation please."

The Hon. ANTHONY D'ADAM: It is not that active consent. I suppose where I am getting at is that there is not that active process of consent and consideration that is proposed under the legislative framework for voluntary assisted dying, and there does not appear to be the two practitioners.

Ms HIGSON: No.

The Hon. ANTHONY D'ADAM: There is not a sort of double oversight process applying to terminal sedation. Is that correct?

Ms HIGSON: No, that is definitely the experience, not just my mum's experience but many—I have got friends, too, this year whose parents died. At the end, it was increased levels of morphine and those discussions were not made with the patient. It was just the family member with the doctor. I think everybody probably knows of cases where that is true, but also the so-called terminal sedation that my mum had at the very end when things were so desperate, it was not like a general anaesthetic. Again—obviously, I am not a doctor and I hope that you will have medical specialists who support assisted dying who can explain in more detail the medical thing—but I can just say from looking on and also from the evidence from all the testimonies that we have written that people are not fully unconscious.

My mum, in those last few days, the leg that was not paralysed was moving up and down on the bed. Her head was rocking from side to side. If that happened when you were having an operation under general anaesthetic I think the anaesthetist would be rapidly changing things. The reason why the level of medication is not high enough to fully take away all symptoms is because that would be pretty much, as Ms Hackett said, admitting that it is euthanasia, slow euthanasia. It is a grey area and that is the whole problem and I would love to see that change, as a personal thing—not representing Dying With Dignity. But I cannot see the difference in terminal sedation over five days or longer and allowing someone to die quickly and peacefully with voluntary assisted dying. It is not such a huge difference in my personal opinion and it would just mean that someone like my mum would not have been forced to endure that last stage suffering.

The Hon. ANTHONY D'ADAM: I want to come back to the issues that the Hon. Trevor Khan raised around the experience in Victoria. Correct me if I am wrong, the Victorian system also has a mandatory training requirement for practitioners who are involved in the process. What can you tell us about the uptake of training? Has that been an issue? I suppose there is a threshold issue about whether a voluntary assisted dying right should be established at law and then there is the question about access. If we say that people should have a right to voluntary assisted dying, how do we facilitate access? I suppose one of the potential blockages is there is not enough practitioners in the system who have the training and who are actually in a position to be able to implement the scheme. Can you perhaps comment on that?

Mr OFFNER: Yes. Look, it has been one of the issues in Victoria and also to our understanding in Western Australia where VAD has been for several months now. It goes some way to answering Mr Martin's question before about what our role might be after the passage of this law. There is a huge need for education and information sharing about the option of voluntary assisted dying. Doctors like the general public may not even be aware. I mean, it might be hard for us to believe because we are so entrenched in the debate, but there would be many doctors in Victoria still who would not know that voluntary assisted dying was an option. The Victorian law itself provides some restrictions on the sharing of information about voluntary assisted dying, which I am happy to say the New South Wales bill avoids. For example, from the patient side, the doctor is not allowed to raise the legal option of voluntary assisted dying. There is a general issue with the profile of voluntary assisted dying in Victoria.

But to answer your question specifically, there was a reasonable uptake in the training initially but like everything that is new it takes time for people to understand the processes, understand what is required, and doctors are very busy people. The training, which is online training over a day or more, is quite strenuous and, you know, it is a 90 per cent pass rate—I think you need to achieve 90 per cent to actually pass—so it does require a lot of doctors. So it is perfectly understandable that some doctors would be reluctant to take up that training, but we imagine that in coming years there will be a much greater uptake, especially by specialists. Especially neurologists in Victoria, there does seem to be a lack of neurologists taking up the voluntary assisted dying training and that is imposing some quite unnecessary barriers to access for people, especially those with neurodegenerative conditions in Victoria.

The CHAIR: Mr D'Adam, do you mind if I come back to you? I have Mr Roberts, Mr Khan and Mr Donnelly who have some questions. Mr Roberts, you have the call.

The Hon. ROD ROBERTS: Thank you, Mr Offner. I direct my question to you, firstly. The last time a bill of a similar nature came before this Parliament was in 2017 and you are probably aware that I was not in Parliament at that point in time. But I just want to ask you: Did you and your organisation support the 2017 bill as it was?

The Hon. TREVOR KHAN: I could give evidence on that.

The Hon. ROD ROBERTS: I am sure the Hon. Trevor Khan can, but I am asking Mr Offner.

The Hon. TREVOR KHAN: They were not enthusiasts.

Mr OFFNER: Look, that is true. I was not with the organisation in 2017 but it is my understanding that Go Gentle was very focused on the Victorian bill and its passage through Parliament. There were elements of the 2017 bill that we were not enthusiastic about, as Mr Khan has said. Having said that, I think the 2021 bill is vastly superior and stronger in almost all respects.

The Hon. TREVOR KHAN: Cruel, but fair.

The CHAIR: Mr Roberts, have you concluded?

The Hon. ROD ROBERTS: That will do. That will answer my next question already.

The CHAIR: Mr Donnelly has now got the call.

The Hon. GREG DONNELLY: Thank you, Chair. Listen, the question is directed to both the organisations. You obviously have a membership base, both organisations. I think you described the membership, or at least one of them, in terms of size and you have a number of supporters, who clearly wish to control the time of their death. Presumably that is one of the reasons they become members of the respective organisations and participate in what you have been doing over a period of time, but they would not—a number of those people would not—be entitled to VAD under the proposed legislation that is before the New South Wales Parliament now, as amended by the Legislative Assembly. Do you not believe that the bill as passed by the Legislative Assembly clearly discriminates against those individuals of your organisation who wish to, as I have said, control the timing of the end of their life?

Ms HACKETT: Obviously, some of our supporters are facing a terminal diagnosis and some of them would qualify under the VAD Bill. For others—

The Hon. GREG DONNELLY: I am talking about those who are not eligible.

The CHAIR: Please allow Ms Hackett to finish her answer before interjecting, Mr Donnelly. Thank you.

Ms HACKETT: People generally understand obviously that death is inevitable. We live in a community where almost everyone will have some contact with the death of someone they know or love at some point in their lives. Many of those people have seen deaths which have caused them to either be traumatised themselves or made them fearful about their own death, and they would like the comfort of knowing that if they were in that circumstance themselves there would be an option available to them. I do not think our 110,000 supporters are sitting there worrying about whether they would be eligible for VAD. They are of all ages and in all locations.

The Hon. GREG DONNELLY: The proposition is that you would have members and, indeed, Go Gentle Australia would have members who wish to and have articulated to both organisations the desire to have the ultimate control over the timing of their death. That is clearly the case with members of both organisations. The proposition I put to you both separately is that with respect to the proposed legislation—I cannot put a number on it, but there would presumably be numbers of people in both organisations who may not be eligible for VAD under the proposed amended legislation. My question is does that not mean that this legislation is clearly discriminating against them in terms of their choice to have control over the timing of the end of their life?

Ms HACKETT: I think you are asking about theoretical discrimination relating to people who do not have a terminal illness. I am not quite sure what it is that you are asking.

The Hon. GREG DONNELLY: I will repeat it again. You have got members of your organisation from various backgrounds who are clearly articulating to both organisations their desire to control the timing of their death. They articulate that position to both organisations. This legislation creates a framework which is not going to enable them to meet their desires. Does that not create a situation of discriminating against them or depriving them of their opportunity to end their life on their own timing?

Mr OFFNER: I think any legislation is drafted within certain parameters, and this legislation has been drafted with quite strict parameters. By definition, there will be people who will fall outside those parameters. I think that is right and just in a piece of legislation like this. Go Gentle Australia is not a membership organisation, but, yes, we have supporters and we do know that some of those supporters would like a broader bill. I think a vast majority of people would like to control the timing and circumstances of their death, but there will always be people who will fall outside the parameters of any legislation, and this legislation is no different. I think that is completely appropriate and I think "discrimination" is probably the wrong word to use.

The Hon. GREG DONNELLY: Just moving on to the issue of the prognostication of end of life and the matter of diagnosis, which goes to the very heart of my point about the eligibility criteria in clause 16 (1) (d) of the bill about the diagnosis of the condition. I presume you would be aware—and this information is quite readily available in the public domain—that oncologists generally have up to a fivefold error rate in prognostication in favour of longer survival than actually occurs. Intensive care physicians generally have a threefold error rate in favour of shorter survival than actually occurs. It is well accepted in medical science and medicine that estimating prognosis has wide—and I repeat the word "wide"—errors of margin.

I note that witnesses coming before the Committee later today, Professor Ben White and Professor Lindy Willmott, did a study which highlighted the high level of inaccuracies of prognostication, which, in fact, Go Gentle incorporated in their submission. Rather than arguing that doctors get the prognosis wrong, I put the proposition to you that the issue of the 12-month window is not satisfactory and that what we really need to be doing is looking to see how we can better diagnose the conditions that people may be suffering to enable them to better understand their circumstances. Thus, there is an argument for providing access to specialised medical individuals, like oncologists, palliative care specialists, et cetera.

Mr OFFNER: I think if there is a way to improve diagnosis of all illnesses then we would welcome it; I do not think there would be anyone who would not. In terms of prognostication, it is an inexact science; any doctor will tell you that. You have referred to error rates. I think doctors usually overestimate the time that people have left, not underestimate. I think the error rate—

The Hon. GREG DONNELLY: That is not what I put to you in my statement.

Mr OFFNER: I think if you are referring to the Ben White and Lindy Willmott study, that is exactly what they found.

The Hon. ANTHONY D'ADAM: Perhaps you can take my question on notice. When Ms Cohen was talking about her situation and her plans to go to Basel in Switzerland, it struck me that there could be significant financial barriers to people accessing the scheme. I wonder whether there has been any analysis around the socio-economic availability of VAD in Victoria. The other issue that would be useful to know about is around regional access and whether the experience in Victoria shows that there has been an imbalance in terms of access for those who live in a region and perhaps are not able to access the consulting doctors necessary to actually meet the requirements to access the scheme.

Mr OFFNER: I would encourage the members of the Committee to actually look at the Voluntary Assisted Dying Review Board reports. They have done six-monthly reports over the first two years of the law's operation, and a lot of that detail is included in those reports. I encourage members to read those. In broad terms about the socio-economic situation, unlike other jurisdictions around the world where there seems to be a skew towards higher socio-economic characteristics, it seems to be quite a balanced spread in Victoria. The same can be said for regional and metropolitan people accessing the law.

There is a slight skew towards people from the city, but there are higher numbers of people in the city. One of the things that those reports makes very clear—and that I think the board has already made recommendations on—is trying to encourage more specialist uptake of the VAD training in regional areas, because that does seem to be an area of great need. People in regional areas in Victoria—and it would be no different in any other State—usually are limited in the number of specialists that they can access. To access those specialists, they usually have to travel to a metropolitan area. Anyone with a terminal illness will find that quite difficult.

The CHAIR: Unfortunately we have run out of time. Mr Farlow, I am so sorry. Are you happy to put your question on notice?

The Hon. SCOTT FARLOW: I am interested that we keep to time, so I am happy to put it to another witness later today.

The CHAIR: Thank you very much. I appreciate that.

Mr OFFNER: Sorry. Just before we finish, I forgot to mention that I do have some booklets to table for the Committee as well.

The CHAIR: Thank you. The Committee staff will liaise with you to get those tabled. For the witnesses that have taken questions on notice, the secretariat will be in contact with you to liaise and arrange for the tabling of those answers. I thank you very much for your appearance today. We will be taking a 15-minute break and will be returning at 11.00 a.m.

(The witnesses withdrew.)

(Short adjournment)

SHAYE CANDISH, Assistant General Secretary, NSW Nurses and Midwives' Association, affirmed and examined

LAURA TOOSE, Legal Officer, NSW Nurses and Midwives' Association, affirmed and examined

APRELLE FLEMING, Member, NSW Nurses and Midwives' Association, affirmed and examined

The CHAIR: Welcome to the second session of the hearing today. Would any or all of you like to make an opening statement?

Ms CANDISH: Yes, thank you, I would. Thank you to the Committee for the opportunity to speak at this important inquiry into the provisions of the Voluntary Assisted Dying Bill 2021. As the Assistant General Secretary of the NSW Nurses and Midwives' Association, I am representing over 73,000 members. Our organisation is the peak professional and industrial organisation for nurses and midwives. Our association believes that a fair and just society is one in which people with a terminal illness are afforded the liberty to decide the health care and medical treatment they receive at the end of their life. This includes access to voluntary assisted dying, which can assure them a good death, one that offers them dignity and compassion.

As referenced in our submission to this Committee, a recent survey of almost 4,000 members found that more than 85 per cent are in support of voluntary assisted dying law reform. Meanwhile, 84 per cent indicated having professional experience in providing care to terminally ill patients and over half of those had been asked by a patient for assistance to end their life. Nurses want to deliver care that recognises and upholds the rights of their patients to make informed decisions about their care. Current laws can prevent clinicians from providing the specific end-of-life care that a terminally ill patient may seek. This conflicts with nursing obligations, which require that nurses must advocate on behalf of people in a way that respects their personal autonomy and decision-making capacity.

We respect that the topic of voluntary assisted dying is confronting for some, and we believe this bill offers a clear process for access to voluntary assisted dying in appropriate circumstances whilst also maintaining the rights of those who conscientiously object to participation. We are also committed to supporting any of our members who exercised their own professional objection. Our association is satisfied with the legislative protections that would be extended to nurses and other healthcare workers who do participate in this process or who engage in discussions with patients in their care. We support the requirement for those participating to be provided with all the appropriate education and professional safeguards for their work.

Importantly, this legislation and its amendments will ensure that people can still access palliative care options. It is our position that those suffering from a terminal illness are entitled to receive well-resourced palliative care as well as having the option to seek access to voluntary assisted dying in the proposed regulated manner. Our members provide high-quality palliative care that for many patients does alleviate their physical pain and provide adequate levels of comfort. However, it is widely acknowledged among our members that palliative care is not effective for all terminally ill patients, and some do experience unbearable pain and suffering for prolonged periods.

As a previous emergency nurse, I can recall several occasions when terminally ill patients would seek access to emergency treatment to relieve acute exacerbations of the symptoms associated with their illness. After a long and often uncomfortable stay in our emergency department, the best we could hope for was to provide those patients with some minimal relief from their discomfort. In closing, on behalf of our members, we sincerely encourage this Committee to choose compassion over politics; to recognise the significance of the suffering by those who are terminally ill; to respect the professional integrity of the clinical practitioners who would participate in the process of voluntary assisted dying; and, finally, to recommend the passage of this well-considered law reform through the upper House. Thank you.

The CHAIR: Thank you very much for that opening statement. Did anybody else on the witness panel have an opening statement? If not, I will pass to questioning.

Ms TOOSE: No, thank you.

The CHAIR: The Hon. Trevor Khan, I invite you to ask the first question.

The Hon. TREVOR KHAN: It seems to me we are confronted, at least in terms of the mountain of emails we receive, with an either/or in terms of palliative care or assisted dying. I take it from your submission that you see them as complementary. Is that the case?

Ms CANDISH: Absolutely. We would not advocate for an either/or option. We think that voluntary assisted dying provides people with additional options for treatment that they do not have access to currently. It is one of the many options that can be considered when they are considering their end-of-life care.

The Hon. TREVOR KHAN: It seems that some people, including some health practitioners, assert that the way forward is more expenditure on palliative care because that will provide the answer for patients. What do you say to that proposition?

Ms CANDISH: We would absolutely welcome more expenditure into palliative care; we think there is much more that can be done in that space. But that does not provide the same opportunities for patients to exercise decision-making as voluntary assisted dying does for those that would want it.

The Hon. TREVOR KHAN: If I go to page six of your submission and the blue bits, the first paragraph is this observation:

> Too many times I have watched people suffer to their death with pain medication no longer relieving their symptoms during palliation.

There are a number of those paragraphs or statements that are repeated over the next page. Is what you are describing bad palliation or is it a question of an ineffectiveness because of the nature of the disease that the patient is suffering from?

Ms CANDISH: I think the value of voluntary assisted dying is in the second example that you have offered there. It is really about when all of the medical options have reached their limits. Sometimes we cannot provide any further symptom relief for people. I have no doubt that there are aspects of bad palliation, but those things can be improved. But there are people who will experience a level of deterioration in their health that all of the modern health care we have for them simply cannot provide symptom relief for. In those instances, voluntary assisted dying really offers people an opportunity to access a level of control over their health care that they do not currently have now.

The Hon. TREVOR KHAN: Just in terms of weighing up—I am not in any way being rude when I say this—which group of medical professionals we should give appropriate notice to, in terms of caring for a patient in those final weeks of life, how much time is spent with the patient, say, by the palliative care specialist as compared with the nurses on the ward?

Ms CANDISH: Ms Fleming, this might be something you might want to talk to.

Ms FLEMING: I am currently employed in a publicly funded specialist palliative care unit in metropolitan Sydney. I have been working there for five years. I mainly do night shifts, where I spend 10 hours with patients. The patient load varies, but I would say that nine out of the 10 hours are direct patient care.

Ms CANDISH: And when you compare that to the palliative care team or the overseeing doctor—how much time would they spend with the patients?

Ms FLEMING: So the overseeing doctors are not there every day. There are doctors that review the patients daily and on a night shift we might liaise with the doctor on call if needed to amend any of their cares. I would say it could be anywhere between half an hour a day to maximum an hour a day once a week.

The Hon. TREVOR KHAN: Much has been made of the issue of suffering and, indeed, one of the amendments that was proposed was that suffering in some way be defined as physical pain or similar words to that. Would one of you describe the nature of the suffering that a patient, say, with a liver cancer experiences? Obviously one of those is pain, but there are other symptoms or things that that patient goes through in the end stages of their life.

Ms CANDISH: Would you like to take that, Ms Fleming?

Ms FLEMING: I am happy to take that. A patient with end-stage liver cancer would be quite symptomatic, often with pain from the liver cancer. They might have metastases to other organs or bones, which is quite painful. They often have an ascites, which is a collection of fluid in the abdomen.

The Hon. TREVOR KHAN: Sorry to break in but that is—and I will tell you this is a description of my father. Their belly will blow up to a very considerable extent.

Ms FLEMING: Yes, spot on. That causes pressure and pain. They may have an itch, which is intractable. There are limited medications that we can use for this itch. It is very distressing and it interrupts their sleep. They have a build-up of toxins because their liver is not processing that properly, which can cause hepatic encephalopathy and confusion. So they are quite distressed emotionally as well.

Ms CANDISH: If I can add as well, as a former emergency nurse—these types of patients would typically present to an emergency department. They would be receiving, usually, palliative care but they would come in to receive some assistance around that acute exacerbation of the ascites. We would tap that fluid and take it off, which would give them some symptom relief in terms of them being able to breathe more capably. The challenge is that the more we do that and we intervene, the faster the fluid would come back. So you provide a level of symptom relief but it is only for a period of time.

The Hon. TREVOR KHAN: I just picked one example because it is close to my heart. But when we talk about suffering, I take it we are not simply talking about fixing pain. There are a whole range of other symptoms that patients experience in those end stages of their lives.

Ms CANDISH: Absolutely.

The Hon. TREVOR KHAN: We could go into some other outcomes of that build-up of fluid but I think we are probably best to leave it alone.

The Hon. GREG DONNELLY: Just in regards to your submission, page number 11 deals with the matter of conscientious objection. Before I proceed with my questions around that, with respect to the NSW Nurses and Midwives Association, do you acknowledge that there is a specialist organisation called the Palliative Care Nurses Australia?

Ms CANDISH: Yes.

The Hon. GREG DONNELLY: What is your association or relationship with that organisation?

Ms TOOSE: We do not currently have any association. We are the registered trade union and also professional association. We are the largest professional association representing nurses and midwives in New South Wales. Palliative Care Australia—you may be better to direct the question to them in terms of their scope.

The Hon. GREG DONNELLY: I am talking about the organisation called Palliative Care Nurses Australia. You have no relationship with them?

Ms TOOSE: No.

The Hon. GREG DONNELLY: You know nothing about what they actually do?

Ms TOOSE: I would say that they are a specialist organisation representing the interests of a discrete group of nurses who are their members.

The Hon. GREG DONNELLY: Palliative care nurses.

Ms TOOSE: Yes.

The Hon. GREG DONNELLY: Moving on to the issue of your organisation, does your organisation enrol and represent student nurses or nurses in training?

Ms CANDISH: Yes, we do.

The Hon. GREG DONNELLY: And they pay union fees and are represented in any other way by your organisation—industrial services and otherwise?

Ms CANDISH: That question has a few elements, I suppose. If they are purely student members then, no, their membership with us is free.

The Hon. GREG DONNELLY: Okay, so free. But they are bona fide members of the organisation?

Ms CANDISH: Yes.

