



HEALTH AND ENVIRONMENT COMMITTEE

Members present:

Mr AD Harper MP—Chair
Mr SSJ Andrew MP
Ms AB King MP
Mr R Molhoek MP
Ms JE Pease MP
Dr MA Robinson MP

Visiting Member:

Mr MC Berkman MP

Staff present:

Dr J Dewar—Committee Secretary
Ms L Pretty—Inquiry Secretary
Ms A Groth—Assistant Committee Secretary

PUBLIC HEARING—INQUIRY INTO THE VOLUNTARY ASSISTED DYING BILL 2021

TRANSCRIPT OF PROCEEDINGS

WEDNESDAY, 14 JULY 2021

Brisbane

WEDNESDAY, 14 JULY 2021

The committee met at 11.29 am.

CHAIR: Good morning, everyone. I now declare this public hearing of the Health and Environment Committee open. I respectfully acknowledge the traditional custodians of the land on which we meet today and pay our respects to elders past and present. We are very fortunate to be living in a country with two of the oldest continuing living cultures in Aboriginal and Torres Strait Islander people, whose lands, winds and waters we all now share.

I would like to introduce the members of the committee. I am Aaron Harper, the member for Thuringowa and chair of the committee. Mr Rob Molhoek, the member for Southport, is the deputy chair. The other committee members are: Mr Stephen Andrew, the member for Mirani; Ms Ali King, the member for Pumicestone, who will be joining us shortly; Ms Joan Pease, the member for Lytton; and Dr Mark Robinson, the member for Oodgeroo. I believe we might have another visiting member at some point today, Mr Berkman.

The purpose of today's hearing is to assist the committee with its inquiry into the Voluntary Assisted Dying Bill 2021. The committee would like to thank the submitters who provided submissions to the inquiry. These will assist the committee greatly with its consideration of the bill. This hearing today is a formal proceeding of the parliament and is subject to the Legislative Assembly's standing rules and orders. I ask that mobile phones and other electronic devices be turned off or switched to silent. Hansard will record the proceedings. Witnesses will be provided with a copy of the transcript.

DENTON, Mr Andrew, Founder, Go Gentle Australia (via videoconference)

CHAIR: Welcome. I invite you to make a brief opening statement before we move to committee questions.

Mr Denton: Thank you, Mr Chairman. My name is Andrew Denton. I am the founding director of Go Gentle Australia. Today is actually its fifth birthday. I am appearing in that capacity. I got engaged in this issue after spending almost a year researching a podcast series I made back in 2016 on the subject of voluntary assisted dying. As I went around Australia and spoke extensively to people on all sides of this debate, I realised that our existing laws created a situation where, for some, deaths were traumatic and intolerable. Some resulted in suicides. I have spoken to families that have been through that situation. What was very clear to me is that our existing laws created and create a deep power imbalance between those who are terminally ill and those who treat them. That is one of the reasons four states now have passed this law. I have been closely involved in those parliamentary debates. The MPs who have engaged diligently in that debate have looked at the evidence and seen that there is a need for a change to our laws on voluntary assisted dying.

I do not want to go on too long, except to re-emphasise that there is clear evidence of public harm in the absence of our laws and clear evidence, particularly now from two years in Victoria, as to how a voluntary assisted dying law can work safely and effectively and for whom it is intended.

CHAIR: The previous couple of days hearings have shown that there have certainly been issues. Clearly from the submissions, which are on the public record, some submitters have talked about institutional objection. I was wondering if you could give an example, perhaps in Victoria, where this has caused distress to someone who has had to—I have read in your submission—leave a facility to start the assessment process. Can you unpack that a little bit for us?

Mr Denton: Yes. I spent some months researching the story of Colin M. His family did not want to be identified because they had a very identifiable surname. I spoke to the family, obviously. All the treating doctors confirmed the facts with the statewide pharmacy service and the voluntary assisted dying care navigators and then put those facts to Mercy Health, who were in charge of the institution.

Colin M was a man who was partially quadriplegic after a swimming accident and who had metastatic bowel cancer. He was 79 and lived in this aged-care facility run by Mercy Health and received excellent care there. The family had nothing but praise for the care they got. However, because of his cancer, which became metastatic—and it was bowel cancer, which is a particularly ugly way to go—Colin applied for voluntary assisted dying. Even though this was during Victoria's COVID outbreak, standing orders allowed doctors to go in and assess him, and he was assessed as eligible.

Colin was not required to tell the facility that this was what he was doing, but he was a man of great moral probity and he felt it would be unfair on his carers, whom he knew and was very affectionate towards, for them to find him dead one day, so he told them what he was doing. He was told that he could not have VAD on the premises. He then asked if the pharmacist would be allowed in to at least deliver him the medication while an alternative facility was found—difficult, as you could imagine, under lockdown in Victoria. He was told then that that would have to go to the ethics committee. Remember, this is a man with metastatic bowel cancer. On any day it was possible that he could die a very traumatic and ugly death.

Despite repeated requests from the family, the care navigators and the statewide pharmacists, and despite repeated assurances from Mercy Health that the ethics committee would give an answer, Colin was left waiting nine days in this condition—in fear, in anxiety—before being given the answer, ‘No, they’re not allowed in.’ More than that, he was told by the facility that he was not allowed to discuss his choice with anybody else who lived there. He was a resident in this facility. I do not know on what authority they told him he could not discuss anything with anyone, but that is what he was told.

This man, who had lived in this place for two years, who had developed friendships, who was at the end of his life, had to leave the facility. He was rushed out of it to Royal Melbourne Hospital. He was not allowed to tell any of his friends. He was not allowed to say goodbye. He went to a facility where he knew no-one, but they facilitated the pharmacists within 24 hours and he took the medication within two hours of receiving it. The family were deeply distressed by what happened, as was Colin. This is an example of where an institution, without any guidance from the law, acted according to their tenets but to the disadvantage of a man who was terminally ill and distressed and fearful.

CHAIR: Thank you, Andrew. I wanted to put that in context. Do you think the provisions in the bill as drafted strike a balance, if someone is unwell in perhaps a Catholic run facility, that they must allow someone to come in if they cannot be transported because of their frail or ill condition?

Mr Denton: Yes. I think Justice Applegarth and his commission have done a very thoughtful job of striking that balance in that it does recognise that institutions, even though in Victorian law they are not given a right to conscientiously object, nonetheless will and do. It certainly recognises as a baseline that any individual may, and that is of course as it should be, but it also recognises that this law is written primarily for people who are terminally ill. It is issued to protect them and it is issued to hand them back a measure of power which without these laws they do not have.

For someone like Colin, what would have happened if he had no protections? In this instance he was able to be transferred out in time, but that may not have happened. He may have died that terrible death in his room—the death he did not want to have, not even with his family around him—because of that institutional conscientious objection.

The way the Law Reform Commission has drafted this law acknowledges that institutions can conscientiously object but they have rights towards the terminally ill person, and if that person is too ill to be transferred, if they cannot be transferred or if they are a resident—as Colin was—then they have legal rights which must be observed.

I guess I put it this way: would anybody think it is fair or right for somebody to die the death that Colin would have died? For those who do not understand it, when metastatic bowel cancer is at its worst, when you die that terrible death—I am sorry if this is distressing information—you end up vomiting your own faeces. Would it be right that he is forced into that situation because the law would not allow him to be transferred or a doctor to be brought in or because there was no alternative facility to go to, simply because somebody in the next room had a conscientious objection to it? I do not think anybody, except perhaps the most zealous, would think that was a reasonable position. Yes, I do think the Law Reform Commission has struck the right balance.

Mr MOLHOEK: Thanks, Andrew, for appearing today. You and I have chatted a little bit offline. I understand and accept, I guess, the premise that people should have greater choice, but in reviewing some of the material, and even hearing some of the testimony in Townsville and then Rockhampton from different organisations, there is a part of me that worries that we are kind of beating up the institutions a bit too much. If you look at the history of care in Australia, whether it be child protection or aged care—even in the earlier days of providing health services—some of the greatest institutions came out of essentially Christian organisations or organisations with Christian conviction and passion. I am not sure of the figures today, but I know that at one stage about 60 per cent of non-government care in Australia was provided by church based institutions.

As sad as Colin's situation was—I do not know the institution or the individuals involved, and it probably varies from one location to another—it sounds like they really messed that up. They perhaps were not very gracious and thoughtful about what they were doing and a bit stuck. I worry about this imposition over the institutions. I would like to hear perhaps a bit more comment on that. Where do we go next? We do believe in freedom of religion and freedom of expression. If you are running a coffee shop, nobody tells you that you have to sell tea, too; you can just sell coffee if you want. I just worry about where this ends up in terms of some of our broader principles as a nation in terms of freedoms.

Mr Denton: The first thing I would say is that I entirely agree with you: I think there is so much beautiful and brilliant care provided across the board but particularly by Catholic services in Australia. I have had the great opportunity to spend a week here at St Vincent's with their palliative care team to see what they do, so I entirely agree with that. I can also tell you from the 11 months I spent researching what was happening in Victoria that there are tremendous examples of Catholic hospitals finding a way to accommodate their objections to VAD but not getting in the way of what patients need to do. There are mixed examples; it is certainly not all bad.

You used the word 'imposition'. I guess I would like the words 'obligation' and 'guidance'. All Catholic care states that their central aim—and of course it is sincere—is to care for patients until the end of their life. I believe in Colin's case they had an obligation to—Colin's case is not the only example; there are different examples I could give you, both here and overseas—care for him in that situation, even if they disagreed with his choice. When you say 'imposition', clearly, with the right to conscientiously object, no individual has to participate in anything Colin is doing to do with the VAD process. By 'guidance' I mean—this is where I think the Law Reform Commission has done an intelligent job—it is actually saying 'in certain situations you must follow these steps' so that that obligation to care for that person is not sundered. I do not think that is an unreasonable thing. I think that is quite different to the idea which I see is being promoted, predictably I suppose, by some that this is forcing these facilities to be involved in VAD. I go back to that example I gave earlier: is it really conscionable to leave somebody like Colin in that situation when he has a legal right to protect himself from that situation? I would use those words 'obligation' and 'guidance' rather than 'imposition'.

Ms PEASE: To Andrew and the Go Gentle team, thank you for your kind, compassionate and measured approach in reviewing this important opportunity for people in Australia to have choice about their end of life. Queensland, as you know, is a very large state. We have rural and remote communities dotted all over that do not necessarily have access to face-to-face medical care. We have a really great telehealth system. I know that Victoria has been confronted with a similar issue with regard to the carriage service. In your submission you have some fairly pointed examples. Perhaps you could expand on that and talk about what you believe we need to do and how we can ensure that people in rural and remote communities may be able to access choice at the end of their life.

Mr Denton: It is often good to put flesh and bones to a legislative conversation. I think of an 82-year-old woman, Margaret, Lisa Hogg's mum, who had a rare neurological disorder called corticobasal syndrome. Essentially, the best way I can describe it is to think of everything that makes you you, then imagine them being taken away one by one. She was in a situation where she had to be moved on a sling from her bed to the toilet. She could not change the channel on the TV. She could not do anything for herself. She was losing the ability to communicate. She was very fearful, in fact, that she would not be able to communicate her request for VAD. There was no painkiller, there was no palliative care, there was nothing that could be done to ease her situation. It was an inevitable decline to death.

Margaret lived two hours out of Melbourne, but because telehealth was not allowed her family had to take her in the car. It was only a two-hour trip, but it took about 3½ hours because they wanted to leave enough time to be sure. It was extremely uncomfortable for her physically. They had to keep stopping to readjust her supports and pillows. By the time they got to the neurologist there were traffic issues. They had to rush her in there. This 82-year-old woman, who was already massively depleted, was exhausted. Then the neurologist gave her a very thorough test that went for over an hour. She managed to pass it, but what it meant for their mother to take her there and back was excruciating. I know of other examples, but I will give you that one.

This has been a question addressed in every state: what to do about telehealth. All of the doctors I interviewed in Victoria over the last 11 months felt there was a place for telehealth but not as the default option. They said 'not in all circumstances'. If they had any questions about competency, for example, they would want to see that person face to face. Certainly for a second consultation, which is required in Victoria for neurological disease, they saw a place for telehealth.

The issue is that in Western Australia and Tasmania—and the proposal in Queensland—the state's law says, as it should, that VAD is not suicide. As you know, state law does not override Commonwealth law, so there is only a political solution to this.

I believe that, as more states legalise VAD, ultimately a combined effort of the health ministers and possibly the premiers of those states may lead to change. In the interim, unless the state is willing to back a doctor in a court case—and I am not sure any doctor wishes to go through that—I think the only likely way to address it is to petition the Commonwealth Director of Public Prosecutions to provide guidance, as they have in England, as to what constitutes an offence and what does not when it comes to voluntary assisted dying. There is clearly a role for telehealth, as we have discovered throughout COVID, in all manner of consultations, as there is with VAD.

Ms PEASE: Have other countries been confronted with similar issues and how have they been able to get around it, if they have?

Mr Denton: Not that I am aware of. They do not have the same Commonwealth code that we have. The Commonwealth code, as I understand it, came into existence largely because of the work of Phillip Nitschke and Exit International. It was a response to that. Our Commonwealth code was obviously written well before VAD existed, but it has been interpreted as catching it in that net by the Victorian government. Like many other people, I believe there is a clear distinction between VAD and suicide, but it does not really matter what I think about this. It comes down to a legal interpretation.

Dr ROBINSON: Thank you again, Andrew, for taking the time to appear today. I have two basic areas of questioning. I will keep it tight for today. I guess we are generally talking about how we relieve suffering for those who are terminally ill. That is how I look at it. How do we do this the best? One of the factors that has come up with regard to palliative care is the lack of resources that are often available for palliative care patients. Sometimes patients are receiving painkillers or palliative care of some kind only weeks before their death and not earlier. In many regional places they do not have any access to palliative care at all. There is a concern amongst some doctors, which has been expressed to the committee as well, that there are times when VAD may potentially end up competing for scant resources that could be spent on providing better painkilling relief as opposed to an action that ends up taking the life of a person. What do you say to doctors in the medical fraternity when there are thousands of people per year—like in Canada—who are accessing VAD and that the cost will detract from the actual relief of pain through providing medicines and treatment that relieves suffering itself?

Mr Denton: Thank you, that is a great question. I will answer it in two ways, if I may. First of all, in a business sense, if you like, you are talking about it affecting funding for palliative care; secondly, on a human level. On a business scale, I did a quick calculation of how much new money has been voted to palliative care in the states where these laws exist since 2017 when Victoria's law was passed, and it is \$410 million in those four states.

You will note already on this committee, and soon to be in your parliament, that the very existence of a debate about VAD brings palliative care into enormous focus right across the parliament, which is to its benefit. I can say that as a basic claim, but I can back it up with Palliative Care Australia's own research. In 2018 they commissioned Aspex Consulting to travel to jurisdictions where voluntary assisted dying and euthanasia are legal specifically to assess the impact on palliative care services. What they found was that, without exception, palliative care services were strengthened and had improved concurrently with those laws. In Belgium, for instance, they passed legislation side by side for palliative care and euthanasia. This is also confirmed by Dr Linda Sheahan, who is a palliative care doctor but is not a supporter of voluntary assisted dying. In 2016, I think it was, she used her Churchill Fellowship to do the same thing. She went to all of these jurisdictions to see what had happened. She reported the same: that palliative care has improved in all of these places. I think that is a direct result of the increased focus.

When I talk about voluntary assisted dying I always argue to politicians that this is a much wider conversation. It is about better end-of-life care for all, which brings me back to the focus of your question. In our submission you will see that I think the Voluntary Assisted Dying Review Board should include in its reporting requirements those who have also received palliative care. In Victoria there aren't official numbers. The unofficial numbers, according to the calculations of Betty King, the Supreme Court justice who chairs the board, is that 95 per cent of people who use VAD were also in palliative care. Every doctor I spoke to and every family I spoke to—and I spoke to an extensive range of people—confirmed that. They had not only used palliative care but were deeply grateful for its benefits. They had also reached a point for different reasons, and I will give you one example.

Ron Poole had a lung disease which essentially meant that his lungs were shrinking from the inside. He had reached the point where literally to walk across the room where you are now he would have to rest for 20 minutes. That was just going to get worse and worse and worse. There was no

palliative care for Ron Poole, although what was available to him was community palliative care nursing. He was grateful for that, but he did not need it because it really would not help him. That is trying to put a human face on it.

The law says—and Queensland law insists—that in discussing voluntary assisted dying you must also discuss palliative care. I view voluntary assisted dying as a safety net. You mentioned that some people may be getting pain relief very late. Well, the safety net of this is these two very specific sets of inquiries. When somebody comes to you as a doctor and says, ‘I want help to die,’ that is a serious request. You do interrogate, ‘What pain relief are you on? Why aren’t you getting this?’ In fact, I spoke to one woman in Victoria who used the law, Fiona McClure. She had metastatic breast cancer. During her second assessment they put her on a very different course of pain relief that materially improved her life, even though she was to die only a couple of months later using voluntary assisted dying. I see it as a palliative care and medical safety net as opposed to something in opposition or excluding palliative care.

Dr ROBINSON: You made a comment with regard to conscientious objection and the position of Catholic and other religious positions. It is my understanding—I just want to clarify this—that the Catholic Church, Uniting Church and some other Christian groups say they have great concerns that the bill does not allow full conscientious objection—that is the statement they are making—and that as individuals, whether it is doctors or people from religious backgrounds who are doctors or nurses—but particularly in the case of doctors—they now have to be involved. This legislation forces them—requires them—to be involved in the process of referral—whereas they do not have to at this point because there is no legislation—but they will have to be involved in that process. I have had a number of people of faith backgrounds say to me that they are very concerned about that. They do not want to be involved. They want to be able to opt out of that. The legislation does not allow them to opt out. Institutions have also said that being involved in any way in the process is something that is greatly offensive to them. I am not sure whether you are reading the same information that is being put out by these communities. They have great concerns about the bill and great levels of opposition at the leadership level of these institutions. Do you have any comment on that?

Mr Denton: I am glad you raised it. There are a few things there. First of all, you said ‘at the leadership level’. I think that is a key distinction, because in fact the leaders of these church groups do not speak for all their membership. They certainly do not speak for the vast majority of their lay membership. In arguing that their rights are being in some way curtailed, they are very effectively driving over the rights of others who may feel quite differently within their own church. I can certainly point you to three very senior Catholic physicians in Victoria who have absolutely reconciled their faith with voluntary assisted dying. Nonetheless, I accept they have that deep conscientious objection.

You say they are being forced to refer. They are being asked by law at a minimum to say, ‘Here is the voluntary assisted dying care navigator service.’ That is it. I think if they are genuine in their mission statement about care, caring to the end and not abandoning people—which is what they say all the time—then I do not think it is an onerous imposition to say, ‘I’m not going to be involved with this for my personal reasons, which is my right. I want nothing to do with it. You need to look these people up.’ I do not think that is an onerous imposition, and I do not think the vast majority of Australians or Christian Australians would think that is an onerous imposition either.

We are talking about, as you said earlier, the best way to treat people who are suffering at the end of life. I would put it back to essentially a Christian and human level, which is that you are trying to help people at the end of life here. It is a hard heart that says, ‘You know what? My universe is so deeply traduced by the idea of simply telling somebody three words—care navigator service—that I can’t do that, no matter how much distress they’re in.’ I would ask them, frankly, to examine their Christian ethics.

Dr ROBINSON: For time, I will leave it there.

Ms KING: Thank you so much, Andrew, for your advocacy for the real needs of people at the end of their lives. When the independent Queensland Law Reform Commission set out to draft this legislation, their essential aim was to draft legislation that was safe, compassionate and accessible. Do you believe they met those aims in the legislation that is before this committee?

Mr Denton: Yes, I do, and I particularly respect the fact that they looked very closely at what has happened in other states and the debates in other states and in New Zealand. I very much respect that they have not gone what might be viewed as the easier political option—which is to just do Victoria’s law for Queensland. They have gone to school, if you like, on what is working well and what could be working better.

With regard to Mark's questions earlier, I think they have made a genuine and intelligent effort to address the legitimate concerns of people of faith and institutions of faith, but I think they have, as they must do, put the needs of those desperately terminally ill people front and centre. I think this is a law that is also very much within community expectations as expressed not just in opinion polls but also by the vast amount of evidence that was brought forward to the original inquiry.

CHAIR: Andrew, thank you very much for your time and for sharing with the committee the views of Go Gentle Australia. It is deeply appreciated and it will help us in our consideration of the bill. We will be moving to the Undumbi Room for the rest of the afternoon for other witnesses. We know you are still in lockdown down there. I could not find a maroon face mask but let's hope Queensland gets up tonight.

Mr Denton: You know that watching a Blues victory is going to make lockdown just disappear!

Proceedings suspended from 12.02 pm to 12.15 pm.

GLASBY, Dr Craig, Vice President, Dying with Dignity Queensland

HALL, Ms Jocelyn, President, Dying with Dignity Queensland

WILEY, Ms Jeanette, Committee Member, Dying with Dignity Queensland

CHAIR: Thank you for coming today and for your submission. Would you like to make an opening statement? Then we will move to questions.

Ms Hall: I have been president of Dying with Dignity Queensland for seven years. My career prior to that was as a registered nurse for 48 years. I will make an opening statement. The other two members of Dying with Dignity Queensland will not make a statement as one statement will cover the three of us.

Dying with Dignity Queensland represents the roughly 80 per cent of Queenslanders who want voluntary assisted dying legalised. We have over 20,000 members and supporters on our database. DWDQ supports this proposed legislation as written and concurs that the Queensland Law Reform Commission has drafted the best legal framework for people who are suffering and dying to choose the manner and timing of their death should they so request.

DWDQ has concerns that there may be temptations by some members of parliament to mistakenly think they are increasing safeguards by focusing on some specific areas of the bill and moving amendments to that end. When taken in its entirety, this bill has an excellent balance of safeguards while still allowing access to VAD for those terminally ill Queenslanders who are suffering intolerably with no hope of relief who wish to have legal medical help to end their life.

Specifically, DWDQ wants: the 12-month time frame to remain and not be reduced; that health practitioners retain the ability to initiate discussion about VAD as part of overall discussion about end-of-life options—this is accepted as good medical practice; that the coordinating practitioner or consulting practitioner does not have to be a specialist in a specific disease; and that the bill's sensitive and balanced treatment of so-called institutional conscientious objection remains intact. These are areas that have presented difficulties in the implementation and delivery of Victoria's VAD legislation. DWDQ considers voluntary assisted dying to be a basic human right available to Australians who live in Victoria, Western Australia, Tasmania and South Australia but not to Queenslanders. This bill will address this inequality.

CHAIR: Thank you, Ms Hall, and thank you for your 47 years of nursing, or was it 48 years?

Ms Hall: Forty-eight years and six days.

CHAIR: In that time, did you nurse in the palliative care field at all?

Ms Hall: Yes, I certainly have. I have not worked in palliative care units, as both of these people have; however, every hospital has people who die in it. I was once asked how many people I nursed during my 48 years who died under my care. I obviously have no way of knowing that, but I would have to say hundreds. I have sat with people. I did a lot of work on night duty. People tend to die in the wee small hours of the morning and, because it is relatively quiet compared to the rush and tumble of the day, when I had time available I would sit with those people and their families who had often been sitting there for days and days and days. I would say to them, 'Go and make yourself a cup of coffee at the nurses station. Just have five minutes out of here. I will call you if anything changes in that five minutes.' I would sit there with their relative and I would do that and I would talk to the patient, talk to the relatives and cry with them.

CHAIR: Thank you for sharing and for your time and for anyone who has worked in that palliative care space. We have heard about it consistently. Some say that they are interlinked—that people who might want to choose voluntary assisted dying have been in a palliative care space for some time. I think there has been some evidence produced—the Oregon study—and our former speaker linked that as well. I want to get a feel from any of you on that. If people are receiving palliative care for a terminal illness, is there a point in time that some say, 'I've had enough and I'd like to access this and end it'?

Ms Wiley: I had 30 years working in palliative care. Can I say that palliative care per se is a relatively new profession. We have actually practised palliative care forever. I have problems with this word 'specialist' because good palliative care can be handled by most people until the time arrives. I have nursed many of the people we are talking about now. With the very best will in the world, palliative care cannot cure all of their problems at the end of life.

CHAIR: Do you have any views on that, Dr Glasby?

Dr Glasby: I am a retired GP. I spent probably 30 years in general practice. Initially, in the early part of my training, I did a stint at what was then called Mount Olivet, which was possibly the only hospice in Brisbane or even Queensland at that stage. I did have some experience going into general practice.

The comment I would like to make is that a lot of palliative care is done in general practice. It is like all medical conditions. There are medical conditions that can be treated quite adequately in general practice, but there are medical cases which are difficult and you need to call in specialists. I did see a lot of my patients through the palliative care phase of their illness and those people died at home and died quite comfortably. I also have to say that I saw good deaths, bad deaths and horrendous deaths. With some of those bad deaths and horrendous deaths, you call in specialists; you call in palliative care specialists. I must admit, like Jeanette said, when I first started it was a bit of a novelty having someone you could call in but there were pain specialists around. In particular cases I remember the person would say every day when you met them, 'You've got to do something about this, Doctor.' The words might have been different from patient to patient, but what they were saying was, 'Can you help me die?' but it was not a legal option.

CHAIR: We heard over the last few days of some people saying that they needed a psych assessment. As a GP of 30-odd years, you would obviously have a relationship with your patients. Do you think the observation of some that people who want to access VAD would need a specialist assessment is warranted or needed?

Dr Glasby: No. As an experienced GP, just from your relationship with them, you know whether the person is suffering from a mental illness or not. I guess this brings it back to the decision-making capacity as well. We are well versed at determining whether a person has mental illness and whether they have decision-making capacity. For most people, it is bleedingly obvious, to be blunt, that they do not have either of those conditions when they have a terminal illness. Most do not. It is only in some that you would have some doubts. If you have doubts, then it is good medical practice in general practice to call in people who have expertise in that area, whether it is a psychiatrist or a geriatrician. I do not see there is a big problem, really.

Mr MOLHOEK: I might go to One Nation or Dr Robinson. I have questions but I feel like I had a fair run in the last session.

Dr ROBINSON: Thank you for appearing before the committee. I have many questions and we could talk for a long time. You made a comment about specialists. I have a concern in the bill in terms of the lack of specialists involved in the process as a requirement. I think highly of general practitioners—they do an amazing job—but we have specialists for a reason. The bill says that if someone requests VAD treatment there are two doctors involved in the process but one of them does not even have to know the patient, so there is no history there potentially and there is not a palliative care specialist or a psychiatrist.

We look at the potential of dementia in terms of those who are aged. One of our Indigenous leaders in Townsville was talking about the need for some kind of Indigenous adviser in cultural matters and respecting that view. Why should we not increase the safeguards and protections in the bill and obviously put in specialists? Again, I am not detracting in any way from the role of general practitioners. If we did that, we would know for sure that the person is getting the proper treatment from the palliative care specialist and we would know for sure that the person has capacity. Again, doctors can understand that to a level—I do not question that—but why would we not put further safeguards in the bill when we know we can?

Ms Wiley: Mark, what would you do if you were in Oodnadatta and you needed a palliative care specialist? Are you saying that the palliative care specialist should actually visibly see the patient and talk to the patient?

Dr ROBINSON: I am simply asking you, from your expertise, why we would make not it a requirement that they have access to that further care and further medical opinion when we so highly value the role of specialists in all kinds of areas? We are dealing with an issue of life and death.

Ms Wiley: I think you will see in the bill that the general practitioner now is able to bring up all of what is open to the patient, including palliative care. As Craig has said, the GP usually knows the patient better than anybody and certainly the GP is capable of requesting a palliative care specialist to come in—

Dr ROBINSON: Can I jump in there for a moment? The GP does not have to know the patient. It can be two doctors who have never met the person in their life. Shouldn't we tighten that up?

Dr Glasby: If you brought in a specialist, they would not have any knowledge of that person either from—

Dr ROBINSON: Perhaps, or maybe not.

Dr Glasby: Perhaps, and perhaps with the GP as well. I am not sure that is an issue. The thing is that in medical practice we are doing that all the time in terms of seeing people. Even in a group practice, you might ask a colleague to have a look at someone. Even if the GP is not seeing the person, they would have access to notes and access to information previously. If a person has got to the stage of palliative care, they have seen numerous doctors and numerous specialists. If they are in a position where they are not able to help someone, they will often speak to their colleagues, ask their advice and get second opinions because this is a very crucial thing. If they are telling a person that this is an end-stage condition for them, that they are unable to help them, then all that information would be there. I really do not see it is a problem.

CHAIR: I think you have answered that well. They would have seen someone who has diagnosed them.

Ms KING: I know that you all bring a range of clinical experience to the committee so perhaps more than one of you might like to provide a response to this. Dr Glasby, in your years of practice, did you routinely make assessments of people's decision-making capacity and their mental health in your regular practice?

Dr Glasby: Yes. In some ways it is a daily occurrence. Often it is obvious that the person has decision-making capacity and they do not have mental illness or any of those sorts of problems. Even if you are not a medical practitioner and you are talking to someone, you can get an inkling that there is some problem occurring or someone is not getting it. Yes, we do that all the time. There are guidelines out there on how to address decision-making capacity so, yes.

Ms Wiley: Can I also say that every patient who is admitted to an aged-care facility is automatically put through what is called a mini mental. Based on the result of that, you have your answer.

Ms KING: Do those assessments occur and are effective whether or not you have a pre-existing relationship with that patient?

Ms Wiley: Absolutely. They are routine.

Dr Glasby: In fact, if I were seeing someone for the first time or if someone had asked me to see a patient, it is a longer process to go through because there are steps that you go through. I have always come from the position that if I am asked to see someone I do not assume previous information or previous knowledge, including X-rays and things like that. I would say that I want to see them myself. I do not just rely on other doctors, because what is the point if I rely on someone else's information or their diagnostic acumen to do it? If they are asking me to do it, I have to start from scratch so it would be a longer process and I would immediately look at the decision-making process.

Ms KING: This is a question for anyone who has done significant work with people at end of life. If a terminally ill person approaching the end of their life expresses a wish to perhaps access voluntary assisted dying, in your experience does that necessarily indicate that they have a mental health condition?

Ms Wiley: Absolutely not, no. Unfortunately, what has happened in the past is that the person these people, particularly if they are in aged care, are most likely to talk to is the nurse. I think it is another great thing about this bill that nurses can have more input than they have ever had before. I asked the Victorian people: if I was a nurse working in Victoria and a patient said this to me, could I go to the doctor and tell him that this was the patient's wish? Their answer was that they did not really know. In Queensland I think most nurses anyway would discuss what the patient had said with them, but the doctor could then go to the patient and say, 'Nurse told me that this is your wish.' Then he can discuss that and discuss palliative care. I think that part of the bill is wonderful.

Ms Hall: From personal experience with my parents, both of them wished to die at the end of their life. My father asked me to help him die and I said no. I believe that he accessed some medication from a friend of his and he took that medication. I have no way of knowing that, but there is no way that he was not very aware of what he was doing. Only a few years ago my mother died in hospital, having thumped the over-bed table when she was speaking to the doctor and saying, 'I want to die. I want you to stop my medication. I want to die.' She was 98. She had a terminal illness. She was clear as a bell. If anyone would say that she was not mentally cognisant, I would challenge any of you at this table here to get into a conversation with her. She was as quick as a whip.

Mr MOLHOEK: One of the more perplexing challenges with the legislation that concerns me is the disparity between South-East Queensland and rural and remote Queensland. Jeanette, you touched on the example of Oodnadatta.

Ms Wiley: It was the furthest away place I could think of.

Mr MOLHOEK: Do you have concerns about how this legislation can work practically in remote and rural Queensland and whether the safeguards and the proposed provisions within the legislation are adequate to deal with the rest of the state equitably, leaving South-East Queensland out of it for a moment?

Ms Wiley: Rob, you have a valid point. I answered the phone calls for Dying with Dignity, which quite often come from the country. Certainly there is a palliative care problem out there. We are getting more financial help for that, hopefully, to train up staff. When Craig and I both worked at Mount Olivet—and I am sure the same thing happens now—they offered that anybody anywhere in Queensland could ring St Vincent's and ask for assistance when it comes to palliative care. It certainly does not solve the problem totally but certainly this interhospital and interprofessional advice—the palliative care specialist does not always have to visually see the patient. It can be done. It is not ideal but it is certainly better than what we have now.

Dr Glasby: Certainly we have seen the value of telehealth with COVID. I see this as having a role for the implementation of voluntary assisted dying. Things like the assessment will have to be done and certainly there are going to be some problems in terms of the sheer geographical remoteness of parts of Queensland. We have seen problems in Victoria where doctors have had to get in their cars and travel hundreds of kilometres; it is going to be even more than that in Queensland. Yes, there will be problems, but that is the challenge that has to be met. We cannot just say, 'No, it is all too hard,' and throw up our hands in the air. There are challenges. I think telehealth has to play a role in this and it is important that we acknowledge that.

Mr MOLHOEK: I want to continue on from the questions that the member for Oodgeroo raised earlier, although I probably have a slightly differing view to him to some degree. I am hearing stories from rural and remote Queensland that in many places people can wait up to three or four weeks just to see a GP. That is becoming quite commonplace on the Gold Coast and Sunshine Coast, where you can wait for a fortnight or longer to see a GP because there is so much pressure on the system. The days of having a traditional GP, a family doctor and all of that, it seems to me, are a thing of the past. How can we be sure that people are getting advice from people who really do have a good connection to them and there is a relationship there and there is trust and a real understanding of that person's needs and emotional and mental state?

Dr Glasby: I think that is a challenge in regional Queensland. I do not know that there is an easy answer in terms of having someone close if you have a very small community, because the small numbers mean that one GP will not have enough work in that area. These sorts of things need to be worked out in terms of people having access to medical practice. I think it is a difficulty that can be worked through.

Mr MOLHOEK: Mount Morgan, which is close to Rockhampton, has not had a permanent GP based at the hospital for 10 years. It has all been locums for the best part of a decade.

Ms Hall: Even locums do leave records on—is it telehealth, Craig? Everything is always recorded. A doctor in Oodnadatta can access in minutes my blood results that were taken in Brisbane. The information is all available. I actually met Steve some years ago. I am well aware that in country areas people do not have the same privileges that we in South-East Queensland do, but all medical information is available to any doctor anywhere. I know about one of your constituents who had some problems because a locum came in who did not know her mother and was very conservative. That information is available. They just have to look at it. It is there.

Mr MOLHOEK: In your submission you mentioned concerns about the need to develop specific advance health directives for dementia, but you did not speak about that earlier. I would be interested to hear your position on that.

Ms Hall: A position on that is really something for the future. This is not a slippery slope. We represent the 20,000 members and supporters that we have. At every public meeting I have ever been to, someone will bring this up. Overwhelmingly it is a concern for our members. In response to their request we have said that in the future, in response to public demand, this be subject to intensive scrutiny and investigation, similar to this inquiry—in the future. It has nothing to do with this bill at this time.

Mr BERKMAN: My question was going to go to the issue of dementia or cognitive capacity and future consideration of that. Extending on the answer that you have just given, do you see a role for the review board that is established under this bill in perhaps being involved in that process of the future consideration of the bill's operation?

Dr Glasby: I would hope that the review board, seeing these cases come across their table, would acknowledge if there were problems and if things came up. I do see the review board's job as putting this before the public and members of parliament. It surely is their job that they should bring Brisbane

this to their attention. Otherwise, what is the point? The review board is there to bring up problems and to bring up possibilities for the future. We should not lock ourselves in, for future generations and future parliamentarians, to what is happening right now.

Mr BERKMAN: You have touched on this very briefly, Jocelyn. Given the prevalence of these issues around capacity, whether that is for folks dealing with dementia or for minors who might have capacity, how would you respond to any future argument that reconsideration of those issues represents the slippery slope?

Ms Hall: I would like the other two to have an opportunity to reply to this as well. It is not a slippery slope, as I said. This is not something that will just start to happen. It will need intensive scrutiny and review by a group similar to this group here.

Dr Glasby: Clearly this is a concern of the community. The members who are on the parliamentary inquiry will have heard this time and time again. We cannot have a meeting without this becoming the central focus of the meeting, so it is clearly a concern out there. It has nothing to do with a slippery slope. These are things that people of Queensland are thinking about right now, so it has to be dealt with at some stage. You will have people knocking on the door all the time talking about this, so it will have to be dealt with. It is in some ways in a different category because of the decision-making capacity aspect of this, so that has to be dealt with as well. As a general practitioner, with this present legislation, if someone came to me with dementia I could not even talk to the person about this. It is in a different category, but it is a matter that everyone is thinking about.

Ms KING: Very briefly, I ask you to outline what would be the real impact on a person, at the end of their life, who had asked for voluntary assisted dying if that process had to be delayed while, say they were in a regional area, a psychiatrist was procured to assess their mental health or their competency, without there being any other indications that those matters were in question?

Ms Hall: My understanding from speaking to people in VAD groups in other states is that people tend to not ask for VAD until the last moment. They have generally and traditionally been through palliative care and hope that that would do. The majority of people say to me, 'I hope I will just die in my sleep.' That is wishful thinking; it does not happen. By the time they come to request voluntary assisted dying, seeing the first doctor, seeing the second doctor, a delay of nine days until they can progress it further—some of these people in Victoria, from the time that they have requested VAD, actually die before the process is completed. That delay may not have a huge impact on some people, but on other people it may be catastrophic.

CHAIR: I thank members from Dying with Dignity Queensland for your submission and your significant contribution here today—and I say 'significant' because between the three of you there is over a century worth of clinical expertise in this area. It is greatly appreciated. Thank you for your time today.

ALEXANDER, Ms Matilda, Chief Executive Officer, Queensland Advocacy Inc.

FOX, Ms Melissa, Chief Executive Officer, Health Consumers Queensland

WIGGANS, Ms Sophie, Systems Advocate, Queensland Advocacy Inc.

CHAIR: Welcome. We will start with an opening statement from you, Ms Fox, and then go to both witnesses from Queensland Advocacy Inc. for opening statements before we move to questions.