The Hon. GREG DONNELLY: They are members of the union and have rights, other than paying fees, equivalent to a fee-paying member of the organisation. Is that right?

Ms CANDISH: They do not exercise voting rights and they do not have industrial representation because they are students. They are not working or having coverage within the industrial framework.

The Hon. GREG DONNELLY: Did you say they do not have industrial representation?

Ms CANDISH: If they are working, then they would be a full fee-paying member. If they are simply students who are not working, then they are not fee-paying members.

The Hon. GREG DONNELLY: Okay. Clause 9 on page 4 of the legislation, which deals with the conscientious objection, states:

> **9 Registered health practitioner may refuse to participate in voluntary assisted dying**
>
> (1) A registered health practitioner who has a conscientious objection to voluntary assisted dying …

It then goes on and lays out the issues or provisions. But it specifically says a "registered health practitioner". Now, if we go to the back of the legislation, under the definition of what a registered health practitioner is—you would be aware of what that definition of registered health practitioner is?

Ms TOOSE: Yes.

The Hon. GREG DONNELLY: So it says:

> ***registered health practitioner*** means a person registered under the *Health Practitioner Regulation National Law* to practise a health profession …

I will not read on at this point. So are nurses covered by that?

Ms TOOSE: Yes.

The Hon. GREG DONNELLY: So all level of nurses?

Ms TOOSE: All level of nurses who are registered. So that is registered nurses, enrolled nurses and nurse practitioners, which are a subset of registered nurses who hold endorsement.

The Hon. GREG DONNELLY: Sure. Then it goes on here in this definition to say, "other than as a student."

Ms TOOSE: Yes. Students are registered under the Health Practitioner Regulation National Law as students and that has a distinct definition under the National Law from registered health practitioner.

The Hon. GREG DONNELLY: Indeed. So my question is this: If there was a member of your organisation—this is if the new legislation passes and comes into effect—who was a student as defined by that legislation and presumably your student classification or category of membership, they would not be covered by the conscientious objection rights in the legislation, would that be right? Because the conscientious objection provision only applies to a registered health practitioner. That has a specific definition.

Ms TOOSE: Yes, but nursing students who are on placement have a very limited scope in terms of what they are able to do on those placements. Participating in a process of voluntary assisted dying would be well acknowledged to be outside of the scope of what a student would do in the course of a placement.

The CHAIR: Just with regard to registered medical practitioner, that is not related to registration with you per se, is it? It would be registration with the New South Wales Health department.

Ms TOOSE: No, a medical practitioner is a category of health practitioner who is registered under the health practitioner regulation national board. So a medical practitioner is commonly known as a doctor. They would be registered with the Medical Board of Australia. A nurse would be registered with the Nursing and Midwifery Board of Australia.

The CHAIR: Separate to your—yes.

Ms TOOSE: Yes.

The Hon. GREG DONNELLY: But for the purposes of this, the definition in the legislation says:

> ***registered health practitioner***—

this is what the legislation provides for—

> means a person registered under the *Health Practitioner Regulation National Law* to practise a health profession ...

Nurses in New South Wales are covered by that definition. Is that the case?

Ms TOOSE: Yes.

The Hon. GREG DONNELLY: But not if they are students?

Ms TOOSE: No.

The Hon. GREG DONNELLY: My question to you is: If you had a student working in a facility and there were voluntary assisted dying arrangements in practice in that facility, that student would not be protected by the provisions of this legislation, would they, in terms of having the conscientious objection rights?

The CHAIR: I remind witnesses that you can take questions on notice if you need to seek some—

Ms TOOSE: Yes, I will take that on notice.

The Hon. GREG DONNELLY: Sure.

Ms TOOSE: I believe that there is a protection, but I would like to clarify whether or not that is in the current—

The Hon. GREG DONNELLY: That is fine. You made the point very clear at the start that nurses are obviously not medically trained to the extent of a doctor, a GP, and certainly not trained to the level of a specialist. With respect to diagnosis and prognostication around end of life, that is, death, it is very hard to predict that, is it not?

Ms CANDISH: To predict the prognosis of a patient?

The Hon. GREG DONNELLY: To predict when a person will die.

Ms CANDISH: I would say that nurses exercise caution in this space, exactly as you said. They are not doctors, and they do not try to be. But they certainly have a certain level of expertise in working with patients, particularly people like Aprelle who work in palliative care day in and day out. Their experience demonstrates some patterns or trends that you will usually see people go through in terms of their illness progression, and nurses are very good at predicting those things.

The Hon. GREG DONNELLY: But you would agree with the statement that you cannot predict when a person will die. You would not claim to know that, would you?

Ms CANDISH: No.

The Hon. GREG DONNELLY: With respect to the death of an individual person, the best one can say is that there is, dare I say, a statistical average or statistical calculation one could do to work out approximately when a person might die. Is that correct?

Ms CANDISH: I do not think I would agree with that, to be honest. There are far too many variables that you would need to take into consideration about a patient's illness and what it precisely is that they have been diagnosed with, so I could not answer that.

The Hon. GREG DONNELLY: So the diagnosis is really important to even think about when the end of the life of a person might be. Is that right? The diagnosis is important to get right.

Ms CANDISH: I would say in all cases the diagnosis is important to get right, because it offers a whole range of treatment options that are directed towards that diagnosis.

The Hon. GREG DONNELLY: That diagnosis ought be made as thoroughly as possible. Would you agree with that statement?

Ms CANDISH: In all cases, yes.

The Hon. ANTHONY D'ADAM: Clause 55 (a) (iv) of the bill allows a nurse practitioner to be an administering practitioner. Will you explain the difference between a registered nurse and a nurse practitioner, and whether there is a higher or lower threshold for the competence and capability of a nurse practitioner?

Ms TOOSE: As I alluded to before, a nurse practitioner is someone who is a registered nurse who holds additionally, on top of their registration as a nurse, an endorsement which is granted by the Nursing and Midwifery Board of Australia as a nurse practitioner. In order to obtain that endorsement a person would have to complete, in this day and age, a Bachelor of Nursing or equivalent and then complete the subsequent postgraduate training in a Master of Nurse Practitioner. Usually it is in a specialised area, and that would give a nurse the ability to have an expanded scope of practice. Those things could include prescribing, diagnosing in very limited circumstances, as well as ordering diagnostic imaging or ordering blood tests and things like that. They are an incredibly valuable resource because they are so highly trained and skilled.

The Hon. ANTHONY D'ADAM: How many years' training, in total, would nurse practitioners have?

Ms TOOSE: I would say a minimum of six years full-time.

The Hon. ANTHONY D'ADAM: How common is it for there to be a nurse practitioner? How many are there as a proportion of the profession?

Ms TOOSE: I would have to take that question on notice. The data is available on the Nursing and Midwifery Board of Australia website.

The Hon. ANTHONY D'ADAM: Thank you.

The Hon. SCOTT FARLOW: Thank you very much for your attendance today and for your submission as well. I want to follow on from the Hon. Greg Donnelly's issues with the right to conscientious objection and the views of your members in regards to that. I note in your submission that some members raise religious beliefs being a concern for them. How do you see the section 9 provisions working in practice for any of your members? Would that be a process by which they would have some form of registration that they had a conscientious objection in place and therefore were not involved, or would it be on an ad hoc basis? What is your experience in the past?

Ms TOOSE: It is not unlike other areas of practice. There are going to be occasions where people may have some discomfort with being involved in the provision of care to particular patients. It could be because they have had an interaction, because there has been something said to them that makes them uncomfortable. There is always a process whereby someone can escalate to the person who they report to and say, "Look, I'm not comfortable with participating in the provision of this person's care", and arrange for care to be provided by one of their colleagues instead. That is common and happens probably every day in New South Wales at least, and I would imagine and envisage that this would be no different. I would also imagine if the Voluntary Assisted Dying Bill is passed that the provision of assistance in dying would happen in discrete circumstances. People who did not want to be involved perhaps would be less inclined to work in one of those areas.

Ms CATE FAEHRMANN: Thanks for appearing today. I want to go back to treating patients who are at the end stages of their lives with some of the terminal illnesses that we hear are particularly excruciating at their end stages. Would any of you care to talk about having some of those patients, which I assume is a very stressful situation for you and your colleagues? Some of the stories in the books from Dying With Dignity and Go Gentle have detailed personal experiences, some of which we will hear this afternoon. For example, one man who had mesothelioma was screaming in the final two weeks or so of his life. Nothing could alleviate his pain. The brother of a woman who we will hear from this afternoon had an awful facial tumour and again was screaming as much as he could, just wanting help in the final stages. That is what we hear from the families, but Ms Fleming and her colleagues would hear that a lot. Will you tell the Committee what that feels like and the stress placed on you? You are obviously able to alleviate a lot of patients' pain through palliative care, but there are those who are begging to have their pain relieved that you just cannot do anything about.

Ms FLEMING: Yes, you are right. We do our best with the resources that we have, but there are occasions where patients' suffering cannot be relieved, whether that is emotional suffering, whether it is physical suffering through symptoms of pain, breathlessness or nausea. It is really hard. There have been a lot of cases recently where people's suffering has not been able to be relieved, even with really high doses of opioids. It is very distressing for the patient, for the family and for the staff. I have recently had patients that have sought methods to end their lives as well because they do not have the option of voluntary assisted dying. They might stockpile their medications. I have had one lady recently that decided to put a plastic bag over her head and slit her wrists and then walked into her son's room and decided, "Oh, maybe I don't want to do this." But she came to the palliative care ward and she spent two weeks there in agony, absolute emotional agony. She was tormented; she wanted to die.

Ms CATE FAEHRMANN: Are you able to tell the Committee what her condition was?

Ms FLEMING: She had a tongue squamous cell carcinoma.

Ms CATE FAEHRMANN: What is that?

Ms FLEMING: It is a cancer of the tongue. She had difficulty swallowing. She had swelling, so she could not communicate properly, and she had terrible pain.

Ms CATE FAEHRMANN: And ultimately, cancer like that just gets bigger and bigger and invades the—

Ms FLEMING: Airway, yes.

Ms CATE FAEHRMANN: Until that is the death.

Ms FLEMING: Yes.

Ms CATE FAEHRMANN: There was a story from a few years ago that I was wondering if you could talk about—not this particular story, but the condition or case of bowel cancer. I have told the story of Angelique Flowers for a number of years now. She was an advocate for voluntary assisted dying for some time, and she died a terrible death. She sought to be able to die with dignity because she knew that the death that she was going to experience was horrendous, including probably dying vomiting up her own faeces. I will say that, and I know it is a horrible thing for us to have to say in a Committee or anywhere.

But that is also the death that people face, isn't it?

Ms FLEMING: Yes, it is quite common for people with advanced bowel and ovarian cancers to have malignant bowel obstructions which are not relieved by medications. They do often die vomiting their faeces or they have massive internal bleeding, and it is very traumatic.

Ms CATE FAEHRMANN: And doctors tell them that this is potentially what they are going to face? Is it quite an open discussion?

Ms FLEMING: They will say that there is a risk of bowel obstruction. Often it occurs a couple of times before their last one. They will not go into graphic details about how horrible their death will be though.

Ms CATE FAEHRMANN: I could go on but if other members have questions—

The Hon. GREG DONNELLY: I am just wondering whether anyone at the table can provide an explanation to the Committee, in the context of the nursing profession, of compassion fatigue. There is a piece of quite significant study that has been done with respect to nursing over a period of time. Do you have knowledge of this research around compassion fatigue and what it means for nurses?

Ms CANDISH: Yes, I do.

The Hon. GREG DONNELLY: Can you explain what compassion fatigue is, please?

Ms CANDISH: My understanding of compassion fatigue is the ongoing demand on not just nurses but all people who work in care roles to continually empathise with the people who are in their care and the fact that that can take a toll over a number of years emotionally on them.

The Hon. GREG DONNELLY: Sorry, just say it again. The degree—

Ms CANDISH: The degree—

The Hon. GREG DONNELLY: To empathise with—

Ms CANDISH: Yes, that they are professionally required to provide can take a personal toll on them.

The Hon. GREG DONNELLY: To provide the actual empathy, that takes a personal toll.

Ms CANDISH: Yes. I do not think it is exclusive to the nursing profession.

The Hon. GREG DONNELLY: No, we are talking about nurses because that is your organisation represented at the table. With respect to nurses, how does this actually reflect in your members? Do your members talk to you as an organisation about their experiences of compassion fatigue?

Ms TOOSE: They would not articulate it in that language. I think the themes that we see are the struggles that our members have when they are unable to provide the level of care that they believe their patients require. That can be based on resourcing or that can be based on limitations with treatment options that are available to them. But that is the challenge ultimately. Nurses and midwives get into this profession because they want to do the right thing by their patients. So when they are in a position where they are unable to do that, it presents a level of distress to them, absolutely.

The Hon. GREG DONNELLY: If you take nurses around the State of New South Wales, away from Newcastle, Sydney and Wollongong, so in regional, rural and remote New South Wales, we know as a matter of fact—I presume you do so as well, as a professional organisation representing nurses—that in many parts of the State there is access to very, very little palliative care. Would you agree with that statement?

Ms TOOSE: I would say access is problematic in a number of areas. I would completely accept that.

The Hon. GREG DONNELLY: So you accept that proposition that palliative care is quite restricted in many parts of the State. Would you agree with that statement?

Ms TOOSE: Yes.

The Hon. GREG DONNELLY: That being the case—in other words that individuals cannot access palliative care who otherwise may need palliative care—that would result potentially in those individuals suffering quite badly. Is that correct?

Ms TOOSE: Potentially.

The Hon. GREG DONNELLY: And by suffering very badly—my words, suffering very badly, I have described it in these terms—if there is no palliative care, that observation of seeing those people who nurses have a vocation to care for and look after and support, would be very difficult for a nurse, wouldn't it, to see that?

Ms TOOSE: I think it is important not to conflate separate issues though. Our members can very clearly articulate when all of the available options within health care fail a patient versus when a patient cannot access the care that they require because they are in a remote area. So that is not something we would hear from our members.

The Hon. GREG DONNELLY: So you would not hear from members anxiety around seeing patients suffering in regional and rural New South Wales—

Ms TOOSE: No more than we would—

The Hon. GREG DONNELLY: —not accessing palliative care?

Ms TOOSE: But they would articulate that the suffering is because of their lack of access to palliative care. Our members who live in those communities know better than anyone when there are limitations to access around palliative care services. They are the first to say that is the problem.

The Hon. GREG DONNELLY: That has been the evidence by nurses right across New South Wales in the inquiry. You would know that?

Ms TOOSE: Absolutely.

The Hon. GREG DONNELLY: And they have been calling out very strongly to significantly improve access to mitigate against people suffering. Would you agree with that?

Ms TOOSE: Yes.

The Hon. TREVOR KHAN: I just want to go back to this conscientious objection issue. Could I just go to the circumstance that has been described earlier and that is the provision of—and I think perhaps this is to Ms Fleming, from your experience—terminal sedation, I think it has been called at various times. I have heard other usages also. Is there a capacity for a nurse to conscientiously object to a patient receiving terminal sedation?

Ms FLEMING: Yes. A nurse always has the opportunity to object to anything they do not feel comfortable with. I think most nurses working with palliative patients would hate to see their patients suffering and if they required terminal sedation, they are happy to do it.

The Hon. TREVOR KHAN: But in a sense there are mechanisms that already exist within the health sector to deal with nurses or other health practitioners objecting to a style of treatment without it having to be written into a piece of legislation. Is that the general drift?

The Hon. GREG DONNELLY: And is it legally enforceable?

The Hon. TREVOR KHAN: I am asking the questions at this stage.

Ms TOOSE: Yes, I would say that is absolutely custom and practice in every workplace. Nurses are bound by a number of provisions like, for example, the five rights of medication administration. I think most nurses would tell you that at least once a day they are given an order that does not fit the bill from that regard and so they have to object to administering it. It is done between the doctor and nurse. It is rectified. A nurse would routinely question a doctor around some treatment that has been prescribed if they do not agree or do not understand. If it is resolved, then that would be the end of it. But if it is not resolved, it is escalated through the nursing pathways. So the nurse would approach their manager and say, "This is what I am uncomfortable about and this is why." And that can be escalated all the way to the highest levels of the patient's treating professional doctor or their medical team.

Ms CANDISH: Can I also add to that. Scope of practice is an incredibly important issue. So a scope of practice for a nurse is anything that they are educated, authorised and competent to perform. So activities of care that they undertake need to conform within that framework. If someone is theoretically providing care to someone who is receiving palliative care and that person decides to access voluntary assisted dying and they have a conscientious objection, it is likely that it would be outside their scope of practice to actually participate in the provision of that care because they would not have done the training. They would not be educated, authorised or competent to be involved in that process. So it is not just a matter of whether they can put up their hand and say, "I don't want to be a part of this." It is actually, "I can't be a part of this because I haven't received the appropriate training."

The Hon. TREVOR KHAN: I will just return to Ms Fleming. It is not uncommon, is it, that in the end stages of a person's life there will be a discussion that may involve the nurse—I am saying with the medical practitioner—with the doctor essentially saying, "Look, we are going to up the dosage."

Ms FLEMING: Yes.

The Hon. TREVOR KHAN: And one of the consequences of that is likely to be the death of the patient at some stage. That is not an uncommon outcome, is it?

Ms FLEMING: The conversation would not go as—

The Hon. TREVOR KHAN: Brutally as that.

Ms FLEMING: No. It would be that the side effect of increasing this medication may be increased drowsiness or sleeping more or it might be a decreased respiratory rate. That would be as far as the conversation would go.

The Hon. TREVOR KHAN: Yes, sure. I am not suggesting—

The Hon. GREG DONNELLY: I think you are.

The CHAIR: Order!

The Hon. TREVOR KHAN: What I was saying is I am not suggesting an impropriety, Greg, if you had allowed me to finish. If a nurse is involved in that style of conversation, is the nurse able in those circumstances to say, "I don't want a part of this"—in essence, "I conscientiously object to this course of action"?

Ms FLEMING: That is entirely up to the nurse.

The CHAIR: Unfortunately, Mr Khan, we have reached our time limit. I thank all of the witnesses for this session for appearing today. For the questions that you have taken on notice, the secretariat will be in contact with you to liaise their tabling. We thank you very much for making your time available to us.

(The witnesses withdrew.)

NICHOLAS RICHARD COWDERY, Immediate Past President, NSW Council for Civil Liberties, before the Committee via videoconference, affirmed and examined

BEN WHITE, Australian Centre for Health Law Research, before the Committee via videoconference, affirmed and examined

LINDY WILLMOTT, Australian Centre for Health Law Research, before the Committee via videoconference, affirmed and examined

SIMEON BECKETT, Barrister, and Co-Chair, Human Rights Committee, New South Wales Bar Association, affirmed and examined

TRENT GLOVER, Barrister, and member, Human Rights Committee, New South Wales Bar Association, sworn and examined

The CHAIR: The witnesses now have an opportunity to make opening statements. I will start with the New South Wales Bar Association. Do you both have an opening statement?

Mr BECKETT: We will make one opening statement now, if that is suitable, and then Mr Glover and I will address various questions because Mr Glover is, in fact, the author of the submission and he is the holder of the technical knowledge, I have to say. First of all I want to say thank you to the Chair and also to the members of the Committee for inviting the New South Wales Bar Association here to make submissions orally and to back up our written submission, which was filed some time ago. Thanks for the opportunity to participate in the inquiry. The subject matter of the bill and this Committee's inquiry is very much the subject of debate around the world. Indeed, the UK House of Lords is currently engaged with considering a private member's bill on the same subject with respect to England and Wales.

The Bar Association's submission engages with what is the most significant of all human rights: the right to life. It also seeks to bring to the Committee's attention other human rights that are engaged by this bill, in particular, prohibition on cruel, inhuman or degrading treatment; the rights to freedom of thought, conscience and religion; the rights to privacy and family life; and, of course, the rights of persons who have a disability. The detail of that is set out in the detailed written submission that we made. The Bar Association's submission focuses on some of the more technical aspects of the bill, and that is really with a view to ensuring that the legislation in the form Parliament sees fit to enact as having a degree of certainty of operation and to ensure certainty for all those people who are affected by the bill.

Of course the Committee has heard and will be hearing from stakeholder groups and individuals later in the day, but the evidence might be expected to focus on the broader policy considerations associated with the legislation. The position of the New South Wales Bar Association is, on a policy basis, neither to support nor oppose the particular bill. Our focus is, really, if the bill is to go ahead and be enacted, that it be done in a way so that it makes sure that the policy outcomes, particularly in terms of certainty, are adhered to. So our focus has been very much on ambiguity: removing ambiguity and trying to assist with understanding how the bill will work in practice and trying to identify those issues where there might be some concern about ambiguity. I will not belabour that other than to refer the Committee and its members to our submission.