Ms Fox: It is a pleasure to share the table with QAI and be with you today. Thank you for the opportunity to speak to you all today. It has been quite a journey for our organisation, for Queenslanders and for many of you.

Health Consumers Queensland has heard, through our statewide consultation, very clearly from consumers. Over the past two years we have heard from over 500 diverse Queenslanders from across the state who have shared their strong support for voluntary assisted dying in an ecosystem of high-quality care at the end of life, high-quality palliative care, and high-quality information and decision-making supports. This will enable individual choice and ensure that all Queenslanders can make the decision that is right for them.

Whether or not they are, as we have heard, living in regional, rural and remote Queensland, whether or not they are First Nations consumers, consumers with a cognitive disability and/or impaired decision-making or those from a culturally and linguistically diverse background, the information and support must be tailored and accessible to them.

Support roles such as nurse navigators must be co-designed in conjunction with the community so that it can meet their needs. Information should be available in a diverse range of methods and mechanisms, again co-designed by them. At the moment, I am pleased to say that we are working with the department of state development to support consumers to revise the information that is on the Queensland Health website now, so it is fantastic to see that continuing now and beyond.

It is also important with access, particularly for rural and remote areas, that the Commonwealth rules around telehealth are revised and changed so that they are not penalised due to a postcode lottery to not be able to access important conversations with healthcare professionals via telehealth.

I would like to finish my speaking notes with a very moving quote from one of the consumers we have heard from on several occasions around this issue. For us it highlights the situation for Queenslanders now and why it is important that this bill is introduced and that the supports are put in place. He states—

Having the right to choose for my end of life meaning voluntary euthanasia and not having to travel to another state to access it, I am facing going through to stage 4 of metastatic melanoma and ceasing all treatments due to it not working. So now I live with my wife in Queensland, but I am originally from Victoria and still own land there and have family down there. So when it gets to the end of my life and I do not want to be a burden on my wife anymore, I am now facing the choice to potentially have to move to Victoria with my family for a period of time so that I can access my right to choose euthanasia there. This potentially means my wife may have to stay in Queensland as she is our sole income earner now. So due to it not being legal in Queensland, I may have to be apart from my wife towards the end of my life for an extended period which is not right and not fair on her.

CHAIR: Thank you very much, Ms Fox. We will come back to questions. Ms Alexander, would you like to make a statement?

Ms Alexander: Thank you to the committee for the opportunity to take part in this public hearing. We would like to begin by acknowledging the traditional owners of the land upon which we meet, the Turrbal and Jagera peoples, and acknowledge the experience of First Nations Australians with disability and the intersectional disadvantage they experience. We pay our respects to Aboriginal elders past, present and emerging, including our president, Byron Albury.

QAI is an independent community based organisation and community legal centre that advocates for vulnerable people with disability. Our mission is to promote, protect and defend the fundamental needs and rights of vulnerable people with a disability in Queensland. Our management committee is comprised of a majority of persons with disability whose wisdom and lived experience is our foundation and guide.

QAI has an exemplary track record of advocating for systemic change and we have provided services for over a decade through the human rights legal services, mental health legal service and NDIS appeals practice. The work of our human rights legal service has increasingly been focused on capacity assessment matters and we represent numerous people with disabilities in QCAT on these matters. This work has given us insight into the skills deficits within the medical profession in performing capacity assessments, in particular in accordance with the Queensland Capacity Assessment Guidelines 2020 and the principles of supported decision-making.

Since its inception—it has been a long journey, as you were saying—QAI has maintained a firm opposition to all forms of euthanasia. However, contemporary considerations have moved our organisation away from this definitive stance, and opposition to euthanasia is no longer contained within our guiding principles. The tabling of this particular bill before parliament, along with the consideration of the developments in medical care, the growth in human rights culture and lessons learned from other jurisdictions where voluntary assisted dying is legal have prompted a timely review of our stance.

QAI upholds the right of people with disability to exercise individual autonomy, self-determination and the freedom to make one's own choices, and this extends to decision-making regarding end-of-life care including accessing voluntary assisted dying. However, because this issue is literally life or death, there has never been a more important time to put the human rights of people with disability at the forefront of our considerations; to remember that people with disabilities are more likely to be the victims of coercion and abuse by carers; to remember that the medical profession has often failed to understand people with disabilities or to assist people with disabilities to live, let alone to live autonomous lives; and to recognise that there is a fear in the disability community that these factors will result in the facilitation of death through voluntary assisted dying. For these reasons, we need to ensure sufficient safeguards, including legislative, cultural and resourcing changes, that will endure for as long as the voluntary assisted dying scheme exists.

Supported decision-making is a diverse and empowering concept that must be at the heart of safeguards for many people with disabilities. Supported decision-making means doing things differently so that diverse voices can be heard through a cloud of vulnerability and abuse. Supported decision-making can include funding specialised disability advocates, allowing communication aids, recognising informal supports or providing structured peer support. We need to have absolute confidence that every person involved in the voluntary assisted dying process has a deep understanding of supported decision-making and we need to ensure that this deep understanding is underpinned by sufficient accountability and resourcing so that we can have confidence that every decision is full, free and informed in the deepest and most meaningful way. I will hand over to Sophie to describe some of the safeguards we are supporting.

Ms Wiggins: Legalising voluntary assisted dying must only occur alongside initiatives that seek to change ableist community attitudes that devalue people with disability. These attitudes will undeniably influence decision-making within the context of voluntary assisted dying which will both be influenced by and will continue to perpetuate negative and potentially fatal perceptions of people with disability in the community. There must be rigorous monitoring of disability services and palliative care services, both of their efficacy and their availability to all Queenslanders.

We recommend embedding access to psychosocial support within the scheme, including ensuring there is autonomy of choice over the support. This is so that the person's pain and suffering of all levels can be addressed and will also help to ensure the person has exhausted all available support services as well as help them to identify potential situations where they may be experiencing abuse or coercion.

We recommend consideration of regularly rotating healthcare professionals in key decision-making roles in order to avoid them becoming desensitised to their decision-making and to the gravity of its consequences. We recommend embedding access to appropriate support for Aboriginal and Torres Strait Islanders, people from culturally and linguistically diverse background and people from the LGBTIQ+ community into the scheme in order to ensure critical conversations remain appropriate throughout. We also consider that the oversight board must include people with lived experience of disability, including of the medical conditions that are typically associated with uptake of voluntary assisted dying. We also recommend including and ensuring that information about rights and protections, such as the prohibition on doctors initiating conversations about voluntary assisted dying, is provided to people seeking access to the scheme alongside requisite information about appropriate complaints processes.

CHAIR: Ms Wiggins, we might move to questions with the time remaining. I know that you have put a submission in with those recommendations and we do appreciate it. I will ask that all members, in the interests of time, try to shorten their preambles—I know we are putting questions in context—to give as much time as possible for responses from witnesses.

Mr ANDREW: Have you taken into consideration that Queensland is a unicameral parliament and that the people who are in power at the time are in full power? There is no oversight of a senate or an upper house. Have you taken that into consideration in your findings?

CHAIR: Before we ask that question, I might get some advice. Member for Mirani, you might have to come back to the context of the bill.

Mr ANDREW: The context of the bill is that—

CHAIR: I do not want to get into an argument. I will come back to you in a moment, but that is not relevant to the bill before the House. I do not want to rule on it, but if you perhaps take a moment I will come down and see you.

Mr ANDREW: I can go with another question. You spoke about palliative care. We had people give information yesterday that hopelessness, due to the lack of palliative care, was present in regional Queensland. Have you looked into this? Have you seen any sort of trends in that respect because of the hopelessness due to no palliative care being available?

Ms Fox: I can speak to that in terms of what we have heard from Queenslanders across the state. There certainly are shortages of access to high-quality palliative care. We are pleased with the increase in investment that we have seen from the government. That is why we have always seen high-quality aged care, palliative care and end-of-life care as important whenever we talk about voluntary assisted dying. What we do not want is people feeling that that is their only option because they do not have access to high-quality palliative care. That needs to be a part of any kind of assessment and assisting people to get the care they need regardless of where they live.

Dr ROBINSON: I have two areas of questioning. One is in terms of embedding access to psychosocial support, which is a comment which comes from Queensland Advocacy Inc. The second question is around disability. In terms of embedding access to psychosocial support, can you clarify whether that is occurring in the legislation now without psychiatrists being mandated in the legislation as a safeguard? Would you prefer to see it mandated? Would that provide further protections to those consumers from disabled backgrounds that you represent?

Ms Wiggans: We would not necessarily be wanting anything to be mandated in that regard as we want to preserve the autonomy of choice and control for people with disability as much as possible. The recommendation in relation to psychosocial support was more in relation to recognising the expertise of allied health professionals such as social workers and psychologists who have expertise in communication skills and talking to people who might be experiencing situations of abuse or neglect and recognising the role that that level of expertise can play as an additional safeguard. We know the power dynamics of abuse are that sometimes people do not realise they are in situations of abuse and control. Having access to allied health professionals who have the required skills and background in understanding what those situations are, picking up on red flags in those situations and being able to handle those conversations in a very delicate and competent way would be a critical safeguard that we would be pushing for.

Ms Alexander: It is really more about resourcing than it is about legislation because we do not want it to be a requirement. That level of support could also be from a specialised disability advocate.

Dr ROBINSON: In the *Second annual report on medical assistance in dying in Canada* where nearly 7,600 Canadians' lives were taken under VAD type legislation in 2020, it said that, of those almost 7,600, 322 people who needed disability support services did not receive that support in any way in terms of that very important decision about whether to end their life. Some have argued that there is no slippery slope. I think we have gone beyond the slippery slope. This was not anticipated when the legislation came into Canada, but it is where Canada ended up. How would you guarantee that we do not end up in the same place with VAD laws—that is, those who are disabled not having the support they need to make a very important decision?

Ms Wiggans: I would argue that that is a very real concern that people within the disability community have. We know that people experience many challenges accessing the support services they need. Again, we would be arguing that, if this were to be introduced into Queensland, it must only be introduced in a situation where that situation does not arise and that it can only be in a situation where people have proper access to the support services they need. That must be a critical safeguard to avoid the situations that you have described.

Dr ROBINSON: I appreciate the theory and intent of that, but that is not what happened in Canada. I do not see any protections in this bill that stop it going that way now—with no specialists, no psychiatrists and two doctors who do not even need to know the person. How do we tighten up the safeguards in this bill that are not currently tight so that for those in the disability sector we can say from this point forward that not one of them in Queensland—not like the 322 in Canada—would have that happen to them in Queensland? I want those assurances from medical experts before we pass the bill.

Ms Alexander: One of the safeguards we have recommended is that all patients be provided with information about the scheme, including the safeguards that are available. One of the questions they might ask is: did the doctor initiate this discussion with you or did you self-initiate it? In that information you could also have: have you been provided with access to the supports that you need?

Ms Wiggans: That could also be tied back to access to that psychosocial support that we referred to earlier. If we were to draw upon the example I gave before of the skills and expertise of, say, social workers, their knowledge of the disability support service sector could really be drawn upon in that situation. They could be helping the person to make sure they have exhausted all available options and there is not any other support they could be accessing.

Dr ROBINSON: That would be a nice world.

Ms Alexander: You could make that information as prescribed information that is provided to patients.

Mr MOLHOEK: Matilda, earlier you mentioned that QAI had changed its position on VAD. Can I ask why? What was the catalyst for changing your position on making VAD available to people with disability?

Ms Alexander: We had held our position since the 1990s. At that point there was not a lot of experience worldwide of how these schemes might work. In terms of the slippery slope argument, for example, we now have abundant evidence that it is not a slippery slope and that that is not a very realistic fear. Having a greater amount of evidence in front of us, we were able to re-evaluate that. Having said that, though, it is still contentious. There are still concerns within the disability community as I extrapolated. Our perspective has grown and changed. There are significant safeguards here and additional ones that we could suggest.

Mr MOLHOEK: With regard to the safeguards—and I think Melissa also commented on this—is it your view that there are enough safeguards in the legislation as proposed or are you suggesting that there need to be further safeguards in respect of people with disability?

Ms Alexander: We have articulated further safeguards that we would suggest.

Mr MOLHOEK: And they are not currently covered in the draft legislation?

Ms Alexander: A lot of them are things like what we were just talking about like resourcing. In terms of the palliative care commitments that Melissa was talking about, there is no guarantee that they would continue on beyond the life of this parliament or beyond the life of the financial year—I have not looked at the detail of it, those kinds of financial resources. We talked about cultural safeguards, legislative safeguards and resourcing safeguards. All of those need to be upheld for it to be an entirely appropriate scheme.

Ms Fox: We would say that this is why it is important that consumers, carers and NGOs such as ours are involved in the implementation, oversight and evaluation of such a scheme: so that we can bring the insights we are hearing from our members, look at information from overseas about what has worked and what has not and hold the government of the day to account around those commitments and safeguards and how they are rolling out.

Ms Wiggans: I quickly add in relation to safeguards that we note the contributions of other organisations to this inquiry. For example, one that we would endorse is from the Queensland Human Rights Commission that recommends that one of the witnesses should not be a family member and must be completely independent of the person. That is something that we would support as an additional safeguard.

CHAIR: Postcode lottery: that is the first time I have heard that term, Ms Fox. Perhaps you could talk about some of the challenges and solutions. QAI might have a position on access and equity.

Ms Fox: We use it a lot across many areas of health. Those of you whose constituents are in rural and remote areas know that it is the reality for many that they do have the same access in the place they live to the wide range of services that we are fortunate to have in South-East Queensland. That can be due to workforce shortages or, in some cases, the small number of specialists or patients who require that specialist care.

CHAIR: I apologise, Ms Fox. It should have been in the context of telehealth and the carriage service law that has been flagged in the bill.

Ms Fox: We have seen some of those barriers to care. In terms of the postcode lottery, we saw it reduce with an increased use of telehealth during COVID. Unfortunately, I understand that we are back to the numbers that we were at pre COVID around the use of telehealth. In this instance, it is of grave concern that health professionals are not able to use telehealth to have these important conversations with consumers and their families. It is very important that that change.

CHAIR: Do you have any commentary around the Commonwealth carriage law access? I will come back to you on that if we have time.

Ms PEASE: I wanted to go back to the eligibility for accessing voluntary assisted dying, particularly for people living with disability. Are you comfortable with the requirements being that the person has been diagnosed with a disease, illness or medical condition that is advanced, progressive and will cause death and is expected to cause death within 12 months and is causing suffering that the person considers to be intolerable, particularly in terms of people who are living with a disability?

Ms Alexander: Yes. From a human rights perspective, our main concern would be where the criteria of disability is the sole criteria for a scheme of voluntary assisted dying. That would not be in compliance with the Convention on the Rights of Persons with Disabilities. As this has those additional criteria which are not related to disability, this is a more acceptable scheme.

Ms PEASE: Do you think that people who are living with a disability have equitable access to voluntary assisted dying or would potentially have access to it?

Ms Alexander: Not exactly equitable. Are you talking about capacity assessments?

Ms PEASE: I guess what I am also alluding to is what you spoke about earlier—I do apologise as I cannot remember the name; I should have written it down—the support person—

Ms Alexander: Supported decision-making.

Ms PEASE: How do you envisage that working is what I wanted to ask?

Ms Alexander: It is as diverse as there are people with disabilities. For some people it might mean a sister or an aunt coming with them to the doctors to fully explain what is happening. For some people it might mean that a one-hour consultation takes two hours. For some people it might mean using communication aids. For some people there are funded disability advocates who can assist. Those kinds of programs should be expanded. There are funded peer support programs as well. These kinds of things can assist somebody who, without those kinds of adjustments, would not otherwise have their voice adequately heard. We are not just talking about an ability to say yes or no flat out, if you asked somebody on the street. We are talking about with a whole lot of support. With every kind of adjustment and help we can give, how can we get that voice heard?

Ms KING: In your view, with those aids and supports, should Queenslanders who have a disability have the same or be able to experience access to a voluntary assisted dying scheme should they wish to?

Ms Alexander: Yes, if they have all those supports. The principle of supported decision-making is that it puts you on par with somebody who does not need those supports.

Ms Fox: Supported decision-making for consumers with a cognitive disability and/or impaired decision-making capacity should exist across the spectrum of decision-making capacity. They should be given information so that they can have their decision-making input maximised into what they want for their life.

Ms Wiggans: That is why we have referenced in our submission the Queensland Capacity Assessment Guidelines as being critical to any training that those involved in the scheme would undergo. They would need to demonstrate sufficient knowledge and competency in applying those supported decision-making principles that Matilda was explaining which are embedded into those capacity assessment guidelines.

Mr BERKMAN: It is so very important that the voices of the disability community are central to this discussion and our consideration of the bill. I have found your observations around the need for legislative, cultural and resourcing safeguards very helpful. Without wanting to shoebox your answer too much, is it QAI's view that, broadly speaking, the legislative safeguards are in the place they need to be, but the focus is much more on the cultural and resourcing safeguards that the disability community needs to ensure they are properly catered for and those safeguards meet the needs of the disability community under a scheme like this?

Ms Alexander: Yes. I would not say the legislative framework is perfect. There are some amendments that we suggest. Broadly speaking, I think the cultural and resourcing safeguards are the ones that are still up in the air.

Ms Wiggans: And will ultimately determine the way in which this model is played out. They are critical.

CHAIR: Can those be implemented in an operational clinical governance way? We heard from Indigenous representatives in Townsville that, in terms of the care navigator service, Aboriginal and Torres Strait Islander representation needs to be considered. Do you think that should be part of the implementation if the legislation is passed?

Ms Alexander: Absolutely. The lived experience of people with a disability also needs to be considered.

CHAIR: One hundred per cent.

Dr ROBINSON: In terms of the legislation understanding disability, are you aware that the legislation does not define disability? Does that cause any concern in terms of potential impacts on those with a disability? I am talking about the tightness of the legislation. We are talking about a very serious piece of legislation, as opposed to some other bills that impact far less. Without it being clearly defined, how do you know what rights are being protected—again, dealing with what I think are not enough safeguards in the bill?

Ms Alexander: In relation to which part of the legislation? For example, capacity is defined—

Dr ROBINSON: It does not even define disability, so how do you know what you are dealing with to start with? If we open the lid on this, the lid does not go back on. How can you be sure that you are defending the rights of disabled people when it is not even defined in the legislation?

Ms Alexander: Disability is defined in other pieces of legislation so I am not quite sure what you mean about this piece of legislation defining disability. The Disability Discrimination Act defines disability. The NDIS Act has its own definition of disability. I am not quite sure what section you are talking about. Do you mean there is a particular section within this bill that talks about disability that is inadequately defined?

Dr ROBINSON: My understanding is that it does not define disability at all so how do we know what we are dealing with in this piece of legislation to ensure that the rights and safeguards of disabled people are built into the legislation? Once you put the legislation in, it is almost impossible to repeal. Once this happens, there is no going back. As consumer advocates for disabled people—especially knowing what has happened in Canada and other parts of the world in terms of the slippage—if this is not even defined in the bill, how do we know our starting point for protecting the rights of disabled people?

Ms Fox: Without being a legal expert, I would guess it is because disability is not a criteria within the core criteria we heard about today. However, if the committee gives careful consideration to QAI's amendments and recommendations and if it is legislated to have increased safeguards for people with a disability then perhaps there could be reference to the other pre-existing definitions of disability.