We have considered the amendments, at least in passing, as a result of what occurred in the other place and we wanted to make specific mention of the new guidelines proposed at clause 186A. The ability to make guidelines and requirements to have regard to those guidelines will serve to assist with clarification of the operation of the bill. We support the guidelines; we support that particular amendment on the basis that we have put in our written submission. Thank you. Obviously, after the others have opened we are happy to take your questions.

The CHAIR: Thank you very much. Mr Cowdery, I now offer you the opportunity to make a submission.

Mr COWDERY: Thank you. I will make a short submission. First, I also thank you for the invitation to appear today on behalf of the NSW Council for Civil Liberties and I thank you for allowing me to appear by videoconference. It is not because of any lack of vaccination; I am, in fact, triple vaccinated. But it enables me to attend to other commitments that I have today. So thank you for that indulgence.

The NSW Council for Civil Liberties' submission was made on 18 November and I rely on that written submission. Our submission is that as a matter of policy this bill should pass and this regime should be enacted. The council has been in support of such a move now for some decades. I also have a personal submission before the Committee, which I note is referred to in the schedule of events for this session.

The civil liberty or human right which is at issue, of course, the principal one—I accept the others that my colleague has referred to but the principal one is the right to life. It is the freedom of an individual to choose how that life is led and to do so in accordance with law, in accordance with morality, with ethical considerations, with philosophical and religious considerations that might apply in any particular case. There are three aspects of article 6 paragraph 1 of the International Covenant on Civil and Political Rights. I am referring to this now in my opening because we have not directly addressed this issue in the written submission. There are three elements of article 6 paragraph 1. It is reflected in other instruments, of course, and in international customary law. It states:

> **Article 6**
>
> 1. Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.

It is an inherent right—that is, every human possesses it by reason of being human—and it is non-derogable. It cannot be taken away by the State, even in circumstances of emergency. But I want to emphasise that it is the person's right, and I will say a little bit more about that in a moment. It is protected by law. It has to be protected against threats to life that might exist in the community. The State has a discretion as to the extent to which it will intervene to protect that right. It must act proportionately to any risk that is anticipated. The article says that a person is not to be "arbitrarily deprived" of life—that is, unlawfully or unjustly. There must be controls to ensure proportionality of action that is taken and so that must be reflected in this kind of legislation as well.

There is an argument as to whether or not the right to life is discretionary or mandatory. I leave that to academics specialised in this particular field. It is an ongoing controversy, I understand, but the State has responsibilities in relation to individuals who interfere with their own right to life. There is a need to prevent compulsion of any kind. If a person ends his or her life, it must be with genuine consent. The State can set the limits. It can set the limits of the authenticity of action that can be taken, the reliability of that action and the safeguards that are in place for everybody involved in the process. It is our submission that the present bill does that. It meets those requirements and, in substance, it appropriately preserves the right to life, but it also gives freedom of choice to the right-holder.

The CHAIR: Thank you, Mr Cowdery. Professors Willmott and White, do you both or either one of you have an opening statement that you would like to make?

Professor WILLMOTT: Thanks, Chair. We each have a brief statement, if that is alright?

The CHAIR: Absolutely. Perhaps you might like to start, Professor Willmott.

Professor WILLMOTT: Yes, certainly. Thank you for the invitation to be a witness before the Committee today. We are particularly grateful, given that we are from across the border, so thanks for accommodating the videoconferencing as well. I acknowledge the traditional owners of the land on which I live. For the past 20 years I have researched almost exclusively in the law, policy and practice of end-of-life decision-making, including in relation to voluntary assisted dying. In the past two years I have also undertaken empirical research into how the Victorian VAD system has been operating, and this research informs my position. As part of our research in this area, Ben White and I have drafted a VAD bill. This bill was adopted by the Queensland health committee as its preferred legislative model in the VAD report tabled in the Parliament by that committee in March last year. The extensive research that we have undertaken into VAD informed that legislative model and also informs the positions that we articulate here today.

In this opening statement, I would like to make two points. The first is that we believe it is possible to have safe VAD laws that give choice to patients who are already dying. In our view, the bill, as passed by the Legislative Assembly, should be enacted. While we suggest some minor amendments to the bill in our written submission, we believe it is a sensible and measured bill that will provide choice for terminally ill patients while operating safely, including protecting the vulnerable in our community. During this inquiry, I expect that the Committee will hear arguments to introduce further safeguards—for example, requiring compulsory psychiatric assessment or compulsory palliative care consultation. I urge the Committee to resist such proposed amendments. The bill, as passed by the Legislative Assembly, already contains sufficient safeguards. Adding further safeguards will only serve to make accessing VAD even more difficult for terminally ill patients.

The second point is to respectfully urge the Committee to pass a bill which is the best bill for New South Wales and not to amend the current bill so it looks more like the Victorian model. A departure from the Victorian model does not mean that the New South Wales bill is inferior or not as safe. The fact that the Victorian Act is the first Act in any Australian State does not make it the best possible Act. The Victorian legislation has been in operation for two years, and there are important lessons to be learned from their experience. We can address the Committee about the results of our research into the Victorian experience if that would be useful. The Victorian legislative model can be improved, and the New South Wales bill, as passed by the Legislative Assembly, has done just that. Thank you. That concludes my opening remarks.

The CHAIR: Professor White?

Professor WHITE: Thank you for the opportunity to address the Committee. I apologise in advance. I received the invitation while I was on leave, and I am still on leave so I am doing this on a tiny mobile phone. My apologies if that is a little suboptimal.

The CHAIR: We appreciate you taking the effort and time to come and talk to us.

Professor WHITE: No, delighted. I acknowledge the traditional owners of the land where I am currently at, the Gubbi Gubbi people. Like Lindy Willmott, I have been researching in voluntary assisted dying for the last 20 years. It is the sole focus of my research at the moment. In 2020 I was awarded an Australian Research Council Future Fellowship, which is a four-year project effectively focusing on how best to regulate voluntary assisted dying in Australia. Also relevant background is that Lindy and I designed and developed the mandatory training for the Victorian and Western Australian governments. I give that background to set the context for the brief statement I will make. I agree with the point that Lindy made about the New South Wales bill being a sensible and measured VAD law. It reflects what is now the broad Australian model and is safe. I would make two comments in my opening remarks.

The first is to respectfully urge the New South Wales Parliament to avoid the ad hoc addition of the many late amendments or safeguards that we have seen elsewhere. We have called this "the piling on of safeguards". As it currently stands, the New South Wales bill is based on the VAD laws passed in other Australian States, themselves the product of extensive consultation and expert input over many years. These add-ons to an established model risk making the law unwieldy, incoherent and indeed even unworkable. It is our view that such proposed additions do not make the law better or safer. In fact, they risk harming the intent of the law by making an already rigorous and very difficult process actually unworkable so the patients whom the law would otherwise deem eligible in theory, in practice cannot access voluntary assisted dying because they cannot get through the process. That was the first comment about avoiding the ad hoc piling on of amendments.

The second relates to evidence and to repeat our call for evidence-based lawmaking. We propose the Parliament's decision about the best VAD law for New South Wales should be based on the large body of reliable and high-quality evidence that is available about how VAD systems work internationally. There is also now evidence about how it is working safely in Victoria. Our article in the *Australian Health Review*, which is attached to our submission, proposes that, like for all science, reliable evidence means enough data, enough cases that we can trust, and that that evidence has been externally and robustly tested.

For example, peer-reviewed empirical evidence is reliable but anecdotes and media reports are not reliable evidence and so are not a safe basis on which to make laws. What counts as reliable evidence is significant because you have, as I am sure we will hear over the course of your inquiry, many conflicting claims. People will say VAD is safe but others will say it is dangerous. Perhaps a concrete example can help. A concrete example of conflicting claims relates to the question: Are vulnerable patient groups more likely to seek VAD? This is an example of where reliable evidence can resolve this factual claim. There is peer-reviewed research of large datasets published in leading international journals, and it concludes that vulnerable patient groups are not more likely to seek VAD. My point here is not for or against VAD but rather that good lawmaking should be evidence-based, and there is an opportunity to draw on a large available body of reliable evidence. Those are my opening remarks.

The CHAIR: I note the time, it is just past midday. I know that there are some time constraints for people at 1.00 p.m. We have just under an hour for questioning.

The Hon. GREG DONNELLY: I direct my first lot of questions to the representatives from the New South Wales Bar Association. Thank you very much for coming along today. First of all, thank you for your submission. It was very helpful in structuring our thinking around some of the matters we need to turn our attention to. It is appreciated. I will go to particular paragraphs in your submission. That might be the quickest way because we have limited time. I am sorry if I sound like I am cutting this tight, but we have limited time. First of all, I will go to paragraph 27 on page 5. This is providing an opportunity to elucidate on, if necessary, the lead-in paragraphs that bring you to the conclusions that are in the paragraphs that I wish to draw out. In paragraph 27, the first part of the sentence, which goes into the second line, states:

> For this reason, the Association suggests that the community of persons with disability be recognised as a community with a significant interest in the operations of the Bill …

It then continues on. Can you elucidate on the thinking behind that and what would be the steps to take to create this significant interest? What would be the process required to achieve what is suggested there?

Mr BECKETT: Mr Glover and I, I would have thought, will probably both reply to that. If I can pick up on the obvious one, that certainly this Committee and the proceedings that we are currently engaged in is an appropriate vehicle in terms of the shaping of the bill and to making sure that the community of persons with disabilities, for which there are many non-government organisations, should be engaged in, and are invited to engage in, this process so that they are heard in the making of the legislation. One of the particular amendments that I will get Mr Glover to pick up on that we have suggested is a safeguard with respect to protecting that part of the community of persons with disability is to ensure that VAD is not applied where disability is the sole ground upon which a decision is made. We have made our position quite clear on that, but I will turn over to Mr Glover.

The Hon. GREG DONNELLY: To clarify, that is disability as we would broadly understand it: both physical and intellectual disability?

Mr BECKETT: Yes.

The Hon. GREG DONNELLY: Is that what we are essentially talking about here? Is that how it is broadly understood?

Mr GLOVER: Yes. I think the Bar Association's concern in this respect did not necessarily touch on the provisions of the bill but more a bringing along in the process of persons with disability because, as you will see in the paragraphs preceding paragraph 27, obviously—as the Committee would be aware—there is a significant international convention that deals with the rights of persons with disability. Indeed, at a Federal level and at a State royal commission level there is an ongoing royal commission which is sitting at the moment. It is really designed to make sure that the voices of people with disability in opposition to voluntary assisted dying laws are heard and that the Committee, and indeed Parliament more generally, takes their views into account.

The Hon. GREG DONNELLY: I put the proposition to you that with respect to this inquiry currently before us, there are roughly 110 submissions that might be called "substantial" or "significant" in terms of contents—indeed, yours is one of them—but, as far as I can see, not one of them is from an organisation that represents people with a disability, either physical or intellectual. Do you think that is something that we should be concerned about, that there has been nothing heard from—broadly defined—the disability community in regard to this proposed legislation?

Mr BECKETT: I think the general proposition is—first of all, we are not aware of the nature of the detailed consultations that have already gone to date, but I would have thought it was within the remit of the Committee to write to such organisations and to solicit submissions, if you were concerned about that particular issue. Mr Glover?

Mr GLOVER: I find that quite interesting. It may not be a cause for concern. There may also be a degree of ambivalence towards this legislation given it was considered previously in the previous versions of the bill by the parliamentary working group. In my submission, it is definitely something the Committee should follow up on.

The Hon. SCOTT FARLOW: In terms of your suggestions of amendments to the bill, at paragraph 75 you outline some changes to the legislation, as you see it, to provide better protections for those with a disability. Do you want to expand on that?

Mr GLOVER: Those proposed amendments are designed to ensure that persons who are deemed ineligible, particularly having regard to disability, are just as safeguarded in the bill. This is not taking up the professor's points in opening. It is an additional safeguard that affects accessibility but it almost operates in the reverse. So it makes it clear that it protects persons who are vulnerable, like those who have disability, from being regarded as ineligible. The other important amendment in that respect in this paragraph of the submission is the one that follows it, which is ensuring reviewability of those decisions about eligibility. That is a useful oversight mechanism on the safeguards. I am aware that in the previous iterations of the bill, even though this is well different, one of the great developments between the 2016 bill and the 2017 bill was a recognition of the jurisdiction of the Supreme Court to provide oversight.

The Hon. GREG DONNELLY: Paragraph 45 on page 8 of your submission states:

> Having regard to the number of different ways the term 'advanced' could be reasonably interpreted, the Association suggests a definition of the term 'advanced' be included in the Bill.

That obviously goes to the question of the eligibility provisions within the bill; you would be well familiar with those. With respect to that point, is there anything that you wish to elucidate or comment on?

Mr GLOVER: Indeed, given that professors Willmott and White are in this session it might be something that they are more qualified to speak on given their role in drafting the Queensland legislation, which picks up on the Victorian provision.

The Hon. GREG DONNELLY: I have to say I am more interested in your evidence this morning. Perhaps directing it to you, you obviously had reasons for putting that in your submission and it stands as your evidence. You had reasons clearly for that. What were the reasons behind that?

Mr GLOVER: It is really to ensure the certainty, or as much certainty as possible, with respect to accessibility or eligibility. Basically, the Bar Association's submission is directed to seeking as much clarification as possible in three discrete aspects of the bill. It is the accessibility or eligibility, the assessment of that accessibility or eligibility, and then the enforcement provisions—enforcement or oversight, I should add.

The Hon. GREG DONNELLY: I am sure my time is running out. Can I take you next to paragraph 54—sorry for the Cook's tour—at page 10. You say:

> For those reasons, the Association suggests that the meaning of the term 'suffering' should be further clarified in the Bill.

Is there anything you would like to say in regard to that particular piece of your evidence?

Mr GLOVER: Again, this is something that has been considered in other jurisdictions, in particular Tasmania, which has that really extensive definition of suffering. Really, again, what the Bar Association was seeking to do was draw out particular expressions that may be capable of different meanings so that if enacted in whatever form Parliament chooses fit, it is as of certain operation as possible.

The Hon. GREG DONNELLY: Okay. I will circle back to it later.

The Hon. ANTHONY D'ADAM: I might just then pick up on that and ask professors White and Willmott—

The Hon. TREVOR KHAN: You have stolen my thunder.

The Hon. ANTHONY D'ADAM: —to address the issues that have been identified around the proposed amendments from the Bar Association—

The Hon. GREG DONNELLY: The restrictions.

The CHAIR: Order! No interjections.

The Hon. ANTHONY D'ADAM: —and their necessity or otherwise. Professor Willmott or Professor White?

Professor WILLMOTT: I am happy to start off, Professor White, if you wanted to chime in after. My apologies, I am afraid I have not had the advantage of reading that particular submission, but obviously I picked up on some of the content. In relation to further defining "suffering", I would certainly be concerned about any attempt to do that. Suffering, as it is currently expressed in the eligibility criteria, is subjective—that is, a level of suffering that is intolerable to the patient themselves, and it can be as a result of cause of physical pain or existential pain. I think that if a patient who satisfies the other criteria, having an advanced progressive illness, is going to die within six to 12 months and say that their suffering is intolerable, I do think that that is sufficiently clear. I do not think that that is a problem in terms of certainty. It certainly has not been something that has emerged that I am aware of from the Victorian experience as to any concerns by doctors about whether or not that is [audio malfunction].

My off-the-top-of-my-head comment in relation to the requirement or the suggestion that the term "advanced" be defined, my comments are similar here. When you look at the combination of all of the eligibility criteria—that the illness is advanced, progressive and will cause death, on the balance of probability, within six months or 12 months for a neurodegenerative disease—those diseases like cancer, if it is at an early stage, it will not be causing death within six months, so it would not be classified as advanced. When you take those terms collectively, I do not think that there is any uncertainty. I think my colleague Professor White might be having some issues with his connection, but when he is back up he may have additional comments.

Professor WHITE: I had a go at taking off my—can you hear me at all?

The CHAIR: We have got your audio, Professor White. So if you are able to add some elucidations to that, that would be fantastic.

Professor WHITE: Of course. I have just taken my video off to try, I guess, for the bandwidth. I agree with the points that Professor Willmott has made. Starting with the "advanced", I think the risk of taking an established Australian law, which is there in place and has not been causing problems in practice, I do not think there are upsides to that. I guess the other challenging thing is medical practitioners are already very comfortable with and aware of what an advanced medical condition is. For example, in cancer there is [audio malfunction] for diagnosis. There is a range of different things to do across different illnesses. The risk of trying to define in sort of a very detailed way is that there may be [audio malfunction] to how that would apply to the diverse range of illnesses that arise. I would support leaving "advanced" as it is because I think that is understood and it is used in other jurisdictions. On the "suffering" point, I agree with the points that Professor Willmott has made. Perhaps the only thing to add might be if there is merit in clarifying that the suffering could include, for example, [audio malfunction] by the treatment [audio malfunction] treating their illness [audio malfunction] that it can, in fact, be existential and emotional suffering as well. Those are the only other thoughts I would add to that.

The CHAIR: Thank you, Professor White. Do you have some more, Mr D'Adam?

The Hon. ANTHONY D'ADAM: I would like to perhaps ask Professor White and Professor Willmott to, drawing on their knowledge of international experience—the "slippery slope" argument seems to be one of the key arguments advanced in opposition to the bill. I wonder whether you can perhaps give us some insights about whether there is any validity to that argument in relation to the international experience.

Professor WHITE: I am happy to start off on that one, Professor Willmott, if that sounds okay. I might [audio malfunction] slippery slope can be met. One of the arguments is that once you allow voluntary assisted dying, other unlawful practices will increase over time. Again, here I would just go to the evidence. There is evidence tracking what has happened in Belgium and in the Netherlands over the last two decades. There was research before voluntary assisted dying was legalised in those jurisdictions and after, and those concerned about a slippery slope would point to, for example, unlawful ending of life happening more frequently due to voluntary assisted dying becoming lawful. In fact, the experience has been the opposite. The Belgian and Dutch teams have collected data on a category of death, which is LAWER, which is effectively ending life without explicit request; it is basically ending someone's life without them seeking voluntary assisted dying. That has actually declined over time and declined after the passing of the assisted dying legislation. There is a range of ways, I guess, we can think about the slippery slope but in terms of that one, that is one I think where I would go to the evidence and the evidence, I think, makes it clear.

The CHAIR: Professor Willmott, do you have further contribution on that question?

Professor WILLMOTT: Maybe only to say that was one aspect of the slippery slope. The other aspect of the slippery slope is that once you enact this legislation, then Parliament will widen the criteria—for example, the eligibility criteria—and, I guess, again, we urge you to look at the evidence. There has been some modification, very limited modification, in some places. For example, in the United States, which has a model very similar to the Australian model, the eligibility criteria have not changed. There is not evidence of that slippery slope that some people claim. The other thing that I would add too in relation to this argument of a slippery slope in terms of changing the legislation is that we do live in a democracy and we are governed by Parliament. Parliament, after extraordinary amount of consideration—committee work, submissions, deliberations in committees such as yourselves—pass or do not pass legislation. If in 20 years society or the community says through its parliamentarians, "We want to change this law", then that is part of being in a democracy. But, certainly, we have not seen that internationally except in very limited circumstances.

The Hon. SCOTT FARLOW: I might return to the Bar Association with my questioning and pick up where Mr Donnelly left off with some of the issues raised in your submission. I might first pick up the point raised by Professor White with respect to the additional safeguards and making legislation unworkable. Do you think that the legislation as it stands is currently so workable that we could not possibly consider any amendments?

Mr BECKETT: That is such a broad question. Which part are you drawing attention to in respect of that?

The Hon. SCOTT FARLOW: I know the Bar Association has taken the position that you are neither in favour or not in favour of the legislation but you are in a position where you are trying to raise some concerns about the legislation and how it could be workable. Do you believe that there is therefore some scope to better refine and define the legislation to make it workable?

Mr BECKETT: We have certainly set that out in our submission.

The Hon. SCOTT FARLOW: Yes, I just wanted to pick up that as the first starting point.

Mr GLOVER: I certainly agree with that. Indeed, I think the amendments that were passed in the other place also improve the operation of the Act. I suppose that, as a lawyer, if you ask generally whether legislation can ever be improved, that is probably the case. I appreciate that I am talking to a room of parliamentarians and lawmakers, but it is invariably the case that legislation can always be improved.

The Hon. SCOTT FARLOW: To go to where Mr Donnelly left off in terms of the issues you raised, I think capacity was the next issue that was raised in your submission. Thank you for your submission because I think it is a useful starting point in assessing each State's parameters and where there are differences as well as where New South Wales may be able to follow from some of the lessons of other States in this area. In terms of capacity, I think at page 14 you recommend that the bill be clarified to make it plain. I will not go into it but perhaps if you would like to further expand upon some of the issues you see in terms of decision-making capacity as it stands presently in the legislation.