CHAIR: With that said, I thank both Health Consumers Queensland and Queensland Advocacy Inc. for their significant contribution today. It has helped inform the committee.

Proceedings suspended from 1.19 pm to 1.46 pm.

MOSS, Ms Michelle, Director Policy and Strategic Engagement, Queenslanders with Disability Network

ROWE, Mr Geoff, Chief Executive Officer, Aged and Disability Advocacy Australia

TAYLOR, Mr Douglas, Dementia Advocate with Dementia Australia, Dementia Awareness Advocacy Team (via teleconference)

WILLIAMS, Ms Karen, Principal Solicitor, Aged and Disability Advocacy Australia

Mr Rowe: Thank you for the opportunity to meet with the committee today. Karen and I are representing Aged and Disability Advocacy Australia as well as ADA Law, our community legal centre, which is funded by the state and federal governments. We will take our submission as read.

ADA, being an advocacy organisation—a fairly simple way of putting it is that we try and give older people and people with a disability a voice. If you are asking what is ADA Australia's view, our view is the view of the people we support. As you would expect, there is a broad cross-section of views: from people who are highly supportive of the VAD to people who are quite concerned about the legislation and its possible impact. We believe that, while we are broadly supportive of the VAD, it has to be based around human rights, and those rights include the rights of older people and people with a disability to have a choice about the decisions around end of life. There also need to be safeguards so that for both those cohorts we are very clear about what it is that they want and what their intentions are.

One of the things we are concerned about, given a number of you will have seen the recommendations from the aged-care royal commission—and we are expecting a similar recommendation from the disability royal commission—is that often people in care, be it aged care or disability care, do not have a lot of choice about their healthcare providers. They do not have a say about who their doctor is and they are not encouraged or supported to access health services outside the facility they are supported in. When you are talking about a state like Queensland, which is very much regionalised, many people in regional and remote Queensland do not have a choice of service provider. It is essential that, if a service provider is not supportive of the ultimate legislation that comes in, there are safeguards in place to make sure that people can access the scheme irrespective of the faith or other views of their accommodation provider. They are an accommodation provider and a support provider; they are not a decision-maker for the individual.

The last comment I want to make—and we have raised it in the submission—relates to advance health directives. We believe that it is really important that the scope of advance health directives over time is changed so that people's views can be captured. We know that many older people lose capacity associated with dementia. It would be quite unfortunate if their long-term desires and wishes were not recognised. While it may not be in the scope at the moment, I would be encouraging the committee to make a recommendation that advance health directives are considered when the legislation is reviewed and would also direct them to the mental health advance health directives, which have been a fairly recent initiative in Queensland and a very good initiative. Essentially, the mental health advance health directive is a health directive made by a person when they are well as to what they would like to happen to them when they are unwell, because when they are unwell they are deemed to not have capacity.

My closing remark in relation to capacity—I always like to say this—is that capacity is not like pregnancy. With pregnancy, you are pregnant or not. With capacity, people have capacity to make a whole range of decisions. We need to be really careful that we do not look at someone and say, 'You do not have capacity to make that decision.' We need to think about what supports they need to make those decisions.

Ms Moss: QDN is an organisation of, by and for people with disability. We have over 2,000 members across the state and represent people with a diverse range of disabilities. We welcome the opportunity to present at this hearing. Our members have provided significant feedback on the issue. Like Geoff said, there are divergent views, but our position would be in principle to support the bill and the right for people to have choice about their end-of-life care. It is really important that this is accompanied by a range of safeguards and protections to balance that right. It is really important that people are able to access well-resourced options for people at their end-of-life supports.

Choice and dignity are fundamental for end-of-life care. Human rights need to be considered. We also think this needs to be accompanied by a skilled and knowledgeable workforce across both health and disability. We know that people with disability need support to understand their rights and options and the responsibilities of healthcare practitioners. We hear reports all the time from people

with disability in accessing health care that often people are not given the information—often that is given to carers, workers or family members—and that delivery of person centred care is often something that is challenging for people to experience. We hear reports of the unconscious bias about people's life and the quality of their life that people experience as they access health care by a whole range of different practitioners. It is a really important consideration in the safeguards around voluntary assisted dying to ensure that bias and unconscious bias does not permeate into the information that is given to people and the decisions that are made.

It is really important to understand and acknowledge the diversity of disability and the need for targeted strategies to ensure the full range of people with disability and their information needs and communication needs are considered. We would also support that people with disability need access to quality end-of-life care, including well-resourced and adequately funded palliative care. We would support, as Geoff has talked about, that decision-making issue and people's capacity and assumed capacity to make decisions and the safeguards that need to be in place, particularly around the coercion and supported decision-making.

People with disability considering voluntary assisted dying need access to professional psychosocial support and disability advocacy that is independent and not biased. We believe that there need to be monitoring mechanisms in place to ensure that, across health, palliative care and disability services, people are receiving effective and high-quality care. The safeguards around the requirements relating to qualifications and training of participating practitioners need to ensure that the workforce supporting people, whether it is the health workforce or the disability workforce, are adequately skilled to be able to effectively understand disability and the needs and to communicate effectively with people.

Mr Taylor: Thank you for the opportunity to address the committee today. I am speaking more as a dementia advocate and providing a personal view from my personal involvement. Some 27 years ago I witnessed my father-in-law, Cecil Morrison, die from Alzheimer's disease, dementia. His death was agonising to witness. In the end stages of his life, he was no longer able to perform even basic tasks to keep himself alive. In between his neurological damage and his muscle weakness, he had lost the ability to coordinate even simple body movement such as his inability to eat or drink appropriately without damaging his own health. It is likely what finally caused his death with pneumonia. He had not walked or talked for two years or more before his death.

I do not want to see my wife, Eileen, die in the same distressing way. Her dementia is genetic early Alzheimer's disease that she has inherited from her father. She is now at an early stage in her dementia journey and there are some signs, such as word and name finding that she struggles with and concentration, but she still can think and rationalise outcomes and choices and still has capacity, in other words.

This bill rightly limits people without capacity to make decisions such as choosing the voluntary assisted dying option; however, our argument is that the bill is too black and white. I like what was said earlier about capacity being unlike pregnancy. It offers no other option. You are either eligible or ineligible based upon your capacity. That extreme has led people, I believe, over the years to either commit suicide or even murder people. What we ask for is this bill to have the option for the person to have the right to decide while they have capacity.

Before being enacted in law, the bill can include and accept an advance health directive made while a person still has the capacity to choose. Surely a person living with dementia has a human right to decide while they still have that opportunity. What we are arguing for is, firstly, that people living with dementia whose capacity for decision-making remains intact should be eligible for choosing a voluntary assisted dying option and that family members be included in the assessment in the assisted dying decision-making process with the person's consent and with the proper protections for the person living with the dementia. Thirdly, we believe that the right of a person living with dementia to be fully informed is upheld and that medical practitioners are suitably trained in dementia care.

Fourthly, we would argue that people with cognitive degenerative disorders such as dementia can make enduring requests for voluntary assisted dying in their advance care plan; fifthly, that psychological pain be acknowledged along with physical pain; sixth, that the application of a time frame is neither desirable nor necessary but, rather, alternative eligibility indicators need to be considered such as the severity of symptoms and the decline in the quality of life or function; and, seven, that a health professional and the person with dementia's power of attorney are solely responsible for determining the appropriate time for that choice that the person makes.

Dementia is a terminal and untreatable condition which presently affects about 459,000 people in Australia and about 87,000-odd in Queensland. We consider that people with living with dementia should have the same human rights as others when it comes to end-of-life choices, with regard to Brisbane

both palliative care and voluntary assisted dying. We request that the committee respectfully deliberate on our arguments made on behalf of the many people living with dementia, their families and their care partners. I thank you for the opportunity for us to be able to share our views on the subject.

CHAIR: Thank you, Mr Taylor. I will stick with you for a moment and talk about those half a million people in the nation with dementia. In the 40 Queensland public hearings we had in the inquiry to consider whether a VAD scheme should be introduced—and we are at that point now with the bill—we heard time and time again from people and we made some recommendations around that in our original inquiry for the Queensland Law Reform Commission to look at this. It does not at this stage remain as part of the bill, but I just want to say that you have absolutely been heard around capacity and I know that this is something that continues to be discussed. I welcome your comments. I will move to questions from the committee.

Mr MOLHOEK: I would like to raise some questions with Aged and Disability Advocacy Australia. I want to understand how many members you have and the composition of your organisation. Are there particular interest groups or groups that are strongly part of the organisation? Just tell us a bit more about ADA.

Mr Rowe: This year will be ADA's 30th year. We are a statewide service. We have offices in Cairns, Townsville, Rockhampton, Bundaberg, Sunshine Coast, Gold Coast and Toowoomba and two in Brisbane. We support probably about 3,000 people each year across the disability and aged-care sectors, working with older people who are users of the Commonwealth funded aged-care system or seeking to use those services. As I mentioned in the opening, we also operate ADA Law, which I suppose targets people 18 years and above who have their capacity questioned and support them through the QCAT process. We also host the Aboriginal and Torres Strait Islander Disability Network of Queensland. Our reach, while it is not huge, it is not insignificant. We are the sole provider of aged-care advocacy, we are probably one of the largest providers of disability advocacy and certainly Karen's service is quite unique. We are a company limited by guarantee and, I suppose for history, we used to be referred to as Queensland Aged and Disability Advocacy, or QADA. We have specialist advocates in the area of CALD and Aboriginal and Torres Strait Islander issues.

Ms Williams: Elder abuse is another.

Mr MOLHOEK: Are you primarily a volunteer organisation?

Mr Rowe: It is a company limited by guarantee. We were an incorporated association, but about three years ago we became a company limited by guarantee with a board of directors that set the strategic direction for the organisation and provide governance.

Mr MOLHOEK: In terms of looking at Queensland, someone earlier today referred to it as 'postcode lotto'. I would prefer to think of it as a two-tier state. There is South-East Queensland, where there is a plethora of services—although there could always be more, I guess—but then there are rural and remote parts of Queensland and regional centres. Are you concerned about how the opportunity for people to take advantage of what the legislation is offering is limited or risky in other parts of the state where there is not the networks of GPs and palliative care support and hospice services?

Ms Williams: There would be concern. A lot of it is around education. I will just use medical understanding of capacity as an example. Over the years I have noticed that there is a greater understanding of a more nuanced capacity assessment. Some people have capacity for some things and not others and it is not good or bad or black and white. That understanding used to be not well understood by the medical profession. That has grown over the years and things like the Capacity Assessment Guidelines that have been recently released assist in that. Education services and the like just narrow as you go further out. It is on organisations like us to try to use the networks that exist across the state. Having footprints in Cairns, Townsville and Rockhampton, our advocates based there work really hard to stretch out into other parts. Yes, there is a challenge there, but we are more connected now as a state than before.

Mr MOLHOEK: That actually leads me to my next question. In terms of that connectivity—we have heard a lot of discussion around telehealth and remote areas—I know that things have changed a lot, but there was a time when a lot of seniors particularly did not have computers let alone access to the internet. In terms of your constituency, is there access to computers and Skype or Zoom and all those sorts of platforms?

Ms Williams: It is changing. There is still a very big digital divide, I have to say, and government agencies are changing in their utilisation of digital platforms as well. There is definitely difficulty there. Some of our clients would have communication disabilities, and the face-to-face format always wins

out to make sure you are capturing what it is they are wanting to get across. There is difficulty there. Particularly the audiovisual, where you can capture the non-verbals, is very good for health professionals.

Mr MOLHOEK: Geoff, earlier you touched on the concept of safeguards, and I note in your submission you are not saying you are for it or against it; you are just saying, 'If it goes ahead, this is what we want.' Do you think there are enough safeguards in place for vulnerable Queenslanders in remote and rural areas outside of South-East Queensland?

Mr Rowe: That is a really broad question. I refer to recommendation 106 from the aged-care royal commission. What they found was that for older people accessing aged care there were not sufficient resources invested in advocacy or independent support provided to vulnerable elder people so that they can raise issues and concerns. To the credit of the Commonwealth government, in the recent federal budget it has tripled its spend on aged-care advocacy services and we will see that rolled out the next 12 months. We will see something like an additional 30 aged-care advocates being located across the state. Picking up Michelle's comment, it is the same for disability. People at times do not know where to go for help so will seek the assistance of an advocate or are not confident enough to raise their concerns.

Picking up on the comment Karen made about older people becoming more tech savvy, that is absolutely true, but what we know about dementia is that the last skill acquired is the first skill lost. That is why you see people who have lived in Australia for decades and have spoken English for decades revert to their native tongue, because they have lost that. In terms of my generation, while I have been happy playing online for the last 30 years, my mum lost that skill several years ago. Information needs to be made available in a whole range of formats, not just relying on IT.

Dr ROBINSON: There are probably several different areas we could look at and discuss, but I am interested in your feedback in terms of the direction this legislation intends to go—very similar to what is in Canada and European countries. In a recent report in Canada, 7,595 Canadians had their lives ended through a similar thing to VAD. Of those, 322 people who needed disability support services as part of that decision-making process did not receive those support services. For me, this goes beyond a slippery slope; we are seeing it happen. We are seeing what has happened somewhere else that is going to come here. How can we ensure this is not 322 Queenslanders if we let this legislation go through?

CHAIR: It is a bit of a hypothetical question. You are dealing with another VAD scheme in another part of the world.

Dr ROBINSON: I would argue that this is happening in a Western country and I think that is your opinion.

CHAIR: Please do not disrespect the chair.

Dr ROBINSON: I am not disrespecting the chair.

CHAIR: I will allow some latitude. Let's remember that Mr Taylor is on the phone as well. Whoever wants to take the question, I will allow some latitude in the answer.

Mr Rowe: VAD is not a solution to inadequate disability services. You will have seen a campaign headed up by QDN and ADA recently regarding the need for disability advocacy services in Queensland. We say that people need to be supported to make that decision. We have some very good disability support schemes in Australia. We know that in Queensland there are about 900,000 people who identify as having a disability. I do not see that it is necessarily a slippery slope. I think it is the responsibility of our elected members of parliament to make sure that the legislation has the necessary safeguards, that people have the necessary support to be able to make an informed decision and also that people at the end of the day make the decision they want to make.

Mr BERKMAN: We appreciate your being here today. I am interested in QDN's and ADA's view on this. QAI appeared just a moment ago, and in the context of safeguards they talked about the need for legislative, cultural and resourcing safeguards and, without meaning to verbal them, essentially their evidence was that, on balance, the legislative safeguards are pretty close to the mark and their focus was much more on the cultural and resourcing safeguards that are needed under a scheme like this. Do you agree with their position or could you share your view on that?

Ms Moss: Yes, we would support that position. I think it is a cultural shift, as I talked about—that unconscious bias and understanding of disability that people with disability experience day to day. In accessing health care, there is a bias that a person's life is not a quality life because they have a disability, that they do not understand what is going on. There is an assumption that they do not

talk to the person or treat the person, and I think there is some very significant cultural change and education that needs to go across our health care. That has been recognised in the disability royal commission and some of the findings of the commission that have already been handed down.

We have already talked about the resourcing issue around advocacy and access to advocacy, but I think people also need access to information that helps them understand their rights and the choice they have across the spectrum of end-of-life options. Likewise, we have a disability workforce that has shifted away from the medical model, which is important and needs to focus on disability supports. That has meant that that workforce does not have the medical and health information, knowledge and skills. I think there is a need across that disability workforce about supporting people from that basis of choice across their end-of-life choices from palliative care so that if the person chooses voluntary assisted dying that is also done without a bias around that and how people are treated and, in relation to Geoff's point earlier, upholding people's rights and their decisions.

Ms PEASE: Thank you very much for coming in. Mr Rowe, you mentioned in your opening statement that people who are aged and people living with disability do not always have a choice as to where they are accommodated or housed and that this accommodation is an accommodation provider rather than a decision-maker. With respect to that, and in light of this piece of legislation, what do you and your organisation think about the requirement for residential aged-care facilities and hospices or entities that are conscientious objectors and what is your position in relation to that?

Ms Williams: We put that in relation to clause 98 in our written submission to make sure that people know that, even if the organisation is a conscientious objector, they will not put a barrier in place if a person takes the decision they want to access the scheme.

Ms PEASE: How do you imagine that would actually work? If an entity has made the decision that they are not going to provide it and someone is ill or unable to be moved, how would that work practically?

Ms Williams: Part of it would be through targeted information so that people know—they have a perspective of wherever they are living—and then accessing services such as QAI, ourselves or QDN. We would have information available as well.

Ms PEASE: What I am getting at is a situation where at the end of life someone has gone in there, they did not think this would come up, they have changed their mind, they are now very poorly, very ill or not in a position to be relocated, and an entity that is conscientiously objecting is not allowing them to have those conversations. How do you imagine that would work? What advocacy could you do on behalf of that particular resident?

Ms Williams: It is a bit difficult to anticipate all of that, but it is certainly not an unusual setting for us to provide advocacy currently, although not around VAD issues, around decision-making issues and other negotiations that we have in aged care and disability care in health systems.

Mr Rowe: Aged-care providers do not get a choice about whether or not an advocate is allowed to come in. It is part of the legislation. I am hoping that the new rights based legislation in aged care will reinforce that. Our Queensland Disability Services Act is rights based and again supports the involvement of advocates. It is a journey that we need to go down. As I said in my opening comments, I am quite concerned that often people in regional Queensland have a choice of one provider, and that one provider needs to be able to leave the gate open for people to access the scheme—end of story.

CHAIR: We are at the end of this session. Mr Taylor, I draw your attention to the full report of the Queensland Law Reform Commission, which delved into that issue of advance healthcare directives and dementia. I am sure you have read it, but I do thank you for sharing your personal stories and for your advocacy in this space.

COSTELLO, Mr Sean, Principal Lawyer, Queensland Human Rights Commission

McDOUGALL, Mr Scott, Human Rights Commissioner, Queensland Human Rights Commission

CHAIR: We would ask you for an opening statement. Human rights is an important aspect with regard to the bill. I will move to questions after your opening statement.

Mr McDougall: Thank you, Chair. May I begin by acknowledging the traditional owners of the lands we are gathered on and note the significance of the issues raised by this bill for Queensland's Aboriginal and Torres Strait Islander people across the length and breadth of the state.

As Deputy Director-General Professor McNeil noted at the public briefing on 14 June, the looming issue in the consideration of this bill—and probably the most difficult challenge in its implementation—is ensuring equitable access to adequate levels of palliative care and to the voluntary assisted dying scheme itself. Under section 39 of the Human Rights Act, the committee is required to report back to parliament about whether the bill is not compatible with human rights and the statement of compatibility.

In our written submission to the committee we have identified a number of rights protected by the Human Rights Act which are engaged—meaning that they are either limited or promoted—by the proposed VAD scheme, including: section 15, the right to enjoyment of human rights without discrimination; section 16, the right to life and not to be arbitrarily deprived of life; section 25, the right not to have a person's privacy unlawfully interfered with; section 29, the right to liberty and security; section 17, the right to freedom from torture as well as from treatment that is cruel, inhuman or degrading; section 37, the right to access health services without discrimination; section 20, the right to freedom of thought, conscience, religion and belief; section 26, the right to protection of families and children; and sections 27 and 28, cultural rights, including those of Aboriginal and Torres Strait Islander people.

As the number of rights upheld and limited demonstrates, human rights legislation cannot provide a definitive answer about whether laws such as this should or should not be passed. Rather, the Human Rights Act provides a framework to assess if such laws are reasonable and proportionate. In our submission we made suggestions as to how aspects of the statement of compatibility could be enhanced to provide greater justification for some of the limitation on the rights.

In considering whether a limitation on a right can be justified, an important consideration will be the adequacy of the safeguards provided for in the bill. It is clear that in formulating the bill the Queensland Law Reform Commission was mindful of the tension that exists between, on the one hand, the need to provide effective safeguards to those individuals whose rights are at risk and, on the other, the need to ensure equitable access to the scheme by everyone in Queensland.

It is also clear that there were two significant factors considered in striking the balance that is set out in the bill. The first is the need to increase the level of funding from a relatively low base to a level that will prevent a situation in which a person could be influenced to choose an assisted death simply because of the lack of available palliative care services. In this regard I note the evidence of Mr Harmer from Queensland Health that annual palliative care funding will increase from \$149 million to \$247 million in the next five years. The commission is not in a position to assess whether this is an adequate increase; however, I note that the chief executive of Palliative Care Queensland has called for an annual new investment of \$275 million. Of course, funding commitments are short term and therefore we recommended that a more enduring safeguard would be to empower the Voluntary Assisted Dying Review Board with a statutory function of independently monitoring minimum levels of palliative care, including quality and funding.

The second significant factor in striking the balance is the distribution of Queensland's population across regional and remote areas where access to medical specialists, palliative care services, witnesses, family support and agents may be compromised. This factor was relied upon in the statement of compatibility as justification for not setting stronger safeguards in the bill, such as requiring the coordinating and consulting practitioners to be independent of each other and/or to possess appropriate specialist qualifications in assessing eligibility. In balancing these concerns, the statement of compatibility does not consider the potential for the availability of increased funding that I mentioned earlier and/or the availability of telehealth services to improve accessibility overall and therefore allow for greater strengthening of safeguards.

We have made a number of recommendations, including that the principles in clause 5 explicitly refer to the Human Rights Act and that those exercising functions under the bill must consider those principles when they make decisions. I am happy to take any questions.

CHAIR: In recent days we have heard issues around institutional conscientious objection. I would like to ask the Human Rights Commission's view. Do you think the bill strikes a balance when it comes to human rights and access to care? As drafted in the bill, there are provisions if someone is in an institution at end of life and would like to access VAD but that institution objects. Do you think the provisions drafted strike a balance? Quite often we have had the debate whether institutional hierarchy or conscientious objection overrides the human right to choose.

Mr McDougall: The right to object on conscientious grounds is limited to individuals, not to institutions. That is the first point. In terms of the balance that is struck on the right to protect freedom of religion, for example, I think the balance that is struck in the bill is the least restrictive way of limiting that right whilst also achieving the objective of respecting the autonomy of people to make that end-of-life choice.

Mr Costello: The only other point I would make is that, while this is not discussed at length in the statement of compatibility, it is in the explanatory notes. It would seem from that discussion, as the commissioner alluded to, that this is a particular question that confronted the Law Reform Commission in Queensland given the question of regional and remote access to services. To further confirm what the commissioner said, I suppose if we are going to have a scheme like this this is one of the issues that the Law Reform Commission and the bill grapple with: how can we ensure that people throughout Queensland can access it?

Mr MOLHOEK: I would like to go a little further around the rights of institutions versus individuals. One of the issues I see that is problematic is in Go Gentle's submission. They talked about dying people who will not have realistic access to a non-Catholic institution. They talked about Catholic Health Australia's submission and the concept that people should have the right to be transferred if they cannot access VAD in that setting.

The question in my mind is: where do they get transferred to, particularly in rural and remote parts of the state or even in places like the Gold Coast? The alternative might be non-Catholic but it also may be non-Anglican, non-Baptist or non-Churches of Christ care, because faith communities have historically played such a big role. Where does that go? You talk about section 20—the right to freedom of thought, conscience, religion and belief. Where does it leave those institutions that perhaps really do have an issue with it, if there is no alternative for someone to go somewhere else?

Mr McDougall: What you are talking about is the implementation of the bill and the real challenge that everyone faces in implementing it. Service providers who are major service providers in remote or regional areas where there are no other options are going to have to confront the reality that this is likely to arise. I would suggest that they implement the necessary policies and procedures and training required to make that adjustment. I do accept that that is not a light impingement on the rights of those people, but it is one that the statement of compatibility has justified.

Mr MOLHOEK: Some of these institutions, particularly in smaller communities—and I will not mention the particular community, but I am aware of one aged-care facility that was built by a group of farmers and families in a small community. The board are probably all still quite elderly themselves and they have very strong convictions and views around end of life. For them, this legislation would almost come across as being quite 'Big Brother-ish'. They might only have 10 beds or 10 apartments in their facility. It is a lot for them to digest and they would probably see that the legislation imposes on their human rights as a group of volunteers that have lived sacrificially to provide those facilities for people they care about.

Mr McDougall: I readily accept that. As we all know, human rights are not absolute in Queensland. They can be limited. It is a question of what reasonably available alternatives there are. I do not think in that situation there are any reasonably available alternatives that immediately spring to mind. It is definitely an educational and cultural piece of work that needs to occur.

Mr MOLHOEK: I do not want to put words in your mouth, but it probably highlights your concerns around safeguards.

Mr McDougall: Absolutely.

Mr MOLHOEK: Government will have to do a lot more to fill that gap in many parts of the state. Is the sort of funding that is proposed for additional palliative care going to be enough? You alluded to concerns about that in your submission.

Mr McDougall: Obviously, adequate funding for palliative care is critical. As an overall proposition, I would say that the safeguards need to be carefully calibrated. I would not profess to hold the expertise to make that call on what that calibration should be.

Mr MOLHOEK: I am not sure I could, either.

Mr McDougall: The Queensland Law Reform Commission has done a very comprehensive piece of work but Queensland is, as we all know, a very unique and diverse state—it has its own issues—and that calibration really needs to be mindful of the Queensland-specific issues. When it comes to tweaking the safeguards, we made a few recommendations about important changes that we think could be adopted, but I am mindful of committing to all of them, because that might tip the balance against those.

Mr MOLHOEK: Where were those recommendations? Were they contained in your submission?

Mr McDougall: They are referred to in our submission.

Mr ANDREW: Thank you, Commissioner, for coming in. If this legislation is put through parliament, is it subject to any change through the regulation act of 1992?

Mr McDougall: I would have to take that question on notice.

Mr ANDREW: Would you, please?

Mr McDougall: I do know that there is a three-year review built into the act and I think that review will be a very important opportunity to address a number of issues, such as the issue that was dealt with in the last session around advance care planning.

Mr ANDREW: Prior to or additional to that review? My question was: could it be changed by regulation?

Mr McDougall: I am sorry, I will have to take that on notice.

CHAIR: We could get the department to comment on that, if you wish. We could write to the department and get clarification.

Mr ANDREW: Given the fact that the last witnesses told us there was little or very little educational placement set up now in Queensland, should we put the bill in first or do you think we should be ensuring we have the educational structure around the framework prior to introducing the bill so that we are not making mistakes, so to speak.

Mr McDougall: That is a valid and good question. There would be an argument not just around education but also around the funding levels of palliative care: if it is going to take five years to get up to an adequate level, should it be delayed? Against that, you would have to consider the rights of those people who are being denied access to the scheme in the meantime. When you look at the submissions that have been made to the committee, there is overwhelming support, from what I can tell, for the introduction of the act and for this service to be available. Those are the things that parliament will have to weigh up.

Dr ROBINSON: Thank you, gentlemen, for appearing. In terms of freedom of religion—we can talk about institutions—now that the bill will force individual doctors to refer people on to somewhere they know they can then access assisted suicide, VAD, as treatment, how does the bill not discriminate against those individuals in terms of their freedom? They have a freedom now that they will not have. They will have to refer professionally, yet it goes against their conscience; it goes against everything they believe in. If they have a view that they do not want to be part of the process, doesn't the bill discriminate and remove their rights?

Mr McDougall: It certainly does limit their rights—there is absolutely no question about that—and that is something that is very serious. The question is whether that limitation on that right can be justified, and that is where you have to look at all the other rights that are affected by that decision. The rights of the patient obviously to have access to the scheme parliament may well consider. In fact, I am sure the statement of compatibility comes to the view that that right balanced against the other right prevails.

Dr ROBINSON: Are you saying that the bill itself may discriminate against them, potentially?

Mr McDougall: I would not use the word 'discriminate', because there is no ground for discrimination.

Dr ROBINSON: But if they said, 'I don't want to do it because of my religious values' and they are told they have to and there is a repercussion, is that not discrimination?

Mr McDougall: Yes, it is, but in terms of the Human Rights Act, where the right is protected, the limitation imposed by the bill can be justified.

Mr Costello: Only to add to what the commissioner was saying. The statement of compatibility does acknowledge the very point that you are making: their right to freedom of religion is limited by the bill, to use the terminology of compatibility in human rights terms. It is a question for the committee whether the justification which is provided in the statement, which goes to the points the commissioner was making, is adequate to justify that limitation.

As far as we can tell, based on the work of the Queensland Law Reform Commission—that is based on their consideration of medical ethics and codes of conduct as well as the rights of other people—the patients who may wish to receive this service and may be preferred. Without dodging the question, it really is an assessment by the committee whether that justification in the statement of compatibility justifies that very issue that you have identified.

Ms KING: Thank you so much for being here, Commissioner, and thank you, Mr Costello. In your assessment, would you say that the independent Queensland Law Reform Commission have carefully considered, weighed up and given due consideration to matters of human rights in their consideration of all of the issues and preparation of both the report and the legislation?

Mr McDougall: Yes, in my view they have. I think there are questions about the statement of compatibility. There could be further justification analysis in the statement of compatibility about some of the limitations on rights, but I think the Law Reform Commission has done a very comprehensive job in analysing the rights. Where we may differ is around the safeguards. One of the witnesses mentioned earlier that we have raised the issue about family members, at least one witness not being a family member. Having some background in elder abuse situations, I can foresee situations where family members will attempt to coerce people into the scheme and support having that requirement that there be an independent witness. Another suggestion has been that the consulting practitioner be in attendance when the witnesses sign. That would be another safeguard. To answer your question, yes I do, but it comes down to that fine calibration of the safeguards. At the time of the three-year review, it will be really important to have a close look at how they are or are not working.

Ms KING: Is there any emerging thinking in the area of human rights about voluntary assisted dying as an area of health care that people have a human right to access? I know it is an emerging issue and area of thinking across the world, as legislative rights to access it become available.

Mr McDougall: Yes. Throughout the history of human rights since World War II we have seen freedom, respect, equality and dignity as the major principles underpinning human rights. In recent times, especially since the Convention on the Rights of Persons with Disabilities, autonomy has really strengthened and emerged as an underpinning principle and you see that reflected in this bill. There are some really challenging future issues that, again, will have to come up in the three-year review that were alluded to by the previous witnesses around dementia and advance care planning. That is a really difficult issue to deal with and I think the bill at the moment strikes the right balance in terms of it being introduced. No doubt there will be strong assertions about the rights to autonomy of people with dementia.

Dr ROBINSON: Chair, can I clarify a point that was just made? A comment was made about submissions showing overwhelming support for the bill; is that what you just said?

Mr McDougall: I do think I said that.

Dr ROBINSON: Can I clarify for the record? According to calculations, 3,217 people were against the bill; 2,455 people for the bill. That is not an overwhelming support, and I put that on the record.

CHAIR: With respect, member—and I am not going to get into an argument about this—this goes to the form of submissions. We did a comprehensive review. I welcome you to read the inquiry leading to the introduction of this bill. Member for Maiwar, do you have a question?

Mr BERKMAN: Yes, I do. Thanks very much for both your time and your submission. I was very interested in the points you made in the submission around additional safeguards, particularly on the question of minimum training. The suggestion is that, as a minimum, practitioners might be required to undertake specialist training in palliative care and in assessing someone's capacity. We have heard a fair bit of evidence from different GPs and even from nurse practitioners about the expertise that they have and that they exercise every day, particularly in assessing capacity. That recommendation strikes me as one that will quite significantly shift the balance between safeguards and access to the scheme. I am keen to understand: is that part of your submission one where you are ultimately looking for better justification in the statement of capability or is it a more definitive or absolute recommendation?

Mr McDougall: That is a good question. I think it is a bit of both. Again, it is about not tipping the balance that is finely calibrated. I am aware that the training that was used in Western Australia and Victoria was developed by Ben White and Lindy Willmott from QUT. I imagine it will be similar in Queensland. That is a really important part of it, obviously. A really important safeguard is that you have people doing the assessments who are able to make the right judgements and also are attuned to the risks of coercion, for example. Complex family dynamics can often result in coercion being experienced by older people, for example. I think we would certainly like to see an amendment in the bill to strengthen it, but, again, it could be a question for justification.

Mr Costello: I suppose it is a cascading level of safeguard options that are available that we are trying to tease out in our submission, some of which we are not necessarily saying should be adopted because they may tip the balance more than perhaps could be further justified. That could be the specialisation of one or both of the relevant health practitioners and that may cascade down to training. It is just about what is going to get the balance right in terms of that expertise.

CHAIR: I thank the Queensland Human Rights Commissioner and Mr Costello for being here. It is a very important aspect of the bill and we do appreciate your time and thoughts.

GUNTON, Reverend Andrew, Moderator, Uniting Church in Australia, Queensland Synod

McINTOSH, Reverend Dr Adam, Associate Director of Mission, Pastoral Care, UnitingCare Queensland, Uniting Church in Australia, Queensland Synod

RYAN, Mr Nick, Chief Executive Officer, Lutheran Services

CHAIR: Welcome. Before we start, gentlemen, I understand that you are tabling a late submission?

Mr Ryan: Yes, Chair. We seek leave to table it. We spoke with the secretariat with regard to that.

CHAIR: Members, do we agree to accept the submission? Thank you; that is tabled. We just needed to deal with that procedurally. Who would like to start with an opening statement before we move to questions?

Rev. Gunton: Thank you for the opportunity to present on behalf of the Uniting Church in Australia, Queensland Synod. The Uniting Church, through our service arms of UnitingCare and Wesley Mission Queensland, provides a significant amount of services in Queensland that will be impacted by this legislation. These include four hospitals; 60 residential aged-care communities, which have about 6,000 residents within them; about 20,000 staff; a number of homes for people with disabilities; in-home care with substantially over 100,000 hours of care each year; and hospital and palliative care services within the Queensland communities.

The Uniting Church holds the Christian belief that every life is valued and unique and is opposed to the legislation of voluntary assisted dying. The church is and will continue to be committed to offering a compassionate and pastoral response to people and families who engage our services and, indeed, the choices they choose to make. We have chosen to constructively engage with this legislation and we propose the following amendments that we believe will continue to provide safeguards to the most vulnerable people in our community.

We recommend amending the bill so that the inclusion of a specified time line for the expected death should not exceed six months, rather than the 12 months that is provided for in the current draft of the bill. The six-month limit is an important safeguard to ensure that only people who are at the end of life have access to this voluntary assisted dying.

We recommend amending the draft legislation to remove the inclusion of mental suffering as a criterion for accessing voluntary assisted dying. This will make it clear that eligibility for voluntary assisted dying is only accessible to those with physical pain considered intolerable for the person and that cannot be relieved by high-quality palliative care.

We recommend extending the designated period of nine days as a minimum amount of time a person can access voluntary assisted dying to at least 14 days. This would fit with the safeguard that the request be an enduring request and not some last-minute fancy.

We recommend amending that any health practitioner, including medical practitioners and nurse practitioners, be prohibited from initiating or suggesting voluntary assisted dying. Our position is that the power dynamic of a health practitioner and patient relationship is always in favour of the health practitioner and therefore they hold that balance of power and should not therefore be allowed to initiate this conversation.

We recommend amending the bill to include the requirement for an eligible witness to be present in the case of the self-administration of the substance that would see this dying happen. This again provides a safeguard for the person, particularly if they require urgent medical assistance if the substance does not work as planned.

We recommend that for entities that do not wish to provide voluntary assisted dying and where it is reasonable for a permanent resident to be transferred then the entity should not be obligated to allow self-administration or practitioner administration of the voluntary assisted dying substance. In cases where it is deemed not reasonable to transfer a person because of health, then we would support a compassionate position to obligate the entity to allow administration or practitioner administration in that facility.

We recommend targeted consultation with First Nations communities to hear their perspective on voluntary assisted dying, because we believe their voice has been silent in this particular consultation, and to be informed of the cultural impact this bill will have on those communities.

Finally, we recommend that the offence of inducing a person to request or revoke a request for access to voluntary assisted dying, which currently has a penalty of seven years imprisonment, be amended to remove the wording 'revoke a request'. This is particularly important for us because it may make it an offence for ministers of religion, spiritual advisers or chaplains, psychological advisers or even counsellors or therapists who would talk with a person who has suggested that they would like to engage in voluntary assisted dying and give advice that would oppose this, and particularly again around those people's rights, to share their particular belief system with those people.

We thank you for listening to those amendments. They are all part of the submission that we have submitted already to this committee. Thank you.

Mr Ryan: I am the Chief Executive Officer of Lutheran Services and I represent the Lutheran Church of Australia for the purposes of this inquiry. I would also like to acknowledge the traditional owners of the land where we gather and pay respect to the elders past and present.

Thank you for the opportunity to appear and to make a statement. The Lutheran Church of Australia approaches the question of death not just from a philosophical perspective but also, similar to our colleagues from the Uniting Church, we provide best practice palliative care to hundreds of Queenslanders every year as part of providing more than 550,000 days of residential aged care and retirement living. We also provide significant housing options and services and care for Queenslanders with a disability. Our perspective, and that is as practitioners in the work of death and dying, is shared by other aged-care providers chiefly here with us today.

Some 40,000 Queenslanders receive more than 10 million days of care from faith based providers. The voice of aged-care providers talks about the support system and the support network that provides care for hundreds of thousands of older Australians every year. Nevertheless, these hearings are not the time for debating the relative advantages or disadvantages of voluntary assisted dying. The role of this committee and its hearings, I understand, is to ensure that the legislation provides considerable safeguards, is balanced, is implementable and crucially does not have unintended consequences or, worse, contain wholly foreseeable perverse consequences. Against those criteria, we believe the bill is flawed.

I am going to build on some of the material that the Uniting Church has provided but I will stay within the time allocation, Chair. We agree that the period predicted by a doctor to be eligible for voluntary assisted dying should be reduced to six months. At the moment, the bill does not require that a palliative care specialist assess a person seeking voluntary assisted dying. It seems curious that I could go to my general practitioner, be diagnosed with cancer and be satisfied with the GP's assessment of me without seeking access to an oncologist. It is at complete equivalence in this case that someone is seeking medical intervention to cease their life prior to its natural end without the requirement to be assessed by a palliative care specialist—not someone training but a recognised specialist. Similarly, there is no requirement in the bill as it stands for a psychiatrist to assess someone for whom the pain is not physiological at that stage—not physical but psychological. Often, people might not be aware of the options available to them. Therefore, we are concerned that a person seeking voluntary assisted dying who needs to make an informed choice does not, under the bill, have the opportunity or the obligation to seek specialist advice on that point.