Mr GLOVER: One of the issues that struck us was the temporal component of the process—the requests and assessment—before the administration of the substance, assuming that you are assessed as eligible and you pass through those gates. I note that some of the amendments in the other place deal with a permanent loss of capacity so that once you have permanently lost capacity you then become ineligible forever to access this regime. To the Bar Association's submission, there was another aspect of that temporal component. That is, how the Parliament intended the legislation to work in relation to a person who may have capacity at some time, loses capacity and then has capacity regained at another time. It seemed to the Bar Association that it is certainly possible to read the legislation as it currently is—or the bill as it currently is—as applying to assessments of capacity at particular points in time of the process. But if that is the case, the bill could probably be improved by expressly recognising that if that is Parliament's intention.

The Hon. SCOTT FARLOW: I think the Bar Association at 16 makes brief comments with respect to the offences provisions. I am particularly interested in 41C as it appears in the bill: "Inducing another person to request or access voluntary assisted dying". Do you believe that this covers the total gamut of areas where duress could effectively be placed upon an individual and that that provision is sufficient?

Mr BECKETT: Are these the new amendments?

The Hon. SCOTT FARLOW: Yes, this is 41C appearing on page 77 of the bill. Do you have a view on that provision at all?

Mr GLOVER: Speaking personally, I certainly thought that the amendments made in the other place, I think by Minister Stokes, that inserted further regard to pressure and duress were useful ones. I think it is difficult to consider on the run, so to speak, whether they—

The Hon. SCOTT FARLOW: If I could invite you to perhaps have some consideration of those provisions on notice, particularly around duress.

Mr GLOVER: Yes.

Mr BECKETT: You obviously have the former Director of Public Prosecutions, Mr Cowdery, online. He might have a view about those particular offences.

The Hon. SCOTT FARLOW: Yes, I am happy to refer to Mr Cowdery on that as well.

The Hon. TREVOR KHAN: I will if you do not.

The Hon. SCOTT FARLOW: I am sure you will. I note that he made comments with respect to those safeguards in his opening statement. I am happy to invite him to comment on that as well.

Mr COWDERY: Thank you. Yes, I am just looking at the proposed section 41C. I think it covers the circumstances that might be encountered by dishonesty or pressure or duress—and pressure or duress are defined in the dictionary to the bill. As I sit here I cannot think of action that might not be included in those descriptions. I would suggest that it does cover the field appropriately.

The CHAIR: The Deputy Chair has just raised with me that in the copy of the bill he has, it is 41 (4) (c). Is that the provision being discussed?

The Hon. SCOTT FARLOW: No, I was referring to 41C in the second print on page 77, which is in schedule 1A to the bill

The CHAIR: Thank you.

The Hon. TREVOR KHAN: I will ask the professors a question at this stage. I now have so many pages open on my desk that I am not going to find your submission again, but you made reference to the Victorian legislation. If I paraphrase correctly, you essentially identified that there are some shortcomings in the Victorian legislation. Are you able to identify what those are and whether the New South Wales bill appropriately deals with any of those shortcomings?

Professor WILLMOTT: I am happy to have a first crack at this. Can I just briefly say what our research was in relation to Victoria? We interviewed 32 doctors who were either consulting or coordinating doctors in the first year of its operation. We were interested in their thoughts about how it had been operating in that first year and, of course, we were particularly interested in the regulatory components of that. As you know, the two main purposes of the legislation are to ensure access to voluntary assisted dying by people who are eligible as defined by the legislation and to ensure that there are sufficient safeguards in the legislation so that ineligible people cannot access voluntary assisted dying. I guess one of the overall main findings of the legislation was that doctors were certainly satisfied in relation to safety of the regime. They were not concerned that people who were not eligible, as defined, were receiving assistance to die. But there were some concerns in relation to access and that the procedure and the process was so difficult that some people were just too sick, too ill, to get through the process; it was just too rigorous. I guess that was the headline finding of our research.

To drill down to specifics, there are a number of issues highlighted but maybe two where I think that the New South Wales bill has, to an extent, addressed issues. One is in relation to the section 8 prohibition in the Victorian legislation, which prohibited registered health professionals from initiating a conversation in relation to voluntary assisted dying. That blanket prohibition was of concern to the doctors that we interviewed. They felt that it disadvantaged people, particularly whose health literacy was not good or people with English as a second language. I think the New South Wales bill has improved that provision because it does allow issues to be raised, provided that other things occur, such as also discussing palliative care and other treatment options.

Professor White and I had a submission that we think that that provision would be better out of the bill because it creates confusion and it might compromise, still, whether or not this is raised when perhaps it might be appropriate to the patient, but that is another story. I guess the other way we think that the New South Wales bill has improved the situation is about eligibility of doctors who are able to be a coordinating or consulting doctor. We think that the provisions there are much better in New South Wales. It still provides sufficient safety because the doctors are experienced doctors—either specialist doctors or had a generalist registration for 10 years. But without the requirement to be a specialist, in Victoria that has had implications for access issues for patients not being able to access specialists. It means that it does not include palliative care physicians, geriatricians and GPs, for example. I just mention those two as clear ways I think the New South Wales bill is superior. I do not know if you had anything you wanted to add to that, Professor White?

Professor WHITE: Look, I guess only just to say I think New South Wales really has followed on the Victorian lead. I know we talk about differences but it really is very much similar to the Victorian, so in that sense it is a narrow and conservative VAD model. There is an opportunity, which has been taken, to fix or tweak a few things but I still think it is very narrow. I think we can say with some confidence that some of the challenges we see in terms of patients finding it hard to get through the process—patients and families talk about the challenges of getting through, as did doctors. We will see that in New South Wales as well but I think that is a function—the price, I guess—of a decision to take this particular model.

The CHAIR: Mr Khan, do you have some further questions?

The Hon. TREVOR KHAN: The only other issue that I will raise—and it is dealt with in your submission—is the residency requirement that exists. Seeing we are the last State to jump on board, has the residency requirement now become somewhat superfluous? For context, I think one of the things that we have learned out of COVID is that there is an interaction between States in the provision of health care that is far more nuanced than I ever thought it was before we had gone through the past 12 months. What is your view?

Professor WILLMOTT: I will just jump in. I cannot see whether Professor White wants to take the question or not. Look, I think that is a really good question. When Victoria first had that enacted legislation you could see that that requirement was that there to stop euthanasia tourism, so you could understand it. But the more States that have passed legislation—I think it becomes less of a requirement. There might be policy reasons for wanting the Australian residency requirements to stay, but I certainly do think there is an argument that maybe that particular residency requirement can be removed as New South Wales is the only State now yet to have legalised voluntary assisted dying.

The Hon. TREVOR KHAN: All right. I will cede the floor.

The CHAIR: Was somebody else just about to make a contribution before I pass the questioning—

Mr BECKETT: I can make a short contribution to that.

The Hon. TREVOR KHAN: Sorry, yes.

Mr BECKETT: Really, it is a question of consistency. Those laws would not be required—those residency requirements—at least for Australians who are resident, or people who are resident in Australia or Australian citizens, unless there is inconsistency between the various States and Territories. That can be sorted out at a ministerial level; that is to say that the Commonwealth health Minister, for example, might convene the other health Ministers who would all come together and they could agree on that, and then legislation could be introduced in each State and Territory removing that residency requirement because there is, in effect, one single law, essentially, across the country. It is just a question of administration and coordination among the various State and Territory governments.

The CHAIR: Thank you. I will pass now to Ms Cate Faehrmann.

Ms CATE FAEHRMANN: Thank you, Chair. I just go back to the Bar Association and the discussion earlier in relation to the section of your submission regarding rights of persons with disability. Are you aware that the Physical Disability Council of NSW did make a submission to the inquiry?

Mr BECKETT: We were not aware.

Mr GLOVER: No, we were not aware.

Ms CATE FAEHRMANN: Just to clarify and reassure you, that submission, which is submission No. 99 to this inquiry, did make a few recommendations in terms of further safeguarding people with disability, but it does state:

> PDCN considers that the NSW Voluntary Assisted Dying Bill carefully navigates these issues and most importantly to us, contains strong safeguards to protect the rights of people with disability, via sound, rights-based principles that we can support.

That is reassuring, is it not?

Mr BECKETT: Yes, indeed, it is.

Ms CATE FAEHRMANN: That is probably all the questions I have, Chair. My other questions are answered in relation to Victoria.

The Hon. GREG DONNELLY: Can I make a personal explanation? I did not intend to mislead any of the witnesses.

The Hon. TREVOR KHAN: No; nor is anyone suggesting that.

The Hon. GREG DONNELLY: No, no, but please, to tidy up—I appreciate that—but I do apologise. I was not aware. I am sure I passed it at some stage but it did not jump out at me. I just want to clarify that I did not intend to mislead.

The Hon. TREVOR KHAN: All good.

Ms CATE FAEHRMANN: That is good.

The CHAIR: Thank you. I know Mr D'Adam has some questions but I just want to check Mr Roberts.

The Hon. ROD ROBERTS: No, no; nothing.

The CHAIR: And Mr Martin?

The Hon. TAYLOR MARTIN: No, thank you.

The CHAIR: So it will be Mr D'Adam and then the Deputy Chair.

The Hon. ANTHONY D'ADAM: I just wanted to get some views from the panel about the requirements around the first consultation needing to be in person and then the consequent workaround from clause 176 (1) (a). This arises as a result of the intersection between Commonwealth law and State law. I just wanted to perhaps give the panel an opportunity to provide some comments on that as an issue for the bill. I will have a follow-up question around the experience in Victoria, perhaps for Professor Willmott and Professor White, around whether there is any evidence that has come out around that being a barrier for regional participants in the scheme, in particular.

Professor WHITE: I am happy to start off on the point of the Commonwealth law intersection with the State law. This is something which our research team, led by Katrine Del Villar, has written on. This is something that we addressed in our submission. This is a challenge that Commonwealth law unintended to cause problems with lawful State voluntary assisted dying regimes is in place. Our submission was that if this bill is to pass, the New South Wales Government should write to the Commonwealth seeking its law to change. To some extent, because of the way that Commonwealth law obviously trumps State, there are some limitations as to what can be lawfully done. In terms of the challenges that have been experienced—so we can talk both about doctors and patients. In the paper that Professor Willmott mentioned, published in the *Medical Journal of Australia*, there were three big problems identified in terms of how the regulations work in Victoria, and this is one of those three.

Doctors spoke about the challenges of having to drive themselves long distances or, alternatively, asking very sick patients to travel as well. As part of the four-year research project I mentioned about studying voluntary assisted dying, we are partway through interviewing patients and families. Again, this has cropped up as a very significant problem. Folks were not suggesting that telehealth would be used at all times. A lot of doctors said they wanted face-to-face time and have the confidence of seeing a patient. But in Victoria, for example, their guidelines take a very strict approach with things like pharmacists having to physically visit or prescriptions not being able to be sent by email. Some of the side effects of this have been significant for access for terminally ill patients.

Professor WILLMOTT: Can I just please add that the current situation is really appalling in that patients are disadvantaged and suffering as a result of this inconsistency between the Commonwealth and State laws, and a significant burden is being placed on doctors who will travel to patients if they are unable to travel to them. As Professor White said, this is the feedback that we have got very strongly in our research. There is a very easy fix by the Commonwealth to amend its Criminal Code. It is an extremely easy amendment and it was recommended in that paper that Katrine Del Villar from our centre led.

I understand the Queensland Premier has written to the Commonwealth Attorney-General seeking an amendment so this problem can go away, and I understand that the Commonwealth Attorney-General is declining to do that and is insisting that the responsibility is on the States to pass laws that are consistent with Commonwealth laws. Unfortunately, I do not think there is much that can be done at a State level. Section 176 is a good attempt, but I think it is very confusing, not because of the drafting but because there still remains this issue of inconsistency with the Commonwealth legislation.

The Hon. ANTHONY D'ADAM: It is fair to say that this impacts disproportionately on those who are seeking to access the scheme in country areas, is it not? Is that fair to say?

Professor WILLMOTT: Absolutely. That is correct.

The Hon. GREG DONNELLY: I will return to the Bar Association and go to paragraph 63 on page 12 of your submission. I would be pleased to hear any thoughts and reflections about the matter of the elements of the New South Wales Attorney General's online publication called the *Capacity Toolkit*, which looks at the matter of capacity broadly provided for in New South Wales and New South Wales State legislation, and reflecting that into the matter of capacity as defined in the bill itself. In other words, the matter of capacity obviously is across a whole range of different domains considered under State law. But you have obviously given some serious thought to looking at what is in the toolkit and how they have endeavoured to try and explain matters of capacity. I would be keen to hear your reflections about its relevance and thinking in terms of what is in the provision of capacity in the bill before us.

Mr GLOVER: Thank you for the question. I think a witness earlier today in the Committee mentioned that capacity in a legal sense is fairly well defined and well understood. But even despite that understanding, particularly at common law when you are talking about testamentary capacity, there is always room for argument. New South Wales has quite a developed *Capacity Toolkit* which is used in a range of other legislative settings, particularly the Guardianship Act. Really, the toolkit, when you go back to our submission, does reflect what the other jurisdictions have in their voluntary assisted dying legislation. It would be my submission that the Committee in the course of this inquiry should have a look at the toolkit—particularly against what is done in Queensland and I think the other good example is Victoria and South Australia—and give consideration to it almost ensuring as much consistency with those frameworks as possible.

The Hon. GREG DONNELLY: Could we just go now to—

Mr BECKETT: Could I just supplement that answer?

The Hon. GREG DONNELLY: Please, yes.

Mr BECKETT: The import of the submission is very much around assisting to analyse and to assess capacity. The guidelines that have been the substance of an amendment in the other place is where these sorts of things—the matters that are set out in the toolkit—could also be picked up in those guidelines. It might not necessarily be something for this Committee to recommend; it might be something that is implemented by the Executive afterwards. It does not necessarily need to be the substance of a substantive amendment to the Act.

The Hon. GREG DONNELLY: Can I just take you now to the back of the bill to the dictionary, which is schedule 1 to the bill. If we go through the dictionary and if one looks at "s"—in fact, there is no "s" at all. No, there is "schedule", "self-administration decision", "specialist registration" and "supply", but there is no definition of "safeguards" or the word "safeguard". That is just a matter of fact that the bill does not define what a safeguard is. The notion of the word "safeguard" gets tossed around a fair bit in this debate over legislating for assisted suicide and euthanasia. My question is what is a safeguard and what is not a safeguard?

In fact, one could put the position—and I invite you to respond to this, taking into account you are not taking a position on the bill and I respect that; I am not asking you to depart from the position. I put the proposition that one person's view of the shortcomings or deficiencies within a bill could be seen by another person as safeguards in the bill. Or, to put it the other way around, that the safeguards in a bill could be argued from the other side as being a provision of an inertia or a break or a moderation or a restriction around access. But, really, it is a matter of how the Legislature ultimately passes the legislation, which contains within it specific provisions.

For example, if we take the Victorian situation that professors have referred to and the matter of section 8 in that legislation about the requests and the issue of consulting doctors not being specialists, which is different from the provisions in New South Wales, they could be argued from the Victorian point of view as safeguards. Presumably, if one reads the debate in *Hansard*, that is in fact what they were advanced for. But to then, after the event, put the proposition that these are shortcomings or deficiencies really is a matter of opinion, is it not? Would you agree with that statement? At the end of the day, the Legislature speaks and determines, but the matter of calling it a safeguard or not really is almost a political discussion, is it not?

Mr BECKETT: You are talking about the formation of policy with respect to the bill and then that policy of introducing safeguards. The bill is absolutely replete with safeguards and constraints placed on every stage of a very detailed process, with numerous checking points throughout that process, I would say, overseen by the board, who obtain relevant documentation at every stage of the process. As to what those safeguards might be and the constraints that are put on the decision-making, it is quintessentially a matter for Parliament to make those sorts of decisions and to weigh, first of all, whether there should be a safeguard and, secondly, the extent of that safeguard. No doubt the debate in Parliament as to whether it is appropriate or deficient is a matter for this very Committee and indeed for the Parliament itself. Having said that, obviously you have a number of eminent experts who are appearing before you, excluding myself, who will have an opinion based on experience and evidence. Professor Willmott was very strong on stating that there is a need and, in fact, a justification for having an evidence-based approach to the enactment of this sort of legislation. I will take by that an implication that ideological considerations should not be to the fore.

The Hon. GREG DONNELLY: Can I put to you that the professor referred to the research being done and undertaken, and specifically referred to a case study of Victorian doctors who are participating in the VAD scheme?

Mr BECKETT: Yes.

The Hon. GREG DONNELLY: They were the sample—the doctors who participated in the VAD scheme. As I understand, the research was not surveying doctors at large. It was specifically surveying doctors who had participated in the VAD scheme. Now, it may well be the case that those doctors who are involved in the VAD scheme have a different view; in fact, it is likely that they would have a different view about issues around its eligibility than doctors who are outside the VAD scheme. It is interesting to say that this is evidence-based research. It is a case, though, of picking what your sample is.

Mr BECKETT: If I could interpolate, I think Professor Willmott referred to the particular study. It is not one that the Bar Association would take a position on.

The Hon. GREG DONNELLY: No, no, but I am making the point. I am only taking the lead from the professor's evidence this morning that the actual sample of the doctors upon which the research and the learnings that they see drawn from that research are from doctors who participated in the scheme, not doctors at large. It seems to me that it begs the question that it may well be a piece of research that is actually producing a result that one would not be completely surprised about, because these are doctors who are participating in the scheme and no doubt have a view about voluntary assisted dying.

Mr BECKETT: With respect, there are a number of assumptions in what you have just said about that particular study. Again, if I could defer to Professor Willmott, who is no doubt itching to address that particular question.

The CHAIR: I will invite Professor Willmott to make a contribution.

The Hon. GREG DONNELLY: I have not finished my questions.

The Hon. TREVOR KHAN: Well, I think other members of the Committee are entitled to time as well.

The CHAIR: Mr Khan and Ms Faehrmann want to ask questions. Professor Willmott, if you could make a contribution, I will then pass to Mr Khan.

Professor WILLMOTT: That's correct; the doctors that were interviewed were specialists. I want to clarify that the general concern they had was broadly that the safeguards, writ large, were providing access issues. I did not say that they specifically made comments in terms of whether the definition of the eligibility of the doctors was a priority or not, but it is a general—

The Hon. GREG DONNELLY: Can I just clarify? You said "specialists". These are specialists participating in the VAD scheme. Is that correct?

Professor WILLMOTT: Yes. There were a range of doctors. In Victoria, one of them has to be a specialist, so not all of the sample were specialists. Some were generalists, such as a palliative care position.

The Hon. GREG DONNELLY: But they were all participants in the VAD scheme in Victoria. Is that correct?

Professor WILLMOTT: That is correct.

The Hon. GREG DONNELLY: Thank you. That is all I wanted to clarify.

Professor WHITE: If I could perhaps add to that, would that be permitted?

The Hon. TREVOR KHAN: If it's not on his time, it's on mine, so you're going to get the chance.

The Hon. GREG DONNELLY: I have more questions, but Trevor Khan has a question, I think.

The CHAIR: Professor White, I will allow you to make a contribution and then I will pass to Mr Khan.

Professor WHITE: Look, the key thing there is that the research question was, "How is the system working?" The only sensible group to interview were those who are actually involved in voluntary assisted dying. That was listed as a limitation of the research. The study is with you; it was sent through as a submission. The limitations of the study, as per usual research conventions, have been fully disclosed. But that is the only sensible sample to talk to. The sort of study that you spoke about of sampling all doctors who do not have engagement with or understanding of the system would not advance understanding on that.

The Hon. GREG DONNELLY: Well, can I ask this question?

The CHAIR: I must pass to Mr Khan because he has indicated—

The Hon. TREVOR KHAN: No, no. If Greg has a further question, I do not want to be in any way accused of stifling debate.

The Hon. GREG DONNELLY: It seems to me that if we are talking about this issue of—I will use quotes—"safeguards" and whether they are at a particular level or need some modification or refinement, I do not understand why you would only choose doctors participating in the scheme. Doctors at large—namely specialists not participating in the VAD scheme or general practitioners not participating in the VAD scheme—may also have views about the matter of the safeguards. They may well be quite contrary views in terms of—the safeguards are not high enough. They may engage with you over concerns that they have with respect to the fact that the safeguards are not rigorous enough. To essentially use a subgroup who are only supporters of the legislation seems to be quite jaundiced.

The CHAIR: I rule that last comment out of order. I am going to provide Professor White an opportunity to respond. I note that the time is almost finished and we do have participants who have a one o'clock freeze.