We join with the Uniting Church of Australia in saying there is a significant risk to there not being a medical practitioner or a witness for self-administration in the event that the medication does not work. The bill is wholly silent on the question of the medication not working. There are instances in capital punishment, say in the United States, where the administration of medications is not successful. Of course, I do not know what a medical practitioner would do in the event that the medication does not work. Do they revive the person in order for that to be attempted again? What other actions would the law prescribe or, even more importantly, what other actions would the law prohibit in the event that the medication does not work?

We also agree that the bill as it stands provides inadequate protection for entities that have conscientious objections. If the state is of a mind to implement a scheme and the state has significant resources, then the state should be able to provide services that do not enact and, in fact, bring into enablement and co-opt aged-care providers who simply do not support this new approach.

Similarly, part of our concern is that a number of people who choose our homes—and this is faith based providers, not just the Uniting Church but it would include us—obviously wish to pass away in a supportive environment and this will go contrary to their choices about the home in which they live. We understand that the Law Reform Commission and, by default, the government are of the view that the person who is seeking voluntary assisted dying has rights. I think it has been very light on the question of the choices that other residents in that home might wish to exercise. We agree

that entities expressing conscientious objection should have to be very clear to the public about what their position is to enable an informed choice by people seeking aged-care services or an aged-care home.

The most objectionable provision, as mentioned by Reverend Gunton, is clause 141 of the bill whereby a person who by coercion induces—each of these terms can be widely interpreted—another person to revoke their decision to access VAD is guilty of an indictable offence. Under statute in Queensland, the maximum term of imprisonment for grooming a child under 16, stalking, stealing and fraud is five years, but a chaplain, a pastor, a family member or a counsellor who says to someone who has already chosen to go down the VAD path, ‘You know that there are choices open to you in terms of palliation,’ is guilty of an offence punishable by seven years imprisonment. I have heard praise and assessments made that it is carefully constructed legislation. Nowhere in the Queensland Law Reform Commission submission is there any mention or justification of the revoke clause.

Our final recommendation would be that the voluntary assisted dying scheme not be conducted within the health portfolio. As a former senior bureaucrat in the Queensland government and as the Commonwealth aged-care regulator for five years, I know what happens in the budget process within government. I know what happens around departmental tables and in ministerial offices. If the state of Queensland wishes to enact the scheme, the state should stand up an independent capability outside of the health portfolio. We do agree to the establishment of a board with clear obligations to report.

On a final technicality, on the title page of the bill there are a number of acts that will be subsequently amended if this bill passes, but it does not include the Criminal Code Act 1899, expressly section 311(b), where it remains an indictable criminal offence to procure someone or suggest that someone kill themselves. If the bill is that carefully constructed, we would have imagined that such amendments would have been made earlier.

CHAIR: That is quite a bit to get through and we have only 15 minutes for questions. I will come back to you; I have made some notations there, Mr Ryan.

I did want to deal with one thing, Reverend Gunton. I shared with the bishop in Townsville about this business of no consultation with Aboriginal and Torres Strait Islander peoples. We would be in breach of the parliamentary standing rules and orders in terms of the previous inquiry. We met with a number of groups throughout Queensland in our travels. We did 40 public hearings. Culturally sensitive information around death and dying in Aboriginal and Torres Strait Islander communities needs to be considered, and I shared that with the bishop. He wrote to me on that. We would be breaching parliamentary standing orders if we disclosed that. Needless to say, there was significant consultation in the inquiry that the former health committee undertook throughout Queensland. I just wanted to deal with that first.

In terms of your four hospitals, 60 residential aged-care facilities, 20,000 staff and those people in home care, who funds the services? Is it state and federal? What is the funding service for those?

Rev. Dr McIntosh: It would be a combination of state and federal, depending on the various services.

Mr Ryan: The majority of residential aged-care services are Commonwealth funded. It would depend on a means test as to co-contribution from the resident, depending on their assets. Residential aged care is overwhelmingly funded by the Commonwealth and really very little by the state.

CHAIR: Thank you. Part of that broad inquiry was aged care as well, and we worked very closely with the royal commission in that section. I wanted to ask a question about your prohibiting of nurse practitioners and your use of the words ‘power balance’. We heard from a nurse practitioner yesterday in Rockhampton who used the words, ‘Often we are the first people there and the last people there as people take their last breath.’

Ms PEASE: Their first heartbeat and their last heartbeat.

CHAIR: Thank you, member for Lytton. She was incredibly passionate about supportive care in palliative care and end-of-life care and was of the very strong view that nurses do form part of that very close working relationship. I would welcome you reading the *Hansard* transcript in that regard. It just offers a different view from the commentary you made. I will allow you to respond to that and then move to questions.

Rev. Gunton: We certainly support and totally agree. Our nurse practitioners travel literally millions of kilometres in this state every year to support people in their homes. They are the face of care for us and are the people who exactly are on the ground. We value incredibly their fantastic Brisbane

work. What we are suggesting, though, is that they not be the people to initiate the conversation around VAD. Again, if a person asked that of them we are not saying they cannot respond, but they should not be the person initiating that because of the particular power dynamic they have with that person. We are not saying that they would be doing it in a malicious or coercive way, but we think they should not be the initiator of that conversation.

Mr ANDREW: Thank you for coming in. I am really taken aback that there is no provision dealing with the situation of someone taking the medication and medication not working. That really frightens me. You are right: that has happened in America and in other places that have capital punishment. I know that you did talk about it, but would you like to go into a bit more detail?

Mr Ryan: The point here is that we are not advocating for a voluntary assisted dying scheme at all; it is the state that is advocating for a voluntary assisted dying scheme. It is really beholden upon the state to say. It has had an 880-page report and significant inquiries—and we do have respect for the process, but we would seek to move amendments. This is a fundamental question for government. You want to stand up a scheme and that this scenario, which could be horrendous in its consequences, is not anticipated in the legislation. It is a question for government.

CHAIR: In the same context, would that not be best left to the clinicians for clinical implementation of the procedure? Is that not left best in the hands of the practitioner?

Mr Ryan: It may be. What I would expect is that the legislation would address that scenario in precise terms. Let's play it out. There is a person receiving medication and they have a convulsion but they are not passing away. Every step is so prescribed—I think that is a good thing—as it ought be if you are to go down this path. At this particular step, do they revive a person, which you would think is contrary to their will? Do they introduce some other form of intervention? Do they take active steps other than the medication, because the bill only allows for the medication? What steps should a medical practitioner take and what protections do they have? Do they take some other step to end life at that point? That is not beholden upon us to explain; that is a matter for government.

CHAIR: Before we get into the whole notion of putting a legislative framework around that, there are provisions in the bill that talk about practitioner administration decisions. I think leaving it to the clinical governance, the review and all the rest of it deals with that. I do not want to take up too much time and get into a debate over this one point.

Mr Ryan: If I may, then, if self-administration is an option, there is no physician there to even make a decision.

Rev. Dr McIntosh: Our suggested amendment is that there is a witness requirement for self-administration. At the moment there is not, and we think there are significant gaps in that. That would be a simple amendment, to at least have a person there. That does not solve all the issues, but I think it would be an additional safeguard.

Ms KING: Thank you, gentlemen, for being here today. Mr Ryan, have you read the bill in detail?

Mr Ryan: I have.

Ms KING: Reverend Gunton, you have read the bill?

Rev. Gunton: Yes.

Ms KING: You describe section 141 and the penalties for dishonestly or by coercion inducing another person to revoke a request for access to voluntary assisted dying as the most objectionable provision in this bill.

Mr Ryan: That was my statement, not the Uniting Church.

Ms KING: Are you arguing that people should have a right to dishonestly or by coercion induce another person to revoke their request for voluntary assisted dying?

Mr Ryan: I am not seeking that anyone should have the right to do anything dishonest. The nature of the legislation is to put parameters around what activity is permissible and what is not permissible. What is said is that any interpretation in a court of law or in some other jurisdiction that says, 'This person sought voluntary assisted dying, was approved at some earlier stage, someone else entered into the picture and said, "You know that you have other options"—especially if they are in a position of power—

Ms KING: I will interrupt you. What you are arguing is that, if a person dishonestly or by coercion leads them to revoke their decision to request voluntary assisted dying, that should not be subject to a criminal penalty?

Mr Ryan: It is not a criminal penalty; it is a misdemeanour. It is an indictable offence.

Ms KING: It is a criminal penalty.

Mr Ryan: Punishable by up to seven years imprisonment. It cannot stand. The term 'dishonest' I will leave out. The term 'coercion' is how it will be perceived in a court of law. The pastoral reality is you have someone who has sought access to voluntary assisted dying—

Ms KING: Dishonestly or by coercion?

Mr Ryan: With respect—

Ms KING: I will leave it at that, sir.

CHAIR: I know that we have questions. I need very quickly to draw Reverend McIntosh to his last words, which were that currently there is no witness to practitioner administration.

Rev. Dr McIntosh: No, self-administration.

CHAIR: Right. Clause 54 of the bill states: 'Witness to administration of voluntary assisted dying substance'. I will not go into the subsections, but perhaps—

Rev. Dr McIntosh: I have read that in detail. I think you will find for self-administration that is very different from practitioner administration.

Dr ROBINSON: Thank you, gentlemen, for coming before the committee. As a person of faith myself, I have real concerns about freedom of religion issues in the bill. In terms of impacts on individuals, church and various religious institutions that provide care—aged care and health care—how could this potentially impact negatively on individuals and on the institutions in providing these services? Could we end up with situations where there is a reduction in services because of the things the bill forces on people of good faith in our nation?

Rev. Gunton: For us, we do not enter into support for vulnerable people with any regard to this kind of legislation. We enter into it because our belief is that we are there to support all people to have life in all its fullness. We will continue always to support vulnerable people in all stages of life, in all walks, wherever they are in life. For us, wherever this legislation lands, we will obviously work within the law of the land. That is our obligation, and we will continue to do that.

I can only speak on behalf of the Uniting Church in Australia. We are committed to making sure, though, that those vulnerable people are as protected as we possibly can make them, and that will be the thing that we will continue to advocate for within our services and within those people who live and find their homes in our spaces. A lot of people who come to our homes—not just people who will choose this—choose them because of our belief system and the values we offer. These are communities of people, homes of people—sometimes as many as 300 or 400, sometimes as small as 10—who come and choose to live there because of the value structure and the belief structure that we have. We will continue to advocate for them and for all those people who come and live with us. We certainly are not looking at any kind of reduction. Hopefully, in fact, we will continue to grow and increase our aged-care presence and our disability support services across the state.

Mr ANDREW: Earlier you spoke about the government implementing this bill and that it is their business to uphold that if someone objects to that person. Given your experience, what would that look like?

Mr Ryan: Could you repeat the question?

Mr ANDREW: You were saying that the government should uphold the implementation of assisting with VAD if that place did not want to participate.

Mr Ryan: We believe that the public should be fully informed as to where we would stand on this. That is, people should have an informed choice as to whether they live in our communities and we should be forthright and very open that 'this is not an environment where you can access voluntary assisted dying and we do not support that', providing the law gives us that opportunity. We think people should make informed choices about their own life; we respect that. We think the witness, the sacrifice and the volunteering that have built up the Uniting Church, Catholic, Lutheran, Anglican or Buddhist homes—across the board—should be regarded. If the state wishes to stand up a voluntary assisted dying capability, it is beholden upon the state to do it in a way that does provide people with access.

CHAIR: I want to conclude on one thing you started with concerning people getting an assessment. Generally, when people get sick they will go to their GP who will refer them, if they have a provisional diagnosis or a differential diagnosis, to an oncologist or whatever for confirmation. Would that not already put them on the path of having an assessment?

Mr Ryan: It depends. If the person is referred to a voluntary assisted dying practitioner, there is a particular toolbox that comes with that. If I am seeking medical advice, I want someone who is willing to assess me based on my prognosis based on their speciality, not necessarily that they might give me access. I would think that if someone has a serious illness likely to result in death in six months or a year or wherever it lands, they should first see an independent specialist and a palliative care specialist.

CHAIR: Would they not already get a diagnosis from a doctor? That is my question.

Mr Ryan: The bill does not—

CHAIR: You do not wake up with a terminal illness and go, 'Right, I am going to seek VAD today.' Would you not go through a process?

Mr Ryan: I think you have raised a good point, Chair. Therefore, the bill should reflect that.

CHAIR: Okay. I really appreciate the time and effort made by witnesses today. We are out of time. I made the statement yesterday that churches plays an important role in spiritual care. The former committee certainly heard that and indeed wrote to the former health minister regarding the services that are provided. It is significant. We thank you for the work that you do in all of those spaces.

Proceedings suspended from 3.18 pm to 3.33 pm.

PIEPER, Reverend Stewart, Director of Queensland Baptist Services, Queensland Baptists

SWENSON, Mr Gary, State Ministries Director, Australian Christian Churches, Queensland & Northern Territory

CHAIR: Would you like to make an opening statement? Then we will go to questions.

Rev. Pieper: Thank you for this opportunity to appear before you. I will provide just a little bit of background to Queensland Baptists which I did not put in the submission. We are a movement of 209 or so autonomous local churches representing a community of 76,000-odd people. We also have an aged-care and disability provider service that we provide on behalf of our constituent churches which has 12 aged-care centres with 1,000 residents and we provide home care services.

The big matters that I wanted to highlight that I felt were significant for our constituents firstly relate to there being no requirement in the legislation for a mental health assessment for those requesting voluntary assisted dying. I will say up-front that as Christians we would remain philosophically opposed to the introduction of laws in this way, believing in the sanctity of life, but we also realise that there is legislation and a bill before the parliament and so we value the opportunity to speak into that democratic process. The other thing I would highlight is point 3 of the submission I made in relation to the impact on aged-care providers that come from a faith based community and some of the implications that these laws may have on those who have conscientious objections to those laws.

Mr Swenson: I am here as the state ministries director of Australian Christian Churches, which is constituted by approximately 103,000 people in 280 communities across Queensland. We are rapidly growing. Regular Sunday attendance would see in excess of 50,000 people, although we have not had too many regular Sundays of late. There is not one person who would be here or come before you who wants to see people suffer unnecessarily.

When it comes to the matter before us today, I think unfortunately members of faith communities are sometimes portrayed as being out of touch and lacking compassion due to holding to what are seen as maybe outdated religious values and beliefs. The truth is that members of faith communities such as ministers, pastors, priests and chaplains work extensively and compassionately with people at end of life and consequently are not without significant experience and understanding at the coalface of this issue, and it is a multilayered, very complex issue.

You as a committee have heard many stories, many even today from different perspectives. We all have them and we will all be impacted by this issue and the issues at hand. I have my story. Over the last five years I saw both of my parents die in palliative care. Ten years ago my wife was diagnosed with early onset Alzheimer's which necessitated her moving into permanent residential care 2½ years ago. As a pastor I have been with many people at end of life and on the journey up to that point over many years.

In our submission, as you will have seen, we have a number of key concerns and I will just very quickly allude to those. I believe there is a lack of what I would call a holistic approach to what is a matter of very serious gravity and a lack of what I have termed adequate professional standards. A lot has been put before this committee in terms of specialists being involved in the eligibility process and determination. The bill refers to and defines suffering as mental suffering and anguish, yet there is no provision in the bill as it stands for somebody to access psychiatric or professional help from a mental health professional. It is not to suggest that a person seeking VAD has a mental health issue. I do not have the time, but I could tell you many stories of people who, part way through a journey, have felt like dying and then something has changed. I do not have time to go there, but that is an important issue.

In relation to protections for individuals—again, this has come before you as a committee on many occasions, even today—and the issue of conscientious objection, we believe it is a violation of individual health practitioners' rights and personal beliefs and values to be forced even to directly refer a person to a voluntary assisted dying care navigator or other service. The person who is seeking VAD certainly needs to have the right to access that if that is their desire, but the issue at stake here is the administration of the procedure with the intent or express purpose to take someone's life. For some people that is a bridge too far: it is an encroachment upon the core of their soul, their values, their beliefs. To seek to establish the rights of some people by violating perhaps the rights of others is not appropriate and it does not speak well to the soul of our culture or society that practises that approach regardless of the validity or otherwise of the issues.

I have another concern and that is around the provisions of section 141—it was raised by my colleagues from the Uniting Church—concerning coercion. As I have said in our submission, I believe that those issues need to be separated very clearly in the legislation. Absolutely there needs to be strong protection around the issue of inducing someone to make an application, but they are very different dynamics. The concern we have as it currently stands is that what may even be a normal, necessary and healthy conversation—it is often emotionally charged—with a family member could be mistaken as coercion by somebody overhearing it and that person could, under the provision as it is proposed, end up in jail. That is, we believe, unacceptable.

In relation to protections for organisations, to require an institution or an organisation to violate the very core values and beliefs upon which it was built and has successfully and effectively operated in the delivery of invaluable health services is a serious breach of fundamental freedoms. We are asking those organisations to change their core identity. I know that there is a lot of talk about the balance of rights of individuals against the rights of an institution—they are challenging ethical issues, no doubt—but we have to remember that institutions even are built on values and a certain ethos and they are run by individuals with those same values. When something goes wrong, it is actually individuals who are held to account. An institution is not some nebulous entity.

Finally, concerning palliative care, to consider providing easy access to voluntary assisted dying and not address the desperately needed area of service provision as far as palliative care goes, which has a proven effectiveness, I think is a serious lapse. In Australia an individual's choice to explore voluntary assisted dying should never be a choice based on a lack of knowledge about or access to palliative care. Thank you for your time. We very much appreciate the opportunity.

CHAIR: We had Mr Andrew Denton first up this morning via videoconference. He talked about this dilemma that is often seen by some of institutional objection. The Queensland Law Reform Commission refers to an institution not having a conscience per se, so it is the right of the individual versus the institution's, as you said, ethos, and maybe they come from an ideological or theological viewpoint of care. It is a difficult one to grapple with, but in the context of what Mr Denton thought, it struck a balance of allowing the person to choose whilst respecting the right of the institution. Earlier we heard from the reverend from the Uniting Church who said they would support the practitioner if the event became too difficult to move someone. What are your views on that?

Mr Swenson: They are difficult issues. There are many grey areas and I think in some of these issues there are no absolutes. It is around this that we have concern. I watched the hearing when the Attorney-General's department and health professionals presented to you back in June. Behind the scenes—and this is part of the concern I have—there are a lot of issues that are still not worked out, that still have not been thought through. There are a lot of things to be considered. Our view is that this has been rushed and more time needs to be taken to address some of the issues. As you heard, I am not unfamiliar with the issues personally and the tension that goes with that. Having said that, I think there is some inherent weaknesses in the bill as it is currently proposed.

CHAIR: Do you have any views, Reverend?