The Hon. GREG DONNELLY: The word "jaundiced" was not appropriate. "Skewed".

The CHAIR: I am going to rule that out of order as well. We are not going to draw conclusions. I am going to ask Professor White to make a contribution, please.

Professor WHITE: I am also conscious of time. I would just invite the honourable member to read the study.

The Hon. GREG DONNELLY: I have.

Professor WHITE: According to research conventions, it contains appropriate limitations. I am not sure there is much more I can say about that.

Professor WILLMOTT: Could I just add that it was published in *The Medical Journal of Australia*, a peer-reviewed journal. I will say nothing further and let the Committee draw its own conclusion.

The CHAIR: We have very little time left. Mr Khan, do you have something quick that you wanted to clarify?

The Hon. TREVOR KHAN: Just very quickly, I will put this to Mr Glover and Mr Beckett. I think this is within your area of expertise. There was a question asked earlier with regards to clause 6 and the presumption in favour of capacity. If you look at such cases as *Hunter and New England Health Service v A*, which was an advanced care directive case—I think you knew that, but others might not. That case reinforced the view that at common law there is a presumption in favour of capacity, did it not?

Mr GLOVER: Yes.

The Hon. TREVOR KHAN: Indeed, if you look at those advanced care directive cases, apart from the patient having capacity, really those cases which deal with the capacity of people essentially terminating their lives through the direction of the removal of medical care, including food, water, et cetera—none of the safeguards that are contained in this bill apply to the making of an advanced care directive that may achieve precisely the same result. That is right, is it not?

Mr GLOVER: Yes, that's right.

The CHAIR: On that note, I note the time. We are about to pass one o'clock. I thank all the witnesses for appearing today. Thank you very much for making yourself available. For the questions that have been taken on notice, the secretariat will be in contact with you to liaise about their tabling. We will now have a lunch break and return at 2.00 p.m.

(The witnesses withdrew.)

(Luncheon adjournment)

ROBERT MARR, Vice President, Doctors Reform Society, affirmed and examined

DAVID LEAF, NSW Convenor and National Co-convenor, Doctors for Assisted Dying, affirmed and examined

GAVIN PATTULLO, Senior Staff Specialist Anaesthetist and Pain Medicine Physician, affirmed and examined

The CHAIR: Thank you, everyone, for returning to this afternoon session of the hearing. Do all three of you have an opening statement? If so, would you like to start, Dr Pattullo?

Dr PATTULLO: Yes, I think we all have opening statements. I am happy to start. Thank you very much. Clearly, the VAD discussion encompasses the areas of pain and suffering. I certainly am grateful for the opportunity to speak to the Committee about those topics as that is an area of my expertise and knowledge. I have been very fortunate in my career that I trained under and then worked alongside Australia's foremost pain management expert, who was world renowned. He did actually write the textbook on pain management. More importantly though, I am actually here to be the voice for my wife, Dr Venessa Pattullo, who, at the age of 42, three years ago took her own life. That was after 14 years of living with recurrent aggressive leukaemia, the treatments for which had left her severely short of breath because it had damaged her lungs—a known side effect. She faced a death by asphyxiation.

Venessa had not been beaten by a cancer. She had not given in. It was quite the opposite, in fact. She took the upper hand and she took control. She beat it at its own game. On 2 July 2018 I went off to work like any other day, thinking that I would come home to see my beautiful wife. I did come home to find my beautiful wife, but she was no longer alive. Venessa had been forced to take her own life alone and without saying goodbye to her loved ones because of the laws of this State. I always knew my wife was going to die before me. But I wanted that day to be with me holding her hand and her holding my hand, so we both knew everything would be okay. Thank you for listening to Venessa today.

Dr LEAF: I am a practising GP with 27 years' experience in that specialty and 31 years' as a doctor. I have both Australian GP specialist fellowships and postgraduate advanced diplomas in emergency medicine. I have worked in three countries, including four tours of duty overseas with the Royal Australian Air Force and the United Nations. I am also a medical educator, training urban and rural GPs with roles in assessment and curriculum development, for the college of rural medicine. I am also an expert reviewer for the *Australian Journal of General Practice*. Most importantly, I am currently providing palliative care and end-of-life care for patients through my practice in their homes, in nursing homes and in hospitals. I have often known these patients and their families for many years. I live in their community. I am currently the only New South Wales active campaigner for assisted dying choice who is currently engaged in palliative care, although I know many of my colleagues sympathise with our cause. I have been campaigning for assisted dying for 18 years after seeing two horrific deaths where palliative care was unable and, in some cases, unwilling to assist.

I speak on behalf of our group, the Doctors for Assisted Dying Choice, which is a national and now an international body, having a chapter in New Zealand. I support this bill for the following reasons. It will assist my profession to offer the full suite of options for patients at end of life. Some patients want this as the least worst option. It allows them to take control and to be assured that their death will come in a timely and peaceful manner when they can withstand no longer—something that my colleague Dr Pattullo's wife was unable to take advantage of. I support their autonomy. The third reason that I support this bill is, like any other medical intervention or treatment choice I offer my patients, it is now supported by international evidence and a wealth of national evidence from our country. And when I say "support"—it supports the utility of this method and the safety of this intervention. I must evaluate these interventions that I give my patients as a scientist and a physician and I am satisfied that it is safe.

Dr MARR: Thank you, Mr Chairman and honourable members of the Committee. The Doctors Reform Society supports the legalisation of voluntary assisted dying in New South Wales and strongly opposes any amendments that would make it more difficult or onerous for terminally ill people to access the law of voluntary assisted dying. I have been a GP in New South Wales for over 40 years and I have had, unfortunately, many conversations with terminally ill people about what they want. Most of them say they want to know a bit about how they might be going to die. Most of them want to die at home. Some of them say to me, "Please don't let me suffer, Doc." Tragically, most terminally ill people in New South Wales die in hospital and they often have distressing and difficult deaths.

Some of you may be aware of the article written by Professor Chris O'Brien's daughter about his last three days. Now, you would think a professor with a terminal illness—a professor of neurosurgery at the Prince Alfred hospital—would be able to organise a decent death. Well, he did not have a decent death. Professor O'Brien wanted to die at home. He had organised palliative care to give him a palliative care bed. That is what they had given him—a palliative care bed. He woke up one morning and he had bleeding from his head and cerebrospinal fluid leaking out of his brain. He knew, as an experienced neurosurgeon, that he was going to die and he wanted to die at home with morphine. So he did the logical thing and he rang his GP and said, "Can I have some morphine?" The GP was away; it was a locum and he said, "I am too busy to come and see you." So then he got his wife to ring the ambulance.

The ambulance arrived and he said, "Look, I am Professor O'Brien. I am dying. I just want some morphine." They said, "Well, we do not have any morphine. You have to ring an intensive care unit [ICU] ambulance for that." He rings an ICU ambulance. They arrive. So he has got two ambulances at his place. He said, "Look, I am Professor O'Brien. I am dying. I have got the palliative care bed here. I just want some morphine so I can die at home." They said, "Oh, we cannot give you morphine like that. You have got to go to hospital if you want morphine." Then he said, "Why do I have to go to hospital?" They said, "Well, we are not allowed to give you morphine at home just if you want to die." I do not know whether they said it could be assisted dying or whatever but they said, "It is illegal. We cannot do it."

He said, "Alright, so I have got to go to hospital?". They said, "Yes." "That is the only way I can get morphine?" "Yes." So they gave him some morphine and he agreed to go to hospital. They took him to Prince Alfred. He spent the next two days, according to his daughter, quite in some suffering, but they were there in hospital. They gave him the best treatment they could, no doubt—probably morphine and all sorts of things. They were all gathered around for over two days waiting for him to die. In the middle of the night he sits up and they think, "Oh, he is going to say something." He just vomits profusely and then collapses back in bed. Then, shortly after that, he died. That is Professor Chris O'Brien, who we named that hospital after. If he cannot get a decent death, who can in New South Wales?

I became personally supportive of voluntary assisted dying through my father's death. My father died of motor neurone disease. Before I had thought about voluntary assisted dying, I used to think maybe palliative care can ease all the suffering of dying people. But then I thought about my father, and he did not have, really, any pain. He was just suffocating to death, and palliative care could not have eased that. I know palliative care cannot relieve all the suffering of terminally ill people, and most palliative care doctors will tell you that.

Even Professor Ian Maddocks, who is regarded as the grandfather of Australian palliative care and was Senior Australian of the Year in 2013—one of his quotes is, "Voluntary assisted dying can be good medicine" when it is seen as part of palliative care. That is what he views: It is a logical path. I know from my discussions with patients that they want to know when it really gets to the end of their life somebody is going to be there who will not just leave them suffering. I guess at the end of the day this law is not really about doctors or even politicians. It is about empowering terminally ill people, which could be any of us one day, to have the legal right to decide how much suffering we have to go through at the end of our life.

The CHAIR: Thank you very much for those submissions. I will now open for questioning.

The Hon. ANTHONY D'ADAM: I want to ask specifically around the submission in regard to the experience in Western Australia. I have a question about the operation of clauses 59 (7) and 68 (1) of the New South Wales bill. Those provisions around the supply of the lethal medications were not in the Western Australian Act. I wonder if you can elaborate on that particular provision, the experience in WA and why you think the provisions in the New South Wales bill are appropriate and necessary?

Dr LEAF: Could you elaborate the question, please?

The Hon. ANTHONY D'ADAM: This is in relation to authorising agents and contact people to prepare the supply of the lethal medication for self-administration. The submission says that this proved a problem in WA, and I wonder whether you might be able to elaborate.

Dr LEAF: Our group has a Western Australian section. To my knowledge the biggest problem in Western Australia at the moment, having only been in operation since the middle of the year, is that the distances involved in Western Australia. It is centrally located, the pharmacy in Perth, of course. Getting the medications moved to wherever it is needed can be a problem. Secondly, the number of doctors who are involved in assisted dying, whilst growing rapidly and satisfactorily, is fairly small at the moment. Last time I heard, it was something like 40 to 50, so the number of doctors involved is a problem for prescribing and getting the process moving.

The Hon. ANTHONY D'ADAM: I asked earlier about terminal sedation. Will you give the medical profession's perspective on terminal sedation and why it is not an appropriate alternative to voluntary assisted dying?

Dr LEAF: Terminal sedation is not what we are talking about here. Terminal sedation is a change in the treatment of a patient who is actively dying, and it is usually used fairly imminently—where death is imminent.

Their symptoms—often pain but sometimes shortness of breath, like Dr Marr was talking about—are unable to be controlled by escalating medication doses. The doses, usually morphine or other drugs like midazolam, are increased well above what we would normally use for non-dying patients. The acceptance is made that that increase in dose will cause their death. It is done in consultation with the treating team, with the patient if possible—sometimes it is not possible because they are comatose or delirious—but certainly with their loved ones.

It is often an expression of their advance health care directive, if they have one. Failing that, if it is plain common sense that that should occur—if they are very elderly with advanced disease and any further curative treatment is futile—then terminal sedation occurs. That is a different scenario to what the New South Wales bill is talking about. I would like to just make the distinction to help you understand that a little bit from the medical profession. The ideal assisted dying conversation occurs with someone like me or Dr Marr or Dr Pattullo in the cold light of day in an office, where there is no time imperative occurring, where there is an open and honest conversation that can occur—with or without the patient's relatives, as they want—where the patient is competent, as opposed to in the last few days where someone is actively dying. If we have got to that stage, we have missed the boat.

Dr MARR: On the topic of terminal sedation, as doctors we know that there are plenty of documented cases of people coming out of terminal sedation, so it is not a guaranteed thing that people stay unconscious. There are documented cases of people coming out saying, "Am I dead yet?" It is not a guaranteed way that a person is going to die, because you have to titrate the doses and people get used to them. Because of the law, a doctor cannot actually give a lethal dose. You are gradually increasing the dose, and some people have different responses. But there is a bigger issue here, really. Terminal sedation is something that doctors do to patients, and that is not really what voluntary assisted dying is all about. What this law is about is empowering terminally ill people, which could be any one of us one day, to decide for ourselves. It is not up to the doctors; it is not up to the priests; it is not up to the politicians. It is up to us, as individually terminally ill people, what we want to do at the end of our life. That is what voluntary assisted dying is all about. That is why it is totally different from doctors administering terminal sedation, which may or may not help end a patient's life.

Dr LEAF: I was going to give you an example of a case where this might illuminate it for you, and pictures paint a thousand words. It was the first case that ever got me involved in the assisted dying cause. It occurred in 2003 with a fellow called Ian, who was a local businessman in his fifties. He had a cough. I saw him one day and got a chest x-ray, and his lung was full of fluid on the x-ray. He said to me, "That's mesothelioma, David, and I want you to help me die." This is 2002. I spun around and said to him, "Hang on a minute. Slow down here." It turned out that he had helped his father, who had died from mesothelioma 20 years before. His father had died a horrible drowning death from mesothelioma. It is an asbestos-related lung cancer; it is horrible. There was no cure and there still is not, 20 years later. Ian had helped his father wash his boiler suit when his father came home from the factory. Ian had acquired mesothelioma; he knew it. He could see it, a non-medical person. I told him I could not help him; I would be there for him.

Long story short, and about eight months later Ian was drowning in his own lungs. The tumour had eaten through his chest wall where a biopsy had taken. It had involved all the intercostal nerves, and he was not only in agony every time he breathed but he was drowning. He was short of breath. He knew what was coming and he had known for eight months, ever since I had shown him that chest x-ray. Colleagues like Dr Pattullo, who are pain specialists, were unable to help him. There was not a specific treatment for that, and even these days it is enormously difficult to treat. The palliative care team were unable to help him. There was nothing they could do to relieve his symptoms. The radiation oncologist could not help him; the surgeons could not help them. I was stuck in my country town with a palliative care team, trying to give him doses of morphine, and the palliative care team would not let me increase the dose. Even though I was the doctor in charge and there was a palliative care physician at a distance in Newcastle, they would not let me increase his doses to a level where his pain, to him, was relieved.

I will never forget Anzac Day 2003, when I visited his home. I happened to be on call that day, and I will see his face to the day I die. He was sweating, terrified and in agony and so were his family. So I started terminal sedation for him, which he was able to get comfort from and relief for three weeks. So we sacked the palliative care team through consultation with his family and he had comfort for three weeks until he passed away. That was terminal sedation. What he wanted had been eight months before, or at least to have the option.

Ms CATE FAEHRMANN: I think Dr Leaf explained it pretty well then. But also Dr Marr you talked about the patient's agency and how empowering it is and their ability to, at a certain point in time when they know potentially what is ahead of them, be able to avoid the worst of it. Dr Leaf, you said that is with the consent of the patient in terms of terminal sedation—I assume by the time you are getting to terminal sedation that is often a difficult thing to get the patient saying, "Yes, I am okay—

Dr LEAF: By definition. Absolutely. Their disease is well advanced, there is multisystem failure, they may be demented and they are not the patients we are talking about here. They may never have had capacity. And, may I say, terminal sedation happens all day, every day, in every hospital in our country and around the world.

The Hon. GREG DONNELLY: Thank you gentlemen for coming in today. Dr Leaf, can I just ask you, with respect to doctors for voluntary assisted dying choice New South Wales, that is a membership-based organisation?

Dr LEAF: It is.

The Hon. GREG DONNELLY: How many members do you have in New South Wales?

Dr LEAF: Is that relevant?

The Hon. GREG DONNELLY: Yes, it is. It is my question to you. You are here appearing on behalf of an organisation as a spokesperson. I would like you to let us know or tell me specifically—

The Hon. TREVOR KHAN: Point of order: Apart from this inquiry being into a bill, if we go down this line, on Friday do I ask—

The Hon. GREG DONNELLY: You may.

The Hon. TREVOR KHAN: I am taking a point of order. Everyone who comes along, "How many people do you have in your organisation? Are you kosher in some way?" And I think what we will do is denigrate both the witnesses and also the quality of the evidence that we receive. I just genuinely ask that we carefully navigate this without ending up crucifying witnesses who are coming here genuinely, on both sides.

The Hon. GREG DONNELLY: Let me make it very clear: It is a very specific question.

The CHAIR: I am going to make a ruling on this.

The Hon. GREG DONNELLY: You haven't even heard from me.

The CHAIR: I am going to rule. The ruling I am going to make is the question was in order. However, I will caution all members that this is somewhat of a Pandora's box. This is opened up here; as Trevor said, it can be opened up elsewhere. I would also caution that this is an inquiry about the bill and I have allowed a little bit of latitude around this but I would just ask, Deputy Chair, that you perhaps reconsider the question. If you still want to press it then that obviously may open up a number of issues later on.

The Hon. GREG DONNELLY: That is okay. We have various doctor organisations appearing before the hearings. You are one of them—your organisation—and Dr Marr, your organisation. It is fair and reasonable to ask the question about the size of your membership in terms of its voice into this debate.

The CHAIR: When you have finished your question, I just wanted to remind witnesses as well that they can take the question on notice. That is the other option I was going to make.

The Hon. GREG DONNELLY: My question is with respect to the membership of your respective organisations Dr Leaf, doctors for voluntary assisted dying choice New South Wales, what is its membership in New South Wales?

Dr LEAF: It is several dozen. I have not counted recently. But I may say that since the last six months our numbers have swelled.

The Hon. GREG DONNELLY: Several dozen is your answer. Is that the answer?

Dr LEAF: Yes.

The Hon. GREG DONNELLY: Dr Marr, with respect to the Doctors Reform Society, I presume that is the New South Wales branch. How many members do you have?

Dr MARR: We have got about 100 members.

The Hon. GREG DONNELLY: Moving on then, could I just ask this question about the issue of pain, because we were talking about pain. We obviously have at the table here some people with some quite significant experience with pain and pain management. Do you agree—and the question is the same question to all of you and you can answer as you see fit but it is directed to all of you—that suffering pain diminishes voluntariness with respect to decision-making? So the experiencing of pain, does impact—shall I say, it can impact and clearly if the pain is strong pain it is probably on balance likely to impact—on the decision-making of an individual?

Dr PATTULLO: I am happy to answer that one for you.

The Hon. GREG DONNELLY: I am actually asking all three of you. So we can start with you.

Dr PATTULLO: I will start. I am an anaesthetist. I have put in several hundred epidurals into ladies in labour and they are all suffering in pain—in extreme pain. And I do a consent for every one of them, either verbal or written. And those all hold up in court. So that is my answer.

The Hon. GREG DONNELLY: No. Sorry, I think you misunderstand my question.

Dr PATTULLO: Can you explain it further then?

The Hon. GREG DONNELLY: I cannot be any clearer than putting it the way I did. With respect to the experiencing of pain, an individual experiencing pain, a human being experiencing pain, do you agree with the proposition that the experience of pain—and let us assume it is a very mild pain, like pricking your finger with a needle, on a scale right through to that sort of existential pain that we are talking about in the context of end of life, looking at the end-of-life pain, that very serious pain at the end of life—can and does impact potentially on the voluntariness of the decision-making of the person about what to do in their circumstances.

Dr PATTULLO: I am not really sure that that is a really appropriate question. I think at that sort of stage of life, where you are suffering that much—

The Hon. GREG DONNELLY: Excuse me.

The CHAIR: Deputy Chair, he must be able to complete his answer before you interject, please.

The Hon. GREG DONNELLY: He said it was not an appropriate question.

Dr PATTULLO: I think if someone is suffering that much, then they are going to be on a lot of mind-altering medications at that point, so you are kind of clouding the question or clouding the answer when you put it like that. Really that is why I said to you about ladies in labour, who are in extreme pain, that they are capable of giving a consent.

Dr LEAF: Mr Chair, may I seek leave to answer slightly obscurely and then I will directly answer the Deputy's question?

The CHAIR: Very much.

Dr LEAF: Can I say that the international evidence is that pain is about the third or fourth symptom which is responsible for patients in the surveys accessing assisted dying around the world. It is not in the top two or three; in fact, in Oregon it is number four.

The Hon. GREG DONNELLY: Thank you for that. That is very important evidence.

Dr LEAF: In front of that is existential crisis and losing autonomy. Those two are the main reasons patients want to access assisted dying choice. In relation to the Deputy's question, when you actually understand, as doctors do—and they have to—the tests for capacity, it has nothing to do with pain. In fact, technically patients who have slight cognitive impairment, which we are not dealing with here today, can still have capacity for specific decisions. So the test of capacity is that the patient can understand what you are saying, they can weigh up the decision, they can then communicate back to you in a reasonable way what their decision is. Pain will certainly get your attention and particularly if it is a horrible, unremitting pain like my patient Ian that I mentioned. But it does not affect the medical or legal definition of capacity.

The Hon. GREG DONNELLY: I understand your answer but my question was going to this point, to follow on. We are dealing with the issue of outside of Newcastle, Sydney and Wollongong—many citizens of this State who just do not have access to even the most basic of palliative care. In fact, towns around the State do not have a GP.

So we have got people in those communities dying today, tomorrow, yesterday, in a week's time, in circumstances of reasonably challenging pain because there is just no palliative care. I am trying to understand, in those circumstances where that is a matter of fact—and no-one is really contesting that, as far as I can tell—that that has the potential to impact on their decision making because they cannot access the palliative care that otherwise would be reasonably available, certainly in the big population centres around New South Wales. For me, that is a matter of concern in the context of this sort of legislation, because we are not talking about delivering Rolls Royce palliative care to every last citizen in the State; we are talking about citizens in country New South Wales where there is not even a GP in the town to provide the most basic of pain relief.

Dr LEAF: I am a rural generalist. I have spent many, many years working in the country. I educate rural doctors. So I am acutely aware of the problems accessing all kinds of medical services, not just palliative care. But may I remind you, Mr Deputy Chair, that at least 80 per cent of palliative care in this country is delivered quite competently by general practitioners—rural or city. That is the first thing. The second thing is that if I was a GP in one of those rural towns, the very first thing I would be telling that patient is what their full suite of options are in the ideal world, as it would be for anything, and one of those options is the benefits and boundaries and limits of palliative care. Palliative care is just like every other specialty I work with on a daily basis—whether it is cardiology, dermatology—and it has its limits. Palliative care is great but it is not magic.

You cannot, Mr Deputy Chair, relieve existential suffering or lack of autonomy with a morphine drip. I have seen it; you cannot do it. If a patient that I was working for in west Goondiwindi or somewhere where they could not get access to the pain relief they need—it is not a default setting then just to give them a magic green pill. The default setting there is to get them to somewhere where they can access adequate pain relief.

The CHAIR: I am just about to pass to the Hon. Trevor Khan for some questions and then I will be asking some myself. Mr Khan?

The Hon. TREVOR KHAN: I am happy to, but you have not had much of a go in any so far.

The CHAIR: Thank you, Mr Khan. Dr Pattullo, I was very moved by your story—not only your submission but you had an article in *The Sydney Morning Herald*, I believe.

Dr PATTULLO: Thank you.

The CHAIR: It was particularly moving. And I noted in your opening address today that you said you were going to be a voice for Venessa. So I wanted to give you that opportunity. Did you have the opportunity to speak with her about what it was that she would have elected to do? Were you aware of what her choices would have been had she been given the opportunity? I am keen to know, through you, what her choices would have been for herself had she had them.

Dr PATTULLO: Thank you. It is obviously quite personal, I guess. It is also very hard—I mean, everyone is in love with their partner. Venessa was an amazing human being. I have never met anybody like her—the smartest person I have ever met. She already had a worldwide reputation in her field. We all thought she was going to be a professor of medicine one day. You could not get anything past her. She had worked most of her life in a hospital; she had seen everything. She had worked on palliative care wards, she knew what palliative care wards were about, and I think that is a really key message when you have got someone like Venessa—super smart, super compassionate, super caring. She chose to die alone without saying goodbye to her loved ones, and that was for a really, really good reason: She knew what the alternatives were. She did not want to die in a hospital; she knew what it would be like.

We have seen it as doctors; it is a stat that we all know. Most doctors refuse most of the medical therapies that are available because we know what they are like. The public does not know what they are like and we tend to refuse them. And that is what you saw with Venessa. She said, "I'm making a choice doing it at home." So I think it is very clear what she would have chosen if VAD was available. She has shown you what it was that she would have chosen because she did it herself; it is just that it was not legalised and she could not say anything to me or to the rest of her loved ones for fear of insinuation, of involvement—

The CHAIR: Incrimination as well.

Dr PATTULLO: Incrimination, insinuation—that is why she did that. She knew that she could not put any of us at risk of that. And yet I think it is a tragedy. It is an absolute tragedy. It burns my heart to think of her walking up the stairs to our bedroom knowing that that was the last time she was ever going to walk up to the bedroom, that I was going to find her on that bed that night when I came home. Do not be too sad; it was beautiful. She was the most beautiful girl I have ever met and on the day of her death she was still the most beautiful girl I have ever met. It was just beautiful.

Dr MARR: Can I just add something?

The CHAIR: Please.

Dr MARR: I have often thought that, as doctors, we see quite a lot of people die and we know that in most cases actually it is not very pleasant, and this is the thing that most people do not realise. I have always thought it would be really good if you died twice because you would say, "Well, I don't want that death again." In most cases deaths are not pleasant. They are distressing, discomforting and upsetting. We do the best we can in hospitals but, honestly, most deaths are not good. If people died twice we would have had voluntary euthanasia years ago because people would come back and say, "Well, I'm not going to bloody die like that again." Most deaths are pretty bloody awful even with the best palliative care.

Dr LEAF: Mr Chair, can I make a point, please, in relation to my colleague's moving story? I have been in contact with my counterpart in the United States, Dr David Grube, who was one of the original doctors in

Oregon who has been involved in assisted dying for 24 years. He came out to Australia in 2019 to assist us with the Western Australian debate and he made a really interesting point, having lived through both sides of the legalisation prior to the legalisation in 1997 and since. He talks about the differences in the families left behind between the two types of deaths, and I think it is something that we need to be, as a community, mindful of.

In those families who have had to come home to find their loved one deceased—and it sounds like my colleague had not as bad an experience of that as some families get, where the person has some sort of horrible end or it has occurred in a surprising way—compared to those deaths where assisted dying has been able to be achieved, Dr Grube has said repeatedly that the families left behind, and especially children and adolescents, are much better off for the rest of their life. You can imagine coming home to find your father or loved one dead in some grisly way compared to having the opportunity to set a date, you know it is coming, the person dies peacefully, there is some music, you get to hold their hand, you get to have a cry and say goodbye. What do you think will be the difference for that community?

The CHAIR: I know Ms Faehrmann had a follow-up question. I have got one more after that and then I will pass to Mr Khan.

Ms CATE FAEHRMANN: Thanks, Chair. It was just in relation to—and I think it is a really important point; I know, Dr Leaf, you have spoken about it before—the fact that, I think, one-third of terminally ill patients who get approved and are able to access a life-ending drug under the scheme in Oregon and, I think, in Victoria—

Dr LEAF: Still.

Ms CATE FAEHRMANN: —they do not end up using it and it is that whole peace of mind.

Dr LEAF: Correct.

Ms CATE FAEHRMANN: I think, Dr Pattullo, maybe it is relevant for you to answer this as well in terms of the peace of mind: that, if Venessa had that, no doubt you would have had probably many more days with her. I do not want to say that as an expectation, but that is what is happening for at least one-third of people.

Dr PATTULLO: Yes.

The CHAIR: That was the question I was going to ask, thank you.

Ms CATE FAEHRMANN: Sorry, Wes.

The CHAIR: I think we are on the same page. You are spot on.

Dr PATTULLO: I was just going to more comment on what my colleague David Leaf was saying, that when it is essentially illegal—what my wife did was illegal so I could not access any counselling services. I do not think I have done too badly. You will not find me wandering down the street at 3 a.m. in my pyjamas, yelling out her name. I think I have coped quite well, but I do not think people always have the sort of resources I had available. I have got a very deep medical-community colleague group who were extremely supportive of me but I did not access formal counselling services, which I think people should be able to do.

I was too scared to see a psychologist for fear that they would have to mandatory report me for a concern that I may have been involved. So I kept quiet to any proper professional, and I only talked to my friends about it. You could imagine, people who are isolated, what devastation that is going to cause them. I can tell you I carry a lot of guilt about going off to work that day and missing things. So you could imagine someone who has not got those resources available to them. You are leaving this collateral damage, not just the person who has died. There is all this other collateral damage. You bring it into the open, get proper counselling, it is so much better for our society.

Dr LEAF: But also the preparation for the event, as I was trying to describe it. Thanks, Cate, for bringing that up. That is why our group would actually prefer to see the qualification period of six months be extended to 12 months because, as we know, 30 per cent, 40 per cent of patients do not take the medication, but they all say, internationally and now in Victoria and Western Australia, that having that medication in the cupboard gives them the power. It is palliative care all by itself, having that there, because they know that if things get really bad they can take it. If you wait six months, often the disease is more advanced. It gets harder to prognosticate. At 12 months, you are allowing that medication in the cupboard all by itself to have a palliative effect.

Dr MARR: I think that is the most important thing—that this is really about empowering terminally ill people. Quite often, in up to one-third of cases, people do not use or do not access the lethal dose, even though they have been approved for it, but it gives them that reassurance. That is really what voluntary assisted dying is all about—empowering terminally ill people. I am always surprised that, like in Oregon where it has been legal for over 20 years, less than 1 per cent of deaths use voluntary assisted dying. Even in the more liberal States like

The Netherlands, it is only about 5 per cent. Very few people actually use it, but it is very strongly supported because most people really would want that option just in case. It is like an insurance policy. First of all, the policy is there, it is legal. Then if you get approved—if you have a terminal illness and you go through all the process and you get approved and you actually have that lethal dose you might not choose to use it because it is still—

The CHAIR: Instead, one-third of those who are approved will not use it. They pass away—

Dr LEAF: Yes, they die with it still in the cupboard.

Dr MARR: Yes, but it gives them great reassurance. Often they live longer than they might have otherwise, and they do not have to take their own lives in all sorts of desperate ways.

The Hon. TREVOR KHAN: In a variety of the emails that we have received, and no doubt in the evidence I suspect that we will receive tomorrow, one of the assertions made is that because a person has received a diagnosis of, for instance, cancer or some other life-terminating illness, these people are depressed and therefore lack capacity to make an informed decision in the context of VAD. I wonder if you would like to comment, as doctors and, Dr Pattullo, quite frankly in terms of a personal experience, as to whether that concept of being depressed as a result of the diagnosis is a valid basis to say that people are not actually making a rational decision.

Dr LEAF: Can I please answer that? There is a big difference between being clinically depressed and being unhappy.

The Hon. TREVOR KHAN: I actually do understand that difference, but it is good that you point it out.

Dr LEAF: I understand that you do, Mr Khan, but I think some people do not. You can be very distressed about the diagnosis. Most people would be, let us face it. But to then stretch it to say that they are so depressed that their clinical decision-making is affected almost never occurs. If we examine the patient, as doctors, and we feel that they are exhibiting significant signs of actual major depression such that their cognition is impaired, then I will guarantee that I will seek assistance from a specialist involved at that point. But I have never met a patient in whom I have diagnosed cancer—and I did it last week for a young lady—who is anything other than distressed and unhappy. But I would not go so far as to say that she is depressed.

The Hon. TREVOR KHAN: Dr Pattullo or Dr Marr?

Dr MARR: I do not think being depressed necessarily removes capacity anyway. I think a lot of people are depressed and they can still make a rational decision. Even if a person was depressed, you could still clinically assess their situation. If it was primarily due to their terminal illness, that is quite rational and reasonable. Probably a lot of us would be depressed if we were going to die within a few months. So it does not mean that you cannot choose to end your suffering. If you are going to die anyway and you also happen to be depressed, what are you going to do? Are you going to force them to stay alive and force antidepressants on them? Basically this whole law is about empowering terminally ill people, not forcing them to endure more suffering. If they are going to die anyway from their terminal illness, we are just enabling them to have the power to legally choose to end their suffering and not to linger on and force them to suffer more.

Dr PATTULLO: Can I just add, sort of on a counter argument, two days before Venessa ended her life we were out celebrating her forty-second birthday at her favourite restaurant. She almost wiped me out, spending money on expensive French champagne by the glass. She was not sad, I can tell you that. She was very—maybe it was because she knew what she was planning. I do not know, but certainly for her I did not pick that she was down or whatever. I think there is a whole spectrum that we are going to see for patients with this sort of diagnosis.

Dr MARR: That has certainly been the experience around the world where voluntary euthanasia or voluntary assisted dying has been legalised—that there is great relief amongst the terminally ill people once they know that they have a mechanism, that they can end their suffering. Then quite often, almost miraculously, many of them do not use it because they have that reassurance: that that thing they feared the most—a horrible death—they are not going to necessarily suffer that and so they often prolong their life and they have a deep sense of relief.

The Hon. TREVOR KHAN: My only other question is this. One of the common arguments put against VAD is—I will shorten it to say elder abuse. If the law passed, how would you, as a treating physician, attempt to deal with and assess coercion of elderly patients?

Dr LEAF: Can I tell you what I do with any vulnerable patient, whether it is a teenager, a refugee, a mentally ill person or an elderly person or a dying person? After you have assessed that they are able to talk to you and they are of reasonable, sound mind, you ask them how they would like you to talk with them about a really delicate topic. This is how we train our registrars, by the way. We offer them—they can talk alone or they can talk with a loved one with them. If I have the slightest suspicion, I ask to speak to them alone. Sometimes if it is a teenager, I will get a nurse chaperone in with me so there is no suggestion of anything improper. If you talk to them and say, "Look, I need to ask you this. Are you being coerced? Is there any pressure on you whatsoever to make a decision you are not comfortable with? I need to know. Can you tell me?" I have never spoken to a dying person who has said they are under any pressure. It has never happened. But can I flip it round? If you were a family member and you were so evil that you wanted to knock off that grandmother for financial gain or something, how will you do it?

You will do it in the dark. You will not subject them to an open, transparent, accountable, government-sponsored process, with lots of people watching. You will do it in the dark in some way. I have not even thought about how you do it, but you would not do it through this process. The international evidence is that it does not happen.

The Hon. TREVOR KHAN: Would any of the other two witnesses like to comment on that assertion by Dr Leaf?

Dr MARR: Well, that is the international evidence. This has been one of the accusations by opponents for years. In the jurisdictions like Oregon, where it has been legal for over 20 years, and the Netherlands, they looked for all that sort of thing and they have strong ombudsman protections and, looking into it, there does not seem to be any evidence in that way. There are strong protections, of course, in the law, like we have here.

Dr PATTULLO: Again, you would have to convince two doctors of your argument. It is a pretty tall order to get it through two doctors, separately, who are not allowed to talk to each other. It is just impossible.

The Hon. TREVOR KHAN: Yes, thank you.

The CHAIR: I know we have only got about nine minutes left, so I will allow Ms Faehrmann to ask another question, then I will come back to the Deputy Chair.

Ms CATE FAEHRMANN: After conversations with your colleagues in other States where voluntary assisted dying has been legal, I just wondered what their feedback is, whether there are any lessons from what their general view is in terms of how it has changed, the way in which they treat dying patients—just anything you can tell the Committee about that. Dr Leaf, I know you are on the national, is that right, voluntary assisted—

Dr LEAF: I am the national co-convenor.

Ms CATE FAEHRMANN: Yes.

Dr LEAF: Thank you. In fact, I was talking to Dr Cameron McLaren last night about this very issue. I believe he is giving evidence for you on Monday, so he may be better to speak to about that because he is literally the horse's mouth, if you will pardon the pun. Essentially, there are a number of minor procedural problems with the procedure of gaining approval, some people waiting too long. A significant number of patients—I forget the number he told me—will actually die whilst waiting for approval. He asked me to emphasise that if you wait for six months, the six months qualifying period, a number of those patients will actually lose capacity because the disease is more advanced and so you are actually denying them access to it by relying on some arbitrary number. For example, he cited a patient who went through the approval process and the pharmacist who delivered the medication telephoned him, when the patient was having the medicine delivered, to say that the patient had lost capacity. So everything stopped right there. So that is a tragedy, because that is just a procedural barrier which should not occur. But may I suggest that that question would be more effectively dealt with by Dr McLaren.

Dr MARR: I might just make a comment on that. There is some research from overseas about doctors' attitudes to voluntary assisted dying, and the research shows that when it is illegal—before voluntary assisted dying becomes legal—the medical profession is often split fifty-fifty or 60 per cent against. As soon as it becomes legal, the majority of doctors support it. You will get something like at least 60 per cent of doctors supporting it. One of the reasons that doctors do not support it is because they thought about it, "It is illegal." So, once it is legalised, the majority of the medical profession in every jurisdiction where it has been legalised back it. They not only back it, they start working with it and realise that this is obviously a logical part of medicine. But while it is illegal, doctors are fairly conservative and they say, "Oh, I don't think we should be involved in that." But as soon as it has become legal in any country or jurisdiction, the majority of the medical profession support it. At the moment the AMA has done polls and it is fairly evenly split, around fifty-fifty—maybe a little bit against, maybe a little bit for.

Dr LEAF: Amongst their members.

Dr MARR: Yes, amongst their members. But as soon as it is legalised, the majority of doctors will support it.

Dr LEAF: Another interesting piece of feedback that I got from Dr Grube from the United States only yesterday is that since the inception of assisted dying and its growth within the United States, the number of US hospices—those hospitals specifically dealing with dying—that incorporate assisted dying into their care model has grown dramatically. So we are seeing not a depredation of palliative care but we are seeing an augmentation, for the patient's benefit, of palliative care with the increased use of assisted dying within the hospices. That was very encouraging to me; I did not know that had occurred.

The Hon. GREG DONNELLY: Dr Marr, I am just noting in answer to an earlier question directed to you, talking about death, you said that most deaths are awful. They are your words: "Most deaths are awful." What do you mean by that?

Dr MARR: I suppose it depends on what experience you have had. There are very few deaths where a person just sort of fades away like in a TV scene. Unfortunately, there is usually some severe pain. I remember asking a person who we resuscitated after having a heart attack. We actually got him back—only 10 per cent of people, when they do have a heart attack, you usually can resuscitate. But unlike what you see on TV—

Dr LEAF: And your numbers are better than mine. That is good.

Dr MARR: Yes. We actually got him back. After he had all recovered and everything, I said, "Well, what was that like?" He said it was horrible; it is like having a tonne of bricks on your chest. You just cannot breathe, and it is a horrible experience. Now, that is what is probably going to happen to a lot of us: We will have a heart attack and die—and that is considered a pretty good death. You will go pretty quickly; it is not too bad. You go unconscious fairly quickly, but it is a horrible experience for that time. It might only be for a short time, but it is horrible. Contrasting that with taking a lethal medication which puts you to sleep, you do not have any experience of that crushing feeling which—probably most lethal medications do involve a heart attack, but you would not experience it because you are sedated. So that is the difference.

The Hon. GREG DONNELLY: Which leads me onto—and I think this is an issue that some people around the table are concerned about—the eligibility criteria in the bill. It is pretty detailed. It is clause 16; I presume you are familiar with it—probably well familiar with it. It seems to me, logically speaking, a number of people caught up by your statement that you made, that for most people death is awful, will not be eligible for voluntary assisted dying under the bill. Is that a fair statement to make?

Dr MARR: In reality, most people do not use it even when it is legal.

The Hon. GREG DONNELLY: No, that was not my question.

Dr MARR: Yes, and they would not be eligible, no.

The Hon. GREG DONNELLY: They would not be eligible under the bill. Is that not the case then that those people legitimately can say, "Well, we're not able to have that definition around the end of our life"? The bill, the Act, needs to be modified to pick up this broader scope of people who are having the bad death, as you have described—they are your words, not mine, that most deaths are awful. You have said that for a reason. It just strikes me that what flows from that is that a piece of legislation like this just does not go close to dealing with the issue that you are really driving at.

Dr MARR: I guess the key thing is a lot of deaths we do not have any control over, like a heart attack and things like that. This is where you do have the opportunity to choose, but a lot of deaths just happen spontaneously—you have a stroke or a heart attack. These are the most common causes of death, sudden death, and we are not dealing with that because you could not even prepare for those sorts of things. We are really talking about when people have terminal illnesses that are definitely going to kill them and we pretty much know how it is going to kill them in not a pleasant way. We are empowering these terminally ill people to choose for themselves how much suffering they want to endure. We will offer them the best palliative care. We can pretty much ease most pain—not all pain, I know; we cannot ease all suffering.

People have to know, people have to be educated, and most people aren't, about how they are going to die. And in most cases, it isn't going to be pleasant. So people should have that option, "This is probably how you are going to die. We'll do everything we can for you, but we can't relieve all your suffering. You can continue on if you want to, or you can choose to have voluntary assisted dying if you meet these criteria." So we are just empowering terminally ill people, which could be any of us one day—because that is one of the realities, death and taxes faces us all—and just empowering terminally ill people to decide for themselves, not leaving it up to the doctors or other people.

Dr LEAF: May I make a point, please. Mr Deputy Chair, if you are asserting that the law may eventually want to be changed then—

The Hon. GREG DONNELLY: No, I am not asserting anything, Doctor.

Dr LEAF: Okay, because in situations around the world where the community has wanted a change or there has been advice, then it has been an Act of Parliament where it has changed.