Rev. Pieper: I will speak briefly on that. Being an aged-care provider, we are also under obligations under the aged care quality standards charter. Around that are issues of due diligence and thinking about the welfare and wellbeing of other residents and their choice to perhaps come and use the facilities or a service that has certain values that they align themselves with. There is also a duty of care to staff who work in those facilities who perhaps also have sensibilities about the issue of voluntary assisted dying. If an institution, for instance, is asked to comply with the legislation in certain ways and that causes a person or persons or other residents or staff some anxiety, some difficulty, stress or distress, then that is a concern for us, too, in terms of a duty of care with the provision that we are looking after staff and other residents as well.

Primarily, it seems to me, this conversation has been around choice of those who feel that they would like to take advantage of processes to end their life, but that has to be balanced with those who choose to stay in institutions where they would not agree or approve or the staff would be traumatised because that happened on the grounds of that facility. That is what I would add.

Mr MOLHOEK: I would be interested in your further comments in respect of the submission we received earlier from the Lutheran Church. They express concerns around sentencing levels and penalties for people who could be seen to be coercing or influencing people in the opposite direction. I would be interested to hear commentary about how that would impact on pastors, counsellors and student advisers—there is a broad scope of services that different churches are involved in—and perhaps a bit of context around some of the fundamental different views. Gary, I know you are a person of incredible faith and I have had the pleasure of hearing you speak on many occasions in the Brisbane

past, although it has been some time since I have been anywhere near you or your church. I think it would be fair to say that you are fundamentally people of hope who have great faith. You would have some very contrary views. I would be interested to hear a little bit about that and why this is of particular concern in that context.

Mr Swenson: Firstly, regarding section 141, I would underline the concerns that were raised earlier around this issue because for pastors, ministers and priests right across the faith spectrum—to be honest, I am not sure if there is even clarity here for family members in terms of what is perceived as coercion. If you play out the scenario where a family member has chosen the VAD option and then the family come and discover that, there is going to be very emotive conversation. With somebody overhearing that, that could be misunderstood as coercion. We have grave concerns around that. Obviously for pastors, priests and chaplains the same applies. That is why I have said in the submission that those issues need to be separated very clearly. They are different dynamics. The first one in respect of coercion to make a decision—absolutely, because that is irrevocable. However, if somebody does revoke, even if there is some influence there, they can still remake the decision. Those issues need to be separated very clearly, I believe, in the legislation. Remind me of the key issue of the second part of your point?

Mr MOLHOEK: An insight into your core values as pastors as to why this is such a hard issue for you. I have heard you and other pastors speak so much about hope, faith and restoration and all those sorts of words. Unfortunately, laws do not necessarily play well with some of those concepts. I am assuming there is a conflict there for you.

Mr Swenson: There is and, to be honest, not being unmindful of the stark realities and the tensions as I walk that journey personally. Having said that—if I could just touch on this very quickly—I have had many occasions over the years where people—my sister 10 years ago was given a diagnosis of stage 4 cancer. She had radical surgery, chemo and radiation and was given a short period to live. Ten years later she is living a very full, active life. I can cite many instances of people who have been on a journey after a serious diagnosis where they have felt at times on that journey that they wanted to die—and I understand it—but who have, through either the treatment or whatever, recovered and gone on to live a very productive life. This is why I have concerns around the issue of no psychological support, mental health involvement, in this decision-making.

CHAIR: We had a fellow, Peter, who appeared before us yesterday in Rockhampton with advanced motor neurone disease. He was very much of the view that he supported voluntary assisted dying. It was tragic to hear his story. We have heard that so many times from people who have advanced through their terminal diagnosis. What do we say to those people who want that choice?

Mr Swenson: I think one of the issues for me, as was alluded to earlier by our Uniting Church friends, is around the 12-month period. It is a different deal when somebody is facing imminent death and it is very obvious that they are going to die—as I said, I have done that journey with people—but 12 months out—seriously, a lot can happen in that time and I have seen it many times.

Rev. Pieper: Similarly, I had an experience when I was pastoring in a church in Toowoomba. One of the members of that church had a condition called multiple myeloma and was told to get their affairs in order. As part of the catharsis of approaching death or imminent death, they had made their own coffin and got their children and grandchildren to decoupage and jazz up the coffin as part of a ritual. He is still alive 15 years later. There was some groundbreaking treatment that he received, stem cell implants and such, and he has gone on to live a fruitful and productive life. However, if he did not have a sense of hope and availed himself of a service—he felt that his life was over and he wanted to take control of that situation, and I can see why many people might want to do that—his life would have been cut short at that time and his family would have missed out on many years of input from him.

I have compassion for people who are suffering and have profound suffering and feel that there is no answer. There is a mystery to suffering in life. However, there is also hope, we believe, and room should be left for things to change, either inexplicitly or through medical research and advances.

Dr ROBINSON: With regard to freedom of religion, earlier the Human Rights Commission made comment about, in answer to my question, that area that the bill restricts—‘potentially limits’ I think was the phrase they used—the rights of Christians or people of faith who are, for example, doctors who may not want to be involved at all in the process and may want to opt out. I refer to the potential of freedom of religion implications for institutions who would say, ‘Just let us opt out. Don’t drag us into this. It really fundamentally is offensive to us as people,’ whether they be Christians, Muslims, Hindu, Buddhists or whatever they are as Australians today. Do you have any comment on whether the rights of institutions and individuals, based on freedom of religion we think is enshrined in our Constitution, that are being impinged on by this legislation should be upheld?

Mr Swenson: I do believe these issues are of major concern. I respect the chair's comment about Andrew Denton's comments earlier on the balance. There has been a lot of talk in these hearings about getting the balance; however, I stand by the issue that to enshrine or to establish anyone's rights at the cost of violating another person's rights has serious ethical questions around it, whatever that might be. The concern I have is that that is what is happening with this proposed legislation as it stands. We want to see the freedom of faith and religion kept intact.

CHAIR: I am not sure whether you were here when the Human Rights Commission appeared, but they used the term in the statement of compatibility with the Human Rights Act that it was justified because it balanced the rights of the person.

Mr Swenson: I did hear that comment, yes.

Dr ROBINSON: This morning Andrew Denton made some comment—and there have been other MPs and commentators talk about it, too—about religious objections to the bill being primarily—some say almost only—the hierarchy of the churches or the leadership of the churches. This morning Andrew Denton said, more or less, that it is primarily the hierarchy or the leadership of the churches. Can you give us a sense, within your denominations and other church denominations that you work with professionally, whether that is true? Is it really only the leaders or is it the majority of the people who make up your faith communities who object to this bill?

Rev. Pieper: That is a good question. It would be impossible for everyone we represent to come before the inquiry. It is like any process: there are those who are set apart to lead, which is for good order. I have been a Baptist minister for 21 years or so; I have a good feel for those who are of the Baptist family of churches. I grew up in a Baptist church and came to faith at a young age, so I have been around this movement that I am now a leader in for pretty much all of my life. I can say that I have a pretty strong understanding of the kinds of beliefs that are held dear and near to Queensland Baptists, and I would say that I have a pretty strong grip on what the majority might believe or understand, without having conducted any polls or any such kind of measures in that way.

Dr ROBINSON: Stewart, would you say that the majority of your people would be for or against this legislation?

Rev. Pieper: Against.

Dr ROBINSON: Gary?

Mr Swenson: Absolutely. I travel all over this state. I will be in Longreach this weekend and I am in Cairns the next. I get a good feel. As I said, we have 103,000 people who call themselves part of our movement, our church. I would say that the vast majority would, particularly once they understand the components of this proposed legislation. There would be shock, horror around some of the issues. A simple answer is yes.

Ms KING: I will begin by reflecting that one of my very closest friends is a Baptist. He and his faith community are, in fact, in favour of the legislation. On that, I want to note some statistics that we talked about in yesterday's hearing. Research of 200,000 Australians found that 75 per cent agreed with voluntary assisted dying but, more interestingly and of relevance to the conversation we are having today, of those, 71 per cent who identified as active participants in the Catholic religion agreed with voluntary assisted dying and 68 per cent who identified as active Protestants and 77 per cent of active Uniting Church respondents agreed with voluntary assisted dying. In light of the fact that many of the people who come to your institutions and your facilities are not necessarily making the choice to join you because of an overwhelming belief in your faith community's ethos but because of the availability of the services that you provide, which I understand are of excellent quality in many cases, could you provide your reflections on that?

Rev. Pieper: On the second bit or on anything?

Ms KING: Wherever you would like to.

Rev. Pieper: I think people coming to the facilities that we provide do so for probably a number of reasons. For some it could be convenience; for some it could be connection; for some it could be family members. However, it is the ethos behind the care that is provided that is significant for it and as part of a faith package that we have. In terms of those statistics, I would be interested to know where they came from—the surveys and such, the sample size and those sorts of things.

Ms KING: That was 200,000 Australians. It was the ABC Vote Compass. Those results have been replicated in other good quality research as well. They are not a one-off.

Rev. Pieper: In terms of the Baptist community that you perhaps have a connection with and feel that there is a contrary view there, Baptists are a broad church. I am not saying that there are not any who perhaps have a contrary view. In fact, I know of probably a couple of pastors who would

support a version of this legislation for various reasons. I know one of them has a wife with dementia and it is very hard for him. I have had conversations with him about this. He talks about the importance of having a pastoral care approach to these things. What we are interacting with are specific elements of the legislation as it is. That is what the submission was meant to represent.

Ms KING: Thank you for your comments.

CHAIR: I apologise, we are out of time. Thank you, Stewart and Gary, for being here today and providing your views to the committee. It is most helpful.

Rev. Pieper: Thanks for the opportunity.

FRANCIS, Ms Wendy, Queensland and Northern Territory Director, Australian Christian Lobby

JOHNSON, Ms Teeshan, Executive Director, Cherish Life Queensland

LONG, Dr Brendan, Vice-President, Right to Life Australia

van GEND, Dr David, Spokesperson, Cherish Life Queensland

CHAIR: Welcome, everyone. We will start with opening statements and then move to questions.

Ms Johnson: David van Gend and I are going to split our time, so I will give a very short statement and he will do the same. Thank you, Mr Harper and Health and Environment Committee members. Cherish Life is opposed to this bill that no doubt, if passed, would lead to many extra deaths in Queensland every year. We know this from data from all jurisdictions that have legalised euthanasia of any kind. Additionally, the bill does nothing to correct the state's palliative care funding deficit of \$275 million per year. We are gravely concerned that, if passed, some people, particularly those in regional Queensland, will opt for euthanasia or assisted suicide simply because they have little or no access to palliative care specialist services.

If it is to proceed, we propose the 13 amendments outlined in our submission, the three most critical amendments being a full institutional conscientious objection, a full conscientious objection for doctors and mandating specialist involvement. Dr David van Gend will speak about these amendments.

I must note that some of our dear Cherish Life supporters are in aged-care facilities that are faith affiliated. It is deeply distressing to them that this bill would allow an outside doctor to come onto the premises to kill a fellow resident, either by assisted suicide or euthanasia. This terrible scenario typifies the legal imbalance of this bill. The bill unfairly elevates the rights of the euthanasia or assisted suicide seeker above the rights of fellow residents, doctors and even institutions that are ethically opposed to euthanasia and assisted suicide. It is very unbalanced. It is very dangerous. If passed, it would lead to many extra deaths in Queensland, including wrongful deaths.

Dr van Gend: I am a GP and for 15 years a senior lecturer in palliative medicine at the University of Queensland. I was also a member of the Queensland Health working group on palliative care in children.

Over the 26 years of my involvement, this debate has always been marked by goodwill.

Those who support euthanasia have often seen a loved one die badly. Those who oppose euthanasia have equal empathy for suffering but they are deeply concerned by the wider implications—for instance, that euthanasia will shatter the very cornerstone of law, which is the prohibition against intentional killing. It will corrupt the role of doctors by making us bringers of death. It will demoralise palliative care, as we have seen overseas. Worst of all, it will usher in a new insidious oppression of the most vulnerable who will see this not as a right to die but more as a duty to die. The UK House of Lords said "vulnerable people, the elderly, lonely, sick or distressed would feel pressure, whether real or imagined, to seek early death". Even Paul Keating said that "it is fatuous to assert that patients will not feel pressure to nominate themselves for termination". That is the injustice upon which this bill should be rejected.

If the bill prevails and if there is that goodwill, it must at least be amended so it does not coerce the conscience of your fellow citizens who cannot and will not collaborate with intentional killing. It must be amended, please, to protect our patients from their own depression, their own lack of information at such a crisis time, by stipulating input from a psychiatrist, a palliative specialist and a specialist in the patient's diseases. Anything less than that is negligent. Committee members, this bill is both reckless and unjust, in my considered opinion, but at least may it have the dignity of not succumbing to a lack of integrity as far as informed consent goes and a certain malice in terms of coercion of conscience.

Ms Francis: This Saturday it will be 15 years since my sister Dianne died from pancreatic cancer. Seven years ago, another of my sisters died from brain cancer. Her name was Karen. They both experienced really good deaths. They were cared for by amazing palliative care health professionals and they were fortunate because they lived in South-East Queensland.

Death itself is awful and I understand the desire to exercise control over it, but good palliative care affords this. Every Queenslanders should have the opportunity for the high-quality care that my sisters were given. Queensland is unique in that most people live outside of our major city, which makes it even more important for our government to ensure that no Queenslanders is offered assisted suicide when they have been denied their right to expert palliative care.

The ACL acknowledges the extensive inquiry the committee undertook prior to the tabling of this bill. What became clear through the inquiry was how inadequate palliative care services in Queensland currently are and how much needs to be done to make them satisfactory, let alone exemplary. We believe the government should be prioritising the critical improvement of palliative care in Queensland but the VAD bill undermines that priority. For euthanasia to be introduced prior to every Queenslanders having access to proper health care is a clear injustice.

Other injustices in the bill include the lack of true conscientious objection for medical professionals and for hospitals and institutions; the lack of protection for the mentally unwell and vulnerable; the normalisation of suicide when our suicide rate is already among the highest in the world; the threat of a seven-year jail term for encouraging someone to choose to extend their life rather than end their life—I know there has been discussion on that and I would love to be able to elaborate on that during question time; and allowing health practitioners to initiate a discussion of euthanasia, therefore applying indirect pressure. The Voluntary Assisted Dying Bill 2021 contains many flaws, jeopardising the care of the vulnerable and the conscience of healthcare workers, which is why a significant majority of submissions received by the committee oppose this bill: for the bill was 2,455 and against the bill was 3,217. We opened every one of them.

Supporters of euthanasia say it is about ensuring autonomy and control, but it is extremely difficult to ensure that someone's decision to kill themselves is free and autonomous. Pressure can be applied directly by other individuals and there are no number of safeguards that will protect the vulnerable against individuals of ill will who are motivated to get around them. Sadly, it is well known that most of the abuse of the elderly comes from within the family. The bill allows a patient to even request VAD by gestures. How easily that could be misunderstood. Mr Andrew's concern is also important. A VAD drug does not always work. For these and many other reasons, the ACL would urge the committee to recommend that this bill not be passed.

Dr Long: Right to Life Australia is a national body, a national member organisation, with many thousands of members and many in Queensland, I might say. I stand here representing them. We are not a religious organisation. We are just a broad based community organisation. I thank you for the opportunity to submit. I will respectfully make a brief comment, if I might, that this process has had an unusual gestation in that the Law Reform Commission was told to advise on a bill, not to suggest whether there should be one. Submissions to the inquiry also must comment on the specific issues of the bill rather than express a philosophical objection to the measure. Also, I might note that Mr Denton was given significant time this morning in a private session and Mr Nitschke will be given time later. I note, as a former political adviser with many years in parliament—six years in fact—that the process seems somewhat irregular.

Moving straight along to be constructive, I might just list a couple of the issues that we have raised in terms of amendments to the bill specifically. We believe that the language in the bill of 'voluntary assisted dying' is misleading. We would prefer that the committee considered the internationally accepted medical definition that is used for this measure, which is acknowledged by the World Medical Association and reaffirmed in October 2019 at its congress. It is called 'physician assisted suicide'. That is the medical definition. Dr Cigolini will be able to speak more about that in the next session. We recommend that that in fact should be the appropriate usage of the term used in the bill.

I think one of the key issues that has occurred in all of the debates around the country is the definition of the length of eligibility. The Victorian scheme started with a bill for 12 months and ended up with a bill for six months. On their initial bill, the initial consideration of the committee in Western Australia was not to have a time period but they ended up with a six-month bill. I would put it before the committee that considered reflection in other parliaments has chosen the original Oregon model of six months rather than an extended period of 12 months. I note anecdotally that if this parliament were to double the eligibility length in this bill that would be a significant extension in the scope of the bill relative to anything else in Australia and would back up the argument that there is something of an avalanche of legislative creep that takes place. I would therefore put it to the committee that the six-month rule, according to the pure Oregon model, would be preferable.

I will quickly move on, knowing that time is short, to indicate that the bill does allow physicians to initiate the conversation. This was a key element of the safeguards in Victoria that the government put forward and in which I was engaged as a political adviser. It is noted in the bill that that safeguard

is not proposed for this bill. I would note the significance of that. I put it before the committee to consider whether in fact that measure also weakens the safeguards rather than strengthens them considerably. I could go on, but noting time is short, I will not.

CHAIR: Thank you very much, Dr Long. I might start with a procedural issue. Dr David van Gend from Cherish Life, I believe you have an updated—

Ms Johnson: No, that is not Cherish Life. The Cherish Life submission is also Dr van Gend's submission which is almost like an extra bit. That is his personal one, but it folds in well.

CHAIR: Members are happy to accept that so it is tabled. Dr van Gend, how long have you been practising palliative care?

Dr van Gend: I did my diploma in 2001 and I was at the Mount Olivet hospice training fellowship in 1997. It is in addition to my general practice.

CHAIR: I am sure you are aware, if you work in the Queensland Health palliative care space—and thank you for the work you are doing; it is very important—of Dr Will Cairns. He came before us in Townsville. He gave some pretty graphic evidence of people suffering at end of life from horrible head and neck cancers and pelvic cancers. He has spent a very lengthy time in palliative care and set up the Townsville and Sunshine Coast centres. He was of the view that—and I will ask what your view is—not all pain and suffering can be alleviated despite palliative care in everyone all of the time. He was of the view that people should have choice. We heard that again in Rockhampton yesterday from a nurse practitioner of 27 years experience who had seen a lot of people at end of life. Their views are perhaps diametrically opposed to your views. We have had palliative care specialists write to us and come before us saying that they are of the view that people should have choice. Could you comment on that?

Dr van Gend: I always tell my medical students that we cannot get rid of all suffering in dying, any more than we can get rid of all suffering in childbirth or in any life event in between—major illness, major accident, sporting trauma. Suffering is part of life. The question is: why should this committee and this parliament be approving suicide as a response to suffering at that phase of life, in the last year, but not for equal suffering or greater suffering at other times of life? That is the question.

Yes, this generation is the first in history that can look forward to tolerable dying and perhaps beautiful dying, as most of my patients have—not all; we let them down sometimes. We just cannot get it good enough. It is the first generation in history that can look forward to a tolerable dying and it is the same generation that is now demanding not to die but simply to be “made dead”—there is a huge difference—to tear those last pages out of our life and avoid the deeply human meaning of those last pages and instead be made dead. Fine, but to do that you are changing the culture so radically rather than accepting that at some point we will have to suffer to some extent: at the end of life, at the beginning of life, in the middle life—all through life. Our job is to work to minimise that suffering. That is our creative option. Instituting the state machinery of mercy killing with its profound cultural consequences is a disproportionate response to an ever-improving field of palliative control of symptoms. That is what I would say.