The Hon. GREG DONNELLY: With the greatest respect, that is not true. In Canada it was the Supreme Court that changed the law to provide for the provision with respect to people with psychological illness.

The CHAIR: Sorry, Deputy Chair, the time has gone 3.00 p.m., so I must draw the session to a close. I thank the three witnesses for appearing today and sharing their stories. I thank Dr Pattullo for sharing Venessa's story and the other two doctors for providing their expertise. The secretariat will be in contact with you regarding the questions you have taken on notice to have those tabled with us. I thank you again for your appearance.

(The witnesses withdrew.)

ABBEY EGAN, Private Individual, affirmed and examined

CATHY BARRY, Private Individual, affirmed and examined

PAUL GABRIELIDES, Private Individual, affirmed and examined

The CHAIR: Welcome to the second afternoon session of today's hearing. Each witness has the opportunity to make an opening statement. I will start with Mr Gabrielides.

Mr GABRIELIDES: Thank you all for your time and your efforts. Today I want to take the opportunity to address the two most common logical arguments put forward by people who oppose this bill. Then I want to share with you the final weeks of my wife, Anne, and her eventual and unavoidable death. It was interesting to listen to the previous session where those two arguments came up. The first one was about palliative care as an alternative. My wife and I were involved—in 2017 she went on a quest to help members of both Houses understand what she was going through and understand the issue. She was diagnosed with motor neurone disease. I think it took about five neurosurgeons and 2½ years to get a diagnosis. We met with Hugh McDermott, Gladys Berejiklian, Trevor Khan and Trish Doyle, amongst others. During these meetings, amongst other things, we spoke at length about the benefits that Anne began receiving, after diagnosis, from palliative care.

Last year, strangely enough in my position as a fundraising manager for a charity, I had the opportunity to speak to Dr Joe McGirr, who is from Wagga Wagga. You may know of him. We are both very passionate about the equality of opportunity in regional New South Wales, especially for health services, and support for vulnerable women and vulnerable youth. I found Dr McGirr to be a really nice guy. He recently—and I believe rightly—succeeded in making an amendment to this bill to ensure that palliative care services were promoted during discussions with terminally ill patients who sought assistance in dying. In your previous sessions you have discussed at length what palliative care has to offer, especially in regional New South Wales. I am a little confused, I must say—I am—because you bring up palliative care and you talk about it. You talk about it a lot, but what you do not do is actually take any action. Although recently in Wagga Wagga you—as a Parliament, as a government—supplied, I believe, a rifle range and a gun club. That does not help Dr McGirr. That does not help palliative care. I am really confused as to where the priorities lie.

You wheel out palliative care as an argument against a bill that tries to help people and empower people, but you are not taking action. When I was invited to speak at this meeting, I was informed that all proceedings would be recorded and statements made would be under parliamentary privilege. It was also suggested to me that I don't be myself—that I be nice. That was what was suggested to me: I want to be nice; I should be nice because I need to convince you of what the bill is about. This is me being nice: You are letting us down. You are letting people down. You sit and talk about palliative care and you sit and talk about empowering people, and you are not. You are letting the community desperately down. I am a simple kind of guy—an average member; just a private citizen. What I am trying to do is reflect on you what you are causing. This brings us to the second argument, the most common argument—the one about duress and coercion. You are causing duress.

You are coercing people to continue to fight on on your terms, not theirs. It's like as if someone is in a race and you are standing on the sidelines saying, "No, you can't stop. I know you're tired. I know you haven't got any legs left. That's it, you're done, I can see that. But you need to keep going until I am ready to let you finish." That is what you are saying. I have run half marathons—I have not run a marathon yet—and I dare say I got to the end of it, the 21 kilometres, and I crossed the line and I went, "Oh, thank you for being over". If I had had to run another 21 kilometres, I would have gone, "Nah, where's the nearest pub. Let me off now." And if you stood by the sidelines saying, "No, no, no, no. You can't stop. You're going to need to keep going"—this is what you are doing; you are taking the power of the person away.

People pose this argument of duress and coercion and, as I heard the good doctor say before me, "This just doesn't happen. It just doesn't happen". I will tell you what does happen. Count how many people—and I want to ask all of you—count how many people you have affected by not having this bill. Sir, you asked how many members in someone's association. I am asking you the same question. How many people has your opposition to this bill affected in the last four years since Anne died? I want a number. You can't give me one.

What is this argument about? It is about choice. It is not about death. It is not about dying. It is not about living. It is about empowerment. It is about choice. I love the analogy and the statistics. I was not aware of the stats. The analogy of having someone or something there that I can call on if I want to call it quits in the cupboard. I am not going to use it; I just want to know it is there. You know, even if you lied to me and told me it was there, I would be good with that.

So what is this bill about really? It is about love. I am going to draw a parallel here because love is about courage and choice. We have heard a lot about consent recently. We have heard a lot about rape, domestic violence, coercive behaviour and that ain't love because there are no choices there. They are all examples of individuals who are being denied choice. They are being denied self-determination. By denying someone choice over their own life, you align yourself with the perpetrators of these unspeakable crimes. You are saying they have no choice, that you have the choice over what they do.

Choice is a mundane seed. This is pretty poetic; I wrote this late at night. Choice is a mundane seed that produces such a surprisingly bountiful crop. What is that crop? Comfort, security and empowerment. I hope you are comfortable. Have you ever gone on a holiday and gone, "I don't care where I go. I just want to land there and I'll make up my mind when I get there." That is comfort. That is empowerment. You are in a privileged position. Now put yourself in the position if you are terminally ill. You are facing it. That is what we are talking about, that point.

Anne made her end-of-life choices crystal clear to me and our children, our extended families, her friends, her doctors, her palliative care nurses and anyone else within reach of a diminishing voice. In her last months of life she had a detailed advanced care plan lodged and certified, all those things. She was going to spend five weeks seeing Italy. You do not want to find out how much trouble I had trying to get on a plane with CPAP machines and battery backups. You name it, we had it. She was going to spend five weeks in Italy. We did that. She was not going to miss out on seeing her granddaughter, which she was due in mid-November. She wanted to make Christmas and she hoped to make it into the new year. But she also wanted to die at home.

Lastly, most importantly, she did not want to be drugged into a stupor. In other words, she wanted to see and experience life. She accepted that her death was not going to be a good one and, despite my assurances and bravado, she was unfortunately right. Look, we were leaving Rome and we were heading back. In the back of a cab she says, "I'm going home to die, aren't I?" And being the person I am, I went, "Stuff this, let's go to Africa. We've got a choice." She went, "Nah, I want to go back to see me kids." Her choice, right? Choice number one. We get to Sydney, she needed to have an operation. She needed what is called a PEG. I cannot remember what it stands for now. I used to be able to tell you. It meant that she would be tube fed so that she could not eat or drink anymore because she would choke.

Trevor, you knew Anne. She liked her food and she liked her wine, so she had a choice to make. "Do I continue eating and tasting or do I go for a tube feed?" Her choice, right? She said, "Nah, I like my wine too much. Thanks. I'm done." I think it took five minutes for her to realise that she was not going to see her granddaughter. She went, "Nah, tell you what, change of mind. Let's do this." We are all sitting there going, "Okay, you're not going to have it." "Okay, You're going to have it. All right. Let's do it." She had it done, lived a little bit longer. Again, her choice.

She saw her granddaughter on 18 November. She made Christmas and wore a silly hat. She then deteriorated very, very quickly. Meanwhile, don't be mistaken, we had palliative care nurses and doctors all around. We had beds, we had lifts, we had everything that could move and shake. I had better change. She lost her ability to communicate very, very quickly early on in the disease but when it came to this time, we were using eye gaze, we were using computers, we were using all sorts of things, and she lost her capacity to use her eyes and her hands completely. So she did what she could. I weigh about 80 kilos. At the time Anne weighed about 70. She'd put on a bit of weight. My legs are probably about a quarter of my weight and I guess yours are too. So you can imagine the noise and the empowerment that picking her leg up off the bed, lifting it to this angle—and I hope nobody minds—and doing this, bang, bang, constantly.

To say that she was angry—my interpretation? She was angry at me because I did not keep my promise. I promised her a nice easy death. That is what I came away with. Unfortunately, my children were there to support me and to support her, so they experienced this for two weeks. I won't not do it for dramatic effect because I've hurt my hand. It came to the crunch I think on 15 January. Remember this went from New Years Day to the fifteenth. The palliative care team looked at me and said, "Paul, you need to call it. She needs to go to hospital. You need a break. Your kids need a break." In a moment of weakness, I agreed. But I realised it was not my choice. She had made her choice. It was not up to me to override it, and it certainly was not up to you. So the ambulance came and I sent them away. Anne died the next morning.

People have asked me for the last four years, "If given the choice and if the laws were in place"—which they were not—"would Anne have opted to use it?" You have heard doctors say, "One in three actually use it," or, "Less than half actually use it." If that had been available, would she have made the decision to end her life, and, if she had, at what point? Right? I tell them this, "The premise of your question is wrong; it is incorrect. You should not be asking whether Anne would have or wouldn't have, what you should be asking is how comfortable and happy would she have lived over those past 12 months knowing that she had an option to do what she wanted to do."

The CHAIR: Thank you for sharing your story, Mr Gabrielides. It was a very powerful opening statement. I will flag that we only have 45 minutes of the session, unfortunately. We could probably have you here for half a day to share your experiences, but I want to offer Ms Barry and Ms Egan the opportunity to provide some opening statements and then have the Committee ask any questions it might have in the little time we have left.

The Hon. TREVOR KHAN: I indicate that I will clearly not have any questions. These witnesses are entitled to tell their stories and if we use up all the time, so be it.

The Hon. ANTHONY D'ADAM: I am the same.

The CHAIR: I am mindful that might be the case, but I also want to make sure that Ms Barry and Ms Egan have the opportunity to make their opening statements as well. Ms Barry, can I trouble you to make an opening statement as well?

Ms BARRY: Yes. I appreciate the opportunity to be here because it is just so important to me to be with decision-makers. I do not want my brother's death to be in vain, so that is why I am here. I am particularly here today to honour my brother Tom, who suffered a truly appalling death. He passed away in February 2020. He ran a successful IT business. He was a very loved and highly valued member of our family, and he was a very interesting man. He was diagnosed with cancer by a specialist team of doctors—totally untreatable facial cancer. It was on the left side and it was a great big gaping, seeping hole on the left side of his face. He was given six months to live and no treatment options were available. They looked all over the world and it was so bad that that was it. Tom died six months and two weeks later after that diagnosis, so the oncologist knew exactly what they were talking about in terms of time.

Tom endured particularly terrible prolonged and unbearable suffering in the last few weeks of his life. I do not want this to happen to anybody else; it was just so terrible. First of all, I want to emphasise how grateful we were and still are to the wonderful medical people for the palliative care that they offered Tom. They tried absolutely everything. He had an excellent GP, a highly competent and compassionate palliative care specialist, teams of nurses who worked with both of them, he was part of a cancer support group and he had wonderful nurses at his independent living unit. Throughout the six months that he lived after his diagnosis, they went through a whole range of treatment options, moving medications up and down and around and about and giving all sorts of other options. But, in the end, the palliative care stopped working a few weeks before he died. I simply cannot put into words how terrible it was. That was not for want of trying from the great palliative care teams that he had.

When Tom was first diagnosed—Tom was a very matter-of-fact person. He was a real numbers and data man because he was an IT person. He said to the oncologist in his own very pragmatic way, "Can you please tell me how I might die?" The oncologist went through a few things like choking, pneumonia, erupting skin lesions, stroke and bleeding. Tom then straight away said to us, his siblings, "Well, obviously I wouldn't want to go through that. If the end is close and I am suffering terribly, will you help me to pass away?" We had to explain to him that no, we could not, because in New South Wales neither we nor any of his medical staff could help him to pass away. He was a very brave person and he continued on.

Over those six months every so often his pain would become unbearable and they would increase the medications and the morphine et cetera. It continued on like that till the last few weeks during January and early February. Two nights before he died, he told us he was the happiest he had ever been in his life. He was not depressed at all, but he said that he knew he was dying and he really wanted that option of being assisted to die. He said that he did not want to be in terrible pain again when he died. About 2½ weeks before he died, Tom said to us, his family, "I am in unbearable pain all over my body. I feel really, really sick. I am ready to die and I want to die." That option was not available to him.

I feel that I have to give you some detail—and I will not spend too long—as to how he died because unless I say how it was, nothing is going to change. I could not stand the thought of anybody else going through what Tom went through. I am going to pass around some photos of Tom, which is a progression. Sorry to do this, but there are a lot worse photos than these. It will give you some idea. Here is my brother Tom when he was well. Because Tom had a facial cancer, it started to grow inwards and outwards. His jaw became terribly deformed and his face started dropping. He started to drool out of his mouth months before he passed away and he had terrible, painful mouth ulcers. But Tom, being the person he was, assiduously followed a pureed diet for the whole six months because his swallowing was so difficult from this cancer.

He had episodes of semi and unconsciousness throughout the six months, where he would lose control of his bowels and we would find him on the floor of his unit soiled. This is my eldest brother lying on the floor with his poo all around him because he lost control of his bowels. He became increasingly frightened and unable to do things that gave him pleasure, including watching his beloved Parramatta Eels. He loved the Rolling Stones and he stopped listening to them. I honestly thought I would never see that day. He stopped reading *Choice* magazine, which he used to even buy his cutlery and socks—he was a devotee. He stopped talking politics, and the worst thing for him was that he could no longer use his mobile phone or computer. He was perfectly with it in his mind, but he could not use his hands properly because of the effect of the nerves in his brain. He was moved from respite care to high care. He was given a pump for his medication, and absolutely nothing alleviated his pain and suffering. It went on and on.

Finally, his palliative care specialist and a GP came to his independent living unit and said, "No, he needs to go to hospital" because they were trying everything to alleviate his suffering and nothing worked. He ended up in hospital in his last week. We thought the worst of it was at the independent living unit before he was transferred. We thought, "Thank heavens. He has been taken to a hospital and the suffering will not be so bad." Let me tell you, it was a whole lot worse in that final week. He groaned, he screamed, he moaned and he held mine and my sister's arms. This went on day and night, day after day, where he would squeeze to the point where we had dents in our arms. He only was able to utter two words that week, one was "help" and the other one was "inhumane". That last photo is when he was calling for help.

The other thing was that the hospital ran out of options in terms of trying to control his pain. Even one of the senior nurses said to me how upset they were about it. They gave him a stress ball to bite down on while all this was going on day and night, day after day, night after night, and he ripped it apart with his teeth in about five seconds. That is the level we were at. I just cannot allow it to go on. I want the day to come where I know nobody else will go through that sort of suffering.

If New South Wales had the VAD legislation when Tom received his devastating diagnosis, he would have fitted squarely into that legislation. He would have at least had the comfort of knowing that, sometime over that six months, if he had needed to pass away with assistance, he could have. We could not give him that comfort; neither we nor his doctors could give him that comfort. More importantly, Tom would not have had to endure the extreme and relentless pain, pressure, discomfort and anxiety that he went through all that time. My sister, Angela, and I promised Tom before he died that we would try to do whatever we could to make sure that voluntary assisted dying was available in New South Wales for other people with untreatable cancer, like Tom. I am speaking on behalf of my sister, my brother Tony, my husband, Martin, and all our extended families. We do not want his suffering to be in vain. We are desperate for this legislation to pass. Thank you.

The CHAIR: Thank you very much for that extremely powerful and moving opening statement, Ms Barry. Ms Egan, can I trouble you for an opening statement?

Ms EGAN: Yes. First of all, I want to say that I am incredibly honoured to be here today. It is not every day that you are asked to come and talk about life and death—and such a good death, in hopes, after we are here talking about our loved ones having a bad death. I think it is really good that you guys can talk about the safeguards and the legislation and the hoops and the paperwork and everything that you need to do, but I do not think you guys would have been able to have the full picture of what this bill would mean to people unless you were to meet people like us, who have had our loved ones go through this. My partner Jayde was diagnosed with cervical cancer in March 2017 and ended up dying in October 2018, so she lived for 18 months. Jayde was misdiagnosed for 12 months in the lead-up to receiving that diagnosis, which means that when she was finally diagnosed it was pretty progressed. She was stage four and we were told that she had 12 months to live from then, so it was fairly downhill from there.

Jayde was probably the best person I have ever known. Her family and friends love and adore her, and still do. She, from the get-go, was a real advocate in terms of wanting voluntary assisted dying. I think because she was so sick from the get-go, she knew that this was not going to end very well. In her journey of having cancer she met other people with her disease and with other types of cancers who had died horrible deaths, and she really, really did not want that to happen to her. In the last six months, her disease progressed so much and the tumours in her body became so large that it impacted her on a daily basis. She had up to five kilos worth of fluid in her legs a day, which was immensely painful, and no pain relief could relieve that towards the end of her time. She wanted to die at home, and fortunately I was able to grant that wish for her and make that happen with the use of palliative care. They were unbelievable but, again, could not relieve all of Jayde's suffering.

In terms of her emotional and spiritual suffering, which is just as important as physical pain, not only could her physical pain not be relieved, but her emotional and spiritual suffering could most definitely not be relieved at all. Jayde's last week on this earth was nothing short of hell, not only for Jayde but also for her family and my family, who were there to watch her leave. She was so dosed up on pain medication that she was hallucinating and thrashing around on the bed. She did not know where she was or who we were or what was happening for her, which was immensely distressing, not only for her but for us. I am going to give some gory details because I think it is really important that you hear it, otherwise it is like I said: You guys can have all the paper and all the facts, but until you hear the actual things, you do not really know. The tumour in her abdomen was so large that it was impacting her ability to use the toilet, so she had a catheter in permanently to help her go to the toilet.

I want you to remember that we are talking about a 32-year-old woman at this point. We are not talking about someone who is 80, not that that is any better. But at 32 years of age, this is not something that she should have gone through. She had a permanent catheter in to help her go to the toilet. Because of the pain medication she was on and because of the tumours, it was impacting her bowels so much that she was unable to go to the toilet that way, so she would end up vomiting her own faeces on the regular. The way that her tumour was positioned in her body—when I would have to change her, parts of her tumour would fall out from her, which was horrendous for everyone involved, especially Jayde, obviously. The tumour was so large in her back that it cracked her vertebrae. In terms of her being in bed, when we would have to move her so she wouldn't get bedsores, trying to roll her over—she would scream in absolute agony because of the cracked vertebrae. You could only imagine.

They are just things that people should not have to go through. Similar to what Mr Gabrielides was saying before, just having that comfort in the cupboard would have made a world of difference to Jayde. Unfortunately for you guys, you did not get to know Jayde. But if you did know Jayde, you would know that she was an incredible fighter and she did not want to die. She wanted—

The CHAIR: Take your time. There's no pressure at all.

Ms EGAN: I just want to get it out. She did not want to die. She wanted to be here. There is no way that she would have taken that medication to end her life had there been any other option. She only would have taken it to end her life at a point of no return, and she was at a point of no return. The way that she was forced to leave this world is horrific. It is just so unjust. When you put the people that you love the most in these positions and you watch the way that they are forced to leave this world, it traumatises you. I was 28 when Jayde died. I am 31 now and it is never going to leave me. It is never going to leave her family. It is never going to leave my family.

It will forever be etched in my memory. These are the last memories I have of the person who I love the most in the world, and that is not a true representation of who she was. I think it is incredibly unfair. Jayde would have done anything for anybody, and for her to be forced to go out the way that she did is incredibly, incredibly cruel. As hard as it is for me and the others to be here today, it is incredibly important. I would do it all again, and Jayde would do it all again, if it meant that it would change the lives of other people so they did not have to go through it anymore. I think that is it. Thanks, everyone.

The CHAIR: Thank you for sharing that story with us. We have about five minutes left. Mr Gabrielides, I am sorry; I wanted to make sure that everybody got the opportunity to share what it was that they came here to share today, but I note that you may have had a few more things to say. With the permission of the Committee, if everyone is happy—

Mr GABRIELIDES: No, I don't. Thank you. I am happy for you to ask any questions; I am not sure if you ladies are.

Ms BARRY: One thing I wanted to add when Ms Egan was talking—I left out a chunk because I was conscious of making sure Ms Egan had some time. Not only was the issue with soiling to see your loved one, your older brother, soiling themselves over and over again, but—when he was in the hospital, he had an incontinence nappy on and he kept trying to pull it off and pull out the catheter with his legs in the air. That went on day after day, as well. I am asking you: How would that be for you? Two weeks before he died Tom again asked us if we could assist him to die, and we could not do that. He would not have had to go through that horror and that lack of dignity if we had had voluntary assisted dying. He asked several times but, formally, twice he asked us—once at the start and once towards the end.

The CHAIR: Ms Barry, my father was named Tom and I had the exact same experience when he passed away from cancer. It cuts very close to home. Thank you very much for sharing that. Given that we have got a little time left, does anybody on the Committee have any questions that they would like to ask—or seek some elucidation? Do any of the members have anything that they would like to add, given that we have got four minutes left?

The Hon. TREVOR KHAN: Can I just suggest—all the stories have been compelling. I need a couple of minutes out of here, thanks, if you do not mind.

The CHAIR: On that note, if there are no questions I will thank our three witnesses today for providing what were very powerful and personal stories to us as a Committee. We will call the session to a close. Obviously, there were no questions taken on notice but I thank you again for coming in and sharing your submissions and stories. We will break now for a couple of minutes.

(The witnesses withdrew.)

(Short adjournment)

EMMA SCHOFIELD, Private individual, affirmed and examined

JAN EDWARDS, Private individual, affirmed and examined

REBECCA DANIEL, Private individual, affirmed and examined

The CHAIR: Welcome back to the last session today for this voluntary assisted dying bill inquiry. Our last three witnesses are with us. Ms Daniel, would you like to start by making an opening statement?

Ms DANIEL: Thank you very much for giving me the opportunity to make a submission. This is a very important subject. It has affected me very deeply and closely, as my husband died five years ago. I am here today speaking on behalf of my late husband, Lawrie Daniel, who desperately wanted the voluntary assisted dying laws. He submitted a story in the book *The Damage Done*. He was interviewed by Andrew Denton on the podcast *Better Off Dead*. He took part in *Q+A* questions about voluntary assisted dying and he submitted a very long submission to the Victorian inquiry into end-of-life choices. I do have some documents that I would like to give to each of you. They are a collection of my husband's writings. They are his submission into the inquiry, a cartoon as well—because he was a cartoonist—and also the letter that he wrote to the coroner and his goodbye letters to me, all of which I am including because they are very pertinent to what he went through: his suffering, his experiences and his feelings and strength of conviction that voluntary assisted or, as he called it, voluntary euthanasia was an absolute necessary right for those who are terminally ill but also incurably ill.

Lawrie had multiple sclerosis. He also had Lyme disease, South African tick bite fever, anaplasmosis and rickettsia. His pain was unending and intolerable. His treatment, care and pain management did not alleviate his agony. He had neuropathic pain, which in his circumstances was unstoppable. I was naive enough to think that the pain specialists, physiotherapists, neurologists, stem cell treatments and specialist GPs could help him—and they did. They were wonderful. They cared for him. The attention he got from his carers and from everyone was thoroughly admirable and I thank them deeply. But the truth is that they could not really make any effect on his symptoms. He chose to end his suffering in September 2016 at the age of 51.

I would like to use many of his own words, as he was so outspoken and passionate about the right to end-of-life choices. He did not get to have the peaceful death he spoke of, surrounded by those who loved him and that he loved. We lost him earlier than was necessary, as he was losing the use of his hands and he felt he needed to take action quickly before paralysis took control. If voluntary assisted dying laws were in place, he would have had peace of mind and security in the knowledge that there was a caring, compassionate and civilised end available to him. I have included the word "civilised" because surely this has to be one of the clearest indicators of a true civilisation: how we as a society treat the ill and suffering, those who are tortured by pain and incurable symptoms. In 2016 Lawrie wrote in the book *The Damage Done*:

> Australian law says that suicide is legal, now go away quietly on your own … and do it … At the centre of that casually imposed cruelty is a minority who have decided that they will tell us what will happen to us at the end of our lives and how we will live our dying. Voluntary assisted dying is voluntary. It is about personal choice and cannot be imposed on anyone. It should be available not only to the terminally ill but to the chronically and incurably ill ... The criteria should be unbearable suffering and quality of life, not some arbitrarily chosen time left remaining before death.

That is the quote. Lawrie often said, when he was at his most wracked by pain and despair, "If I was an animal, they would not let me suffer like this." And we do not. We do not let our pets suffer. We find it intolerable to let our beloved pets suffer needlessly, but our beloved humans do not get the same consideration. It is more compassionate to allow someone to say goodbye to their family. It is more humane to stop someone's pain. It is more civilised to let loved ones be supportive and involved. Ultimately, fear will be lessened, life may be extended and damage will be considerably less for all concerned. I lost time with the love of my life, my best friend. My children missed out on precious experiences with their father. Lawrie missed seeing his pride and joy, his children, growing into the wonderful people they are. He said, "There are some things worse than death."

Now, I cannot say how long he would have lived if he had not taken matters into his own hands but I do know that the peace of mind that he would have had—the knowledge that he could have had someone in a caring and compassionate manner to give him something that would end his suffering—would have made a difference and we would have had him for longer. I know that he was well aware that there are so many different criteria for people who may or may not benefit from this law, but he felt so deeply and strongly that this was something that he wanted other people to have. I hope that I have done him proud. Thank you.

The CHAIR: Thank you, Ms Daniel. You have done him proud.

Ms EDWARDS: Thank you for allowing me to speak to this group. I could talk ad nauseam about facts versus views and about how I believe that some of the terms such as suicide and euthanasia are being misused in the conversation we are having about voluntary assisted dying, but what I want to do is I want to talk about Tim.

Tim was my husband. He was strong, he was smart, he was vital, he was challenging and he was also pretty good-looking. He died of mesothelioma. As with Ms Daniel, he was the love of my life and my best friend. We thought we were very lucky, because we felt that way after being together for a lot of years. Together we raised four talented and useful kids, who became our friends. Tim trained as an economist but his skill was strategy, and he used that strategy with a laser focus to try to improve the world. The kids and I would often tease him for being the second Don Quixote, always tilting at windmills, but he kept on tilting.

He loved a good discussion, and our family had them all the time. Whenever we had a discussion, it was not a chitchat. It was about something, and we loved it. Our family was close. We had a solid foundation of trust and respect, but we were not demonstrative. We did not show affection that readily. But in the year after Tim's diagnosis, something very interesting happened: The relationships we had became softer, they became more emotive and they became tighter. It was a lovely period, despite the fact that we all knew we were on a countdown. The strength and quality of that connection gave us real comfort and gave us a sense that perhaps Tim could end his life well, with our support and our love. That was all he wanted: He wanted to go out on his own terms, having had a final wry and philosophical chat with each of us. But that is not what happened. The final weeks of his life were horrendous for Tim and for his family in the end—a cycle of intense suffering and incapacity. In that, Tim lost himself. We lost Tim, the person, the husband, the dad, well before we lost Tim, the physical being.

The really sad thing is that he knew it was happening, and his whole being was being consumed by the suffering. I knew that had happened. I remember the night that I realised that this had happened. My eldest son, Matt, could not be with us in the last two weeks of my husband's life, so he wrote a beautiful letter and he asked me to read it to his father. I can remember sitting in bed beside Tim, reading him this letter. I glanced over and I realised then that he could not absorb what I was saying. He could not relate to it, and he could not react. That was when I knew that Tim was gone, and what was left had no consciousness for anything but his suffering. Tim accepted death, but not the way he died. He died angry and frustrated. He died disconnected and suffering in the extreme. We did not get to say goodbye to Tim, the person. We did not get to have that last wry conversation that he so loved. We did not get to help him pass well and peacefully. We felt like bystanders in a tragedy, and we all felt really badly that we had let him down.

The outcome of those weeks was a good man who died badly in slow motion and a fractured family who could no longer relate to one another or get past the guilt of letting him down. Three years later, we remain a fractured family. It is as if the kids have got some kind of PTSD and they do not know how to mend. Tim would have hated that, and I do not have a magic wand. I am not even sure anymore that I will have my whole family there when I die, and that is a hurt that just sits there with me all the time. I guess I am here today to say that it could have been really different. If there had been voluntary assisted dying, Tim could have and he would have chosen his moment in those last weeks, when he was still himself and his family was still part of his universe.

We both respected, and I continue to respect, that voluntary assisted dying is not for everyone. I myself was raised a Catholic, so I understand that some religious beliefs believe that suffering is a pathway to God. But I ask that those views and beliefs not be imposed on those that do not share them. I ask that the Tims of this world, who are going to die anyway, be allowed to die in a way that gives them some peace and their loved ones some way forward. Finally, I ask that we construct a law that protects the dying but does not add a layer of difficulty that increases the suffering in an already intolerable situation.

The CHAIR: Thank you very much, Ms Edwards. Ms Schofield, may I offer you the opportunity to make an opening statement?

Ms SCHOFIELD: Yes. I really appreciate being asked to be here. I particularly appreciate that we have this forum together. I do not particularly want to be here, to be honest, because it is difficult and it is re-traumatising. But I feel a responsibility to—not just to Amal, who I said I would do this for, but also to myself and to my parents and to the people I love, because I know personally I am not as brave and tolerant as Amal was. Amal was my partner. My experience is in caring for him for three years with motor neurone disease. I think the things from my experience that are relevant to the VAD Bill are firstly that, as a lot of other people have said, knowing that VAD existed was worth everything for enjoying our life that we had—for tolerating the anxiety and panic and fear, which for me was crippling. I had a certain amount of PTSD afterwards. I was looking after my young daughter, and it took a couple of years to recover from the anxiety.

Other than that, the VAD is relevant in our story mainly towards the end of his disease. I do not know that he would have used it earlier on in the disease; I do not know if he would use it at all. It is actually not particularly my business if he chose to use that in the end, but it was our business and it affected both of us knowing that it was not there for him if he needed it. What I am saying is that the impact of knowing that VAD is there would be beneficial both to carers and to the person, although it is that person's own choice whether they use it in the end. It has a double benefit in that way. Secondly, there was a big power imbalance in our relationship with the palliative care team. There were a number of doctors who were excellent and the nurses were excellent, but we had a fraught relationship with the head of palliative care, who certainly caused us grief. Lastly, part of our stress was the inadequacy of the current law.

I like to think I was quite diligent in looking after him and trying to understand what the right thing was to do and to think how to work with the people that we had to make sure that his death was perfectly fine. I am a collaborator. I don't like conflict. I didn't want to do anything that people say is wrong. But at the end of the day I was overwhelmed by the responsibility that as his carer and as his partner and as his enduring guardian, it was down to me to ensure that he was okay; it was not down to anybody else. At one point I just felt abandoned by palliative care because they decided they did not want to go that extra step and have a very frank discussion with us about what end of life was. I don't know how long I have gone on, but I will just tell you a bit about his disease.

The CHAIR: I will just say, Ms Schofield, there is no pressure on you. You can take all the time in the world. And if you need to take a break, by all means do. We are here to support you.

Ms SCHOFIELD: I think I'm getting better. Amal really genuinely loved life. He did not want to die. He was positive and he was confident and he always wanted to find fun and adventure. He was passionate about his soccer and sailing with his close group of friends. He had a large family and he just loved the big meals and the getting together and the love that they created. We travelled a lot together. We rock climbed and we camped, and it was a really good life. And I got pregnant and it was really exciting and we were ready to get old together with our little family. And 11 weeks later he was diagnosed. I actually know a bit about motor neurone disease because I did medical research in neurodegeneration. It is merciless. It is thought to be one of the worst neurodegenerative diseases, if you can say that. He was 33 when he was diagnosed in 2016.

Very quickly we learned what would happen, that it would progressively kill all of his muscle function through his body until his breathing muscles could no longer expand his lungs. His prognosis was about three years. He would lose his mobility, his ability to stand on his own, the ability to hold his head up and to empty his bladder and bowls. He would end up completely trapped within his body, 100 per cent dependent, unable to talk and increasingly struggling to breathe. We knew that at the end he would be choking because his larynx and pharynx would collapse and he would inhale his saliva and most likely die from aspiration and pneumonia. We could not stop him dying this way. It was going to happen no matter what we did. I think back to that time and I imagine what it would have meant to us if I could have just told him, "If all that is too much, if it gets too frightening or you just can't breathe properly, it is your choice whether you have to cope with that or not." I think that is my main story in that it would have meant everything to that whole three years of dealing with the illness.

My next main points are about how the current law is inadequate and how—even though Amal underwent a death that anyone pro-VAD or anti-VAD would have been proud of in squeezing everything out of life and tolerating everything it threw at him until the last minute; even though he did that—we had terrible trouble with the existing law. Our palliative care physician we knew was against euthanasia and we were suspected, I think, of secretly planning euthanasia and so it clouded all our conversations. There was one point where Amal could not breathe well when we were transferring him to the toilet because it was strenuous and he had what is called non-invasive ventilation, which is a mask on his face to push air into his lungs. It was not sufficient anymore. He would get breathless, so he would need morphine as well to take the edge off and to give him a baseline, because morphine removes that panic associated with breathlessness.

But we had a nurse advocating for us and she told us, even though we were asking for relief, that she was having conversations with the head of palliative care. She was having long discussions and arguments with her. She was trying to get us some relief. But it then took another three weeks for that physician to allow us to get morphine in the house and then we were able to put him on a syringe driver, which means it slowly pumps a baseline level of morphine. I felt offended and upset that we were distrusted when I was trying to do the right thing. I didn't know what to do, really. I was just trying to learn. So otherwise with the other palliative care physicians we had a great relationship. We relied on them, and no doubt they were the reason for Amal's longevity, because of the care that they put in.

The other situation where I feel there were power dynamics at play and our relationship with palliative care was hindered by the existing law is in our conversations of end of life. There was a point where Amal said to me—we had been using a cough assist machine which suctions the phlegm out from the lungs. So you put it on, he tries to cough, it sucks it out and then you put a suction in the back of his throat to suck the rest out, which I would need to do at various times in the evenings and then sometimes throughout the night. He had an episode where part of his lung must have collapsed or bled and he could not breathe. He was typing with his remaining finger, "Knock me out", and pressing it on the iPad, but we did not have the morphine in the house. We had our subcutaneous morphine but it takes 20 minutes to act, so we gave it to him but we had to sit through 20 minutes of him not being able to breathe. And after that I think he knew he did not have long to live. He kept getting bladder infections. He wrote on his iPad, "I've got fuck-all time left. I need to get things organised."

We talked to the palliative care team and she went away and came back and she said what they can offer us is to wean him off his mask over a period of two weeks. Now this was end-stage disease, so he had a non-invasive ventilation mask on 100 per cent of the time so he could breathe. He could not take it off. If you took it off he would probably die within about half an hour. This is what a couple of neurologists had confirmed with us based on what we had said. We had an oxygen meter. If I took it off, his oxygen saturation would go down. We knew that he could not live without the machine. So really to remove that treatment would have been a legal way to kill him but he would need pain relief.

But she came back and she said, "What we can offer is to wean him off over a couple of weeks." We said, "How?" She said we would get a respiratory physician to increase the carbon dioxide slowly over a couple of weeks. I said, "What are you going to give him for pain relief?" And she said, "We can't accelerate his death, so we need to see that he is distressed before we give him pain relief." So they would need to take his mask off and wait for him to be slightly suffocating, I guess—I don't know what they would look for—and to become distressed and then they would give him some morphine. They said he would probably be asleep within a couple of days. I said, "Well, once he's asleep, how do you know he is distressed?" She looked a little bit bemused and almost amused. She said to a registrar, "Oh, this is a good question for you. What would you choose?"

He sort of stumbled and she said, "Well, what I use is the eyebrows. If the eyebrows start furrowing I'm guessing they need some more morphine", which surprised me because for someone who is losing muscle function, using their face to tell you whether they are distressed or not does not seem like a reasonable solution, plus I have been a neuroscientist for 20 years and I am pretty sure that we do not know a lot about levels of consciousness and what people feel. Unless you have got someone in a functional imaging scanner, you cannot tell what they are aware of, and that is confirmed by some of the material we teach medical students at the moment about continuous sedation.

Anyway, I asked if they could just give him more in anticipation of the fact that he would suffer from suffocation, seeing as we knew, and she said, "No, because that would be euthanasia", and I said, "Well, what is the difference really? It is just that you are stringing it out. I mean, he is already almost dead. Can't he just choose to go?" I was envisaging myself sitting by his bed, staring at his eyebrows, trying to work out what he was feeling, just waiting for his breathing to stop and I did not think I could tolerate it at that stage because I was in such a desperate state of exhaustion and anxiety, and I had a little baby that I was waking up at night for as well. But when I said that, she said, "We are palliative care", which was it—it was designed to end the conversation, and I do not think that is where the conversation should have ended. I did not see the logic; I was trying to understand and it did not make any sense.

So at the very least, I think the current law is just inadequate. VAD would put the control in the patient's hands. I do not think we should see doctors as having some sort of divine insight into someone's suffering and awareness of their suffering at end of life. I think doctors often really do not know what a person is experiencing because we are all so vastly different. Any one person's response to things is different to another's; there are so many different variables involved. A palliative care physician cannot exactly know what that person is going to experience. So if their role was to educate patients instead about how their end of life could be, to educate their carers, to have that full conversation with me and him and we all agree that that is suitable care, then I think that with voluntary assisted dying it would be safe to put it in the patient's hands to decide and not give you a sort of potluck as to what your palliative care physician is going to say and going to decide for you. We have taught our medical students at University of New South Wales about continuous sedation. There was just one thing, if you do not mind, I was going to read out from one of the articles.

It is from Rady and Verheijde 2010 *Continuous deep sedation until death: palliation or physician-assisted death?* This is one of the readings that we give them. It states, "When sedatives are titrated to unconsciousness in continuous deep sedation other vital functions are simultaneously depressed, such as respiration, blood pressure, heart rate and airway and swallowing reflexes. It diminishes control of the muscles in the face and throat causing poor pharyngeal and airway muscle tone. The inability to swallow or cough can accelerate the onset of pulmonary aspiration and hypoxia. It triggers metabolic disturbances from rapid dehydration and asphyxiation from airway obstruction. These metabolic disturbances can exacerbate restlessness, agitation and delirium and may necessitate further increases in sedative medication doses to maintain deep sedation. Therefore, it sets in motion a series of predictable, self-perpetuating pathophysiological events that are not only directly linked to the desired mechanism of action, deep sedation, but also have a direct life-shortening effect."

If this palliative care physician was against euthanasia but is quite happy for that to occur, I cannot understand it. So I am frustrated, and when I look at the new law I just see that it articulates well how things should be and protects the rights of the most vulnerable. That is all. I am sorry it took a long time.

The CHAIR: It did not take any time at all. Thank you very much for sharing that with us. I am going to look around the Committee and see if anybody has any points they would like to raise or address. In the circumstances, I will offer the three witnesses—is there anything further that you would like to put on the record? We have got a little bit of time. There is no pressure. If you have got something that you would like to include, we are here to hear you.

Ms EDWARDS: I would just like to add—I did not include it in my opening remarks but it is relevant, especially what was raised with Ms Schofield—we had a similar experience with our palliative care team to Ms Schofield's. We had the lead doctor who was resistant to the discussion. All we had to say was it was Tim's wish to die peacefully and I can remember sitting at the kitchen table with my children, giving a very long lecture about we had no right to do anything—we had not suggested doing anything—that he was strong and he could be around for a long time and it was her job to make sure that happened. The nurses were wonderful. We lived in a regional area at the time, so she was it—that was our only choice. After that particular conversation and the way she handled Tim, I had to tell our GP—who was excellent, by the way—that we did not want to see them again. So I think there is a mixed experience with palliative care.

The other item I thought that offended me a little bit was in the reading of the amendments part of the debate in the lower House where the member for Mulgoa quoted the expert evidence of palliative care experts "who seek to assure the good people of New South Wales that they can confidently face death from … terminal illness knowing that modern palliative care can provide relief from pain and other physical symptoms and can … assist a dying person in dealing with the emotional, psychological, existential and spiritual challenges that can surround death." I do not know how she made that statement, knowing that there are large sections of that specialty that say they cannot. That is what I was alluding to earlier when I talked about views versus facts. In general, I can commend the philosophy of palliative care, and the nurses particularly were excellent, but it is not consistent and it is, or is allowed to be, quite subjective.

The CHAIR: Thank you very much for that. Could I ask if anybody else had anything that they wanted to address this afternoon?

The Hon. TREVOR KHAN: I think it should be explained that, at least from my perspective, this is not a time for asking questions; it was an opportunity for the witnesses to explain their circumstances. Anything else, I think, becomes pretty trite. So I hope you are not offended by any of us not asking a question. This is hard going for you, a little hard going for us.

Ms CATE FAEHRMANN: That is a good point.

The CHAIR: Yes, I probably should have explained that. Thank you, Trevor. I think we are all very moved by what we have heard today. Given that we are only a few minutes away from our stated closing, we will draw the session to a close for today. I again thank not only the three witnesses here at the moment but all the witnesses who have appeared today. We will be returning again on Friday morning for the next day of hearing. Thank you very much for coming today and sharing your stories and being the voice for those you love.

(The witnesses withdrew.)

The Committee adjourned at 16:24.