CHAIR: I wanted to pull you up on the point where you said sometimes we do not get it right all the time and we let people down.

Dr van Gend: Sometimes we as doctors are not skilful enough to look after patients as they should be. We all admit that. Someone with more skill would have looked after that patient possibly to the point of no active symptoms. That is my point. It is never perfect, but a rejection of euthanasia does not depend upon perfecting palliative care. It does not depend on that. It does not depend on anything else. It is certainly not a religious issue. It depends on the issue of injustice to the vulnerable in our community who will be intimidated by this new development. I can tell you that because I know them in nursing homes. They will know what society is telling them. They will know when their welcome has expired. They will do the right thing by their family and by society not because they are compelled but because there is an irresistible cultural expectation.

Mr ANDREW: Ms Johnson, I note that you talk about wrongful deaths. Could you expand on that for me?

Ms Johnson: Wrongful death in the context of assisted suicide or euthanasia refers to somebody accessing euthanasia or assisted suicide who should not have. I know Dr van Gend spoke about this. We know that there is no requirement to be seen by a specialist in your area of suffering or a palliative care specialist or even a psychiatric specialist to check that you are okay. In this scenario there could be a wrongful death because they have had not seen a specialist. They might not be aware of the treatment that is available to them. They might not have access to palliative care

services. That would be a wrongful death if they simply felt like they had to take VAD—assisted suicide or euthanasia—because there was no palliative care. That is a wrongful death—social suicide, social contagion of suicide.

We have seen in a number of jurisdictions—there is evidence of it in Victoria, Oregon and the Netherlands—where the non-assisted suicide rates go up as well as the assisted suicide and euthanasia rates. In fact, every jurisdiction around the world that has legalised euthanasia of any kind always has a massive increase in the overall suicide rate. As I said, they may be unaware of the treatment available. Dr van Gend, do you want to elaborate on wrongful deaths?

Dr van Gend: The essential thing is that we must protect patients from themselves. When you are in an advanced diseased state, your brain chemistry is gravely altered. It is very difficult for us as doctors to tell between a brain depression, which we have a duty to treat because it is disturbing the person's perception, and just the reaction of grief and existential distress of being a terminal patient.

I would put it to you that this bill is negligent in permitting some junior doctor who is only five years out of university—typically two years as a junior house officer in a hospital and three years as a GP trainee—to qualify under this bill to issue a 'tick' that this person knows all about the palliative care options, tick that this person knows all about the new treatment possibilities in the special field of their disease and—worst of all—'tick' that they can say that this patient is not affected by depression, by dissociative states, by the cognitive changes of these powerful medications. They cannot. I promise you. I lecture these students—these GP trainees. They are not competent to do that. Under this bill they are allowed to do it. That is a gross piece of negligence, which I am sure you can fix.

Please let there be a psychiatrist. Only they can protect the patients from their altered brain state. Let them make their true decision, not their distorted decision. Please let there be a palliative specialist. It is a profoundly complex field of medicine. Some GP or junior doctor simply does not know what is possible. Surely this patient should be freed from unrealistic fears and returned to a state of reasonable expectation of how hard it will be—not an unreasonable one. That is what the palliative doctors can do. Finally, the specialist in the field is vital. Without that, it is a wrongful death.

Dr ROBINSON: One of the things that has come up a few times is the issue of it being an offence to encourage someone not to go through with the decision to access VAD or assisted suicide and the potential of their misunderstandings in this space. I will put it in those broad terms. I know at least the ACL submission, and maybe others too, has commented on concerns in that area—potential grey areas and potentially areas where people could be seen as coercing someone when in fact they have not and the potential for prosecutions as a result of that. ACL may want to comment on that.

Ms Francis: I would love to make a comment on this because it is hard to read the bill and see that the government has made a moral equivalence. I want to explain what coercion means too. There is no moral equivalence to talking somebody into taking their life as talking somebody into keeping their life. That is not moral equivalence. We cannot possibly think that. The other thing I would say about it—and do not want to spend too much time on it—is that in the explanatory notes a promise is actually explained as coercion. If I promise my dying mother, after she has seen the doctor and said she would like to be killed, that I will stay with her and will not leave her and she changes her mind then I have broken the law under this bill. Coercion is actually in the explanatory notes as a promise.

Ms PEASE: I want to clarify something that Dr Long was talking about in his opening statement. For the benefit of everyone in the room, you mentioned that the Go Gentle people had the opportunity to have a private meeting. That is actually incorrect. It was a public hearing. It was televised. It was just that we had to use a different room. It was open to the public. It was a videoconference. I wanted to correct that for the record.

Dr Long: Thank you for the clarification.

Ms PEASE: It is on the program as being a public meeting.

Dr Long: In an earlier draft it might have said something slightly different.

Ms PEASE: As of today's date it was up there. I also want to clarify some of the statements you made around the lack of work that had gone into this and how the Law Reform Commission report had come about. We undertook a fairly extensive inquiry in 2019. The current chair, the member for Maiwar and I were on that committee. We had over 40 hearings across Queensland for the inquiry on this matter and received significant submissions from across Queensland. That went to the QLRC for the drafting of their report. That is just to give you some context around this. This all began in 2019. Now we are at the point where we have a bill to discuss. If you were not aware, I wanted you to know that that had taken place.

Dr Long: May I respond at some stage?

CHAIR: At a point. Let us get to the question.

Ms PEASE: We talked about choice and the fact that at the end of life people are not well and sometimes the doctors get it right and sometimes they do not. What I would like to understand is: what does 'getting it right' mean? Is that terminal sedation?

Dr van Gend: That is part of symptom control, but it is not intending to kill the patient. I have done it once for a patient with horrendous breast cancer pain. At one point she was in such pain that even the medicines we had were not sufficient. I said to her, 'We've reached the end here. Do you need to just rest for a day or so just with twilight sedation? You will still probably be able to rouse.' She said yes. We did that. For a day she was at complete peace. When she roused, she sat up and asked for some ice cream and we gave her some ice cream. We were not trying to end her life. People should not misrepresent terminal sedation as trying to end their life. We are not. They are dying of their underlying disease. We are just doing what we must do to stop the pain.

Ms PEASE: Thank you for that. We have heard significant testimony from a number of expert witnesses who, similar to yourself, are doctors and university lecturers. They talked about the number of suicides that people undertake because they have no relief. They are in intolerable pain and there is nothing they can do. There are seven suicides a month that support that. In terms of terminal sedation, you have been fortunate in that you have only had that experience once. That is contrary to much of the information we have heard from other witnesses, who have come across it often. My comment with regard to that is that often there is no conversation. You have indicated one occasion on which that did occur, but that does not necessarily happen in each and every case. Could you speak to that across the arena with other doctors you may have come into contact with?

Dr van Gend: Not really, because it is relatively rare. The intention is what matters, and the intention is to relieve the symptoms, never to take the person's life. You look after their symptoms while they die of their underlying condition. That is all I can say. Each case would be different.

Ms PEASE: Would those conversations take place with a patient? Maybe you are not in a position to have had that conversation if you have never done that, so we might just end it there.

Dr van Gend: No, it has been had because it is part of us caring for their suffering. This is just another aspect of it. It is all agreed in advance.

CHAIR: From a clinical perspective, Doctor, with enough opioids and sedatives, generally morphine or fentanyl and a mix of perhaps midazolam—and we have heard from people who said that when their relatives were dying they would get this incrementally and sometimes they would last days or weeks—at a point in time there is enough of that depressed breathing, a reduced heart rate and the person dies. I know your intention is to reduce harm and suffering, but it is not called terminal sedation lightly because at a point in time they do pass away.

Dr van Gend: True, but they are going to pass away of their disease. I will tell you the truth: we do not know if we have extended their dying process or shortened it. We honestly do not know. We do know that morphine can often prolong someone's life because it relaxes their system and they do not have a heart attack or stroke, but we honestly do not know. We do not care, because that is not the point. You are never trying to prolong somebody's dying—never—but nor do you shorten their life. You deal with their symptoms. That is our only mindset. It is very simple.

CHAIR: If you are on opioids, opioids and opioids throughout the day, can you tell me what the side effects are?

Dr van Gend: If you have enough, your pain is relieved. You may get the side effect of sedation; you may not. The art is to match the medicine to the symptoms. When we give more, we only increase it if their symptoms increase. If their distress rises, we match it. We do not crank it up because it is a Tuesday, a Wednesday or a Thursday—no. That is very poor medicine.

CHAIR: I ask that because in our broader inquiry it was referred to as 'euthanasia lite'. We heard from palliative care nurses who said they would ask for more, and eventually they would just stop breathing.

Dr van Gend: If so, that is very, very, very bad medical practice. They obviously missed out on my lectures.

Ms KING: Thank you all for being here. I know that you are all here today as people with deep values, and I recognise those values. This committee and the former committee have heard the submissions of thousands of people who also brought incredibly deep values and deep personal experiences before us. Their submissions described family members starving themselves to death to

relieve themselves of symptoms and suffering, whether physical or mental, which they found unbearable. They described family members committing suicide, sometimes in very traumatic ways, to bring an end to a process they could no longer bear. They described family members who, despite having access to good palliative care, had absolutely had enough and took the step of committing suicide.

You have recommended changes that you want to the legislation. You would like people to have access to a palliative specialist for an assessment. You want a six-month time frame. Cherish Life would like doctors to be limited in the number of VAD assessments they can make in a given time frame. I put it to you that those proposed amendments are actually just seeking deliberately to create barriers to access for people whose own values tell them they themselves in their dying would like to seek voluntary assisted dying. I put it to you that your values are values that you are trying to impose on people who have different values.

Ms Francis: Ms King, I would refute that. From my own personal experience as well, there are also many incredible stories of elder abuse and incredible stories of inheritance impatience, so there is another side to this story. Everybody has a story. Each one of us here today has their own story too, and every story is valid.

Ms KING: They were not the stories that overwhelmingly this committee has been told, however. I am not saying that they were not provided, but they are not the stories we mostly heard.

Ms Francis: Your submissions are not on elder abuse or inheritance impatience. Your submissions have been asking about that, so that is what you are going to hear. I have told you good stories of death too, and overwhelmingly the stories of death are actually good, but we do not hear those stories; we hear the really sad stories, and they are sad. I think all of us at the table will have experienced sad deaths because we work in churches. When there is a societal good and a societal bad, we have to choose what is in the best interests of all society. There are many, many stories on the TV just about every night, which is pretty nauseating, of elder abuse and inheritance impatience but also so many other stories of good deaths.

People have said that people are suiciding because of their pain. Suicide rates go up when we introduce VAD, so that does not even make sense. Since VAD was introduced in Victoria the suicide rate has gone up over 20 per cent, so it does not make sense to say that people are suiciding because they want VAD. When we introduce VAD, suicide rates actually go up. People's pain is not ameliorated or reduced because we introduce VAD.

Ms Johnson: It is definitely not imposing our views upon people. It is trying to make sure there is less wrongful death. This is a dangerous bill. There will be wrongful deaths. The Australian Care Alliance submission covered wrongful deaths extensively. We are trying to make there be fewer deaths. We know there will be a marked increase in deaths every year. At the time of the debate in 2017 the Victorian health minister at the time said there would be 50 fewer suicides. When the bill was enacted there were four more unassisted suicides plus all of the people who accessed the voluntary assisted dying scheme there.

Ms KING: Four more suicides, did you say?

Ms Johnson: Yes. She said there would be 50 less a year, but comparing 2017 and 2020 there were four additional ones.

Ms Francis: I need to correct that. In 2016 there were 595; in 2020 there were 645.

Ms Johnson: There you go. I am sorry, I was comparing the 2017 data. So it does not decrease by 50, so there are wrongful deaths. That always occurred. There are no safeguards in the world that can stop wrongful deaths occurring. We are trying to make it more secure.

Ms KING: I put it to you that the numbers you are quoting are not statistically significant.

Ms Johnson: We have done an economic analysis. It is in my submission.

Dr van Gend: On the question of values, as you said, it should not be a competition of values and a competition of tragic stories. As our representatives who make the law, the question is whether we overturn the foundational cornerstone of law in all societies in all times for the sake of these competing values stories. The other great question to you as lawmakers, I suggest, is whether you overturn the one genuine human right at stake here, which is liberty of conscience and freedom of association. The central concern, besides the injustice of this bill, is that it will use state power to coerce the conscience, both of individuals who will have no part in intentional killing and of associations of individuals—what you call entities—who have built up their entity around a moral viewpoint, a philosophy of life, which utterly opposes intentional killing.

The grievous thing about this is that part 6 will trample on the liberty of both conscience and association. Please, it is unnecessary. If you look at the suggested amendments I made in the submission, it is not difficult to get the balance. Doctors will hold to one part where they will say, 'I cannot do this for you, but other people can,' but you will not compel them to give names or contact details of somebody who will perform this gravely evil act. You cannot ask a person to collaborate in something they consider gravely evil. You cannot do it. You are violating a fundamental universal human right.

Please, if there is any goodwill in this committee and any goodwill in this government and you are not trying to just exert ideological power over Christian people or others, please do not trample on the conscience of individuals or church based institutions who want to live by their ethos of care and do not want some junior five-year doctor, a coordinating practitioner, coming in and decreeing: 'Mrs Smith will die on your property because I have the power under this law to say that she will be euthanised on your property.' That is so unjust and so unnecessary.

CHAIR: Dr van Gend, I do not think you were here when the Human Rights Commissioner spoke about the rights of the individual versus the rights of institutions. He thought that the well-considered draft legislation of the QLRC had struck a balance. Please read *Hansard*. I want to move on very quickly.

Ms Johnson, you talked about palliative care. We heard an observation this morning from Andrew Denton that every state that has implemented a law has had a significant increase in palliative care funding as a result. You would know that the other work we did was around aged care and palliative care. There were some 77 recommendations. We were very pleased to put in more funding that was needed, and in fact it has been announced as part of that work. I just want to make that observation.

Ms Johnson: Do you want me to comment?

CHAIR: It is entirely up to you.

Ms Johnson: Mr Harper, we are pleased that \$170 million extra has been announced, but it is over six years. That is only \$28.5 million a year for six years with no promise of renewal. That is only about an eighth of what is needed, according to Palliative Care Queensland.

CHAIR: We are working closely with Palliative Care Queensland, but the figure we got from Queensland Health was \$247 million by 2025. Those conversations will continue, but that is the work we did.

Dr Long: Mr Harper, there is a large admitted shortage of palliative care specialists, particularly in North Queensland. While I accept there have been increases in palliative care funding, it is generally held to be the case that there is still a large unmet need.

CHAIR: Part of that funding was to increase the workforce, which would be welcome, because it is really hard to get palliative care specialists.

Mr BERKMAN: Thank you for being here today. Ms Johnson, looking at the Cherish Life submission, part 2 is described as an analysis. This is analysis that was done by Cherish Life; is that right?

Ms Johnson: We got an external economist. My background is economics as well. We were happy with the analysis. Yes, it was done by Cherish Life looking at overseas jurisdictions as well as Victoria.

Mr BERKMAN: Cherish Life is a lobby organisation.

Ms Johnson: Yes.

Mr BERKMAN: Are you content that you as an organisation have the necessary expertise to present a genuinely impartial analysis to the committee that it is not clouded by the—

Ms Johnson: Mr Berkman, we employ professionals when we need them. We employ lawyers when we need a lawyer. We employ economists. There are network doctors. Dr van Gend is helping us today. We do have a lot of affiliates. We also employ people as contractors as we need them. Yes, I am happy to say that I believe this is accurate. We would not present inaccurate data, so my answer is yes.

Mr BERKMAN: Your contention, if I have read this correctly, is that Cherish Life would not publish anything that you did not feel was absolutely backed up by the evidence and the facts and circumstances.

Ms Johnson: Indeed. I am surprised you have to ask this question, but yes.

Mr BERKMAN: I am interested because I have here an email that I have received from you, and I do want to quote it because I feel as though it is important in terms of framing the credibility of certain statements and evidence. It is dated 23 January this year. I will read it out so we have the full context. It says—

While the debate on whether the US election was stolen is outside the scope of Cherish Life, it is probably fair to suppose that people who are complicit and happy to fund the killing of innocent unborn human beings think nothing of stealing and lying. In our humble opinion, it is likely the Democrats did steal the election.

Ms Johnson: Can I ask what on earth this has to do with this?

Mr BERKMAN: I am interested in testing your suggestion that you would not publish anything that you did not think was supported by evidence.

Ms Johnson: This is out of order. That is one of our emails—

CHAIR: Let's all take a breath. We are nearly at the end of the day. I am very sorry, member, but we will rule that question out of order and get you to ask a supplementary question.

Ms Johnson: Are you interested in the data quite genuinely, because I am very happy to talk to you about it?

Mr BERKMAN: I am interested in your credibility as a witness, Ms Johnson. I have been ruled out of order so I will move on.

CHAIR: That has nothing to do with the bill.

Ms Johnson: I am just going to talk about the data, Chair. I did get a question about it. We have done a projection that shows that the overall suicide rates in Queensland will go up by about 57 per cent if this is enacted over the next 10 years. It is a scary projection and it is based on data from seven different jurisdictions. This is a warning. I am pleased you raised it so thank you, Mr Berkman.

Mr BERKMAN: You are very welcome. I will put a pretty straight yes-or-no question to each of the witnesses here at the moment. You have all taken firm positions against VAD. Is it the case that, irrespective of any amendments to this bill, you would not support any scheme that would legalise voluntary assisted dying, voluntary euthanasia—however you might want to term it? You would not support such a scheme?

Ms Johnson: No, definitely not.

Ms Francis: I do not support the killing of an innocent person.

Dr Long: There is no way that we could support the state taking the life of a human being.

Dr van Gend: You cannot bring in a law that gives increased liberty to some and oppression to the more vulnerable. It is an unjust law. It should not be getting a showing.

Ms KING: So it is in fact the case that the amendments you propose are designed to create barriers to access?

Ms Johnson: No, it is to soften the severity of the bill.

Dr Long: They were inspired by the concern for vulnerable people and the desire to bring in greater protections for vulnerable people, for the sake of the common good.

Ms Francis: We would do it in a different—

CHAIR: Order. We will go to the deputy chair for a final question, please.

Mr MOLHOEK: My question is to Dr van Gend. We talked about the issue of institutions and the application of the legislation to them in terms of providing access to VAD or transfer or whatever else. What would you suggest would be viable alternatives to having those sorts of provisions in the legislation as proposed?

Dr van Gend: These are private institutions. They should operate like any private institutions and only offer what they are prepared to offer. People who come to access those private institutions—not government but private institutions—will know clearly in advance that this product is not for sale. I fully support part 6, division 2, subdivision 4, clause 98, which says that these entities will clearly advertise that they do not provide VAD. That is only proper, because then the person going into the nursing home or the hospital knows that it is not on and that if they are going to ask for it later they will just have to make their own arrangements. These entities are not going to be callous if they make a decision like that. They are going to be as kind and supportive as they can, but they will never refer. They will provide that patient with all of the relevant information regardless, but they will never refer. All we ask is that those entities which are exercises of free association by people of free conscience

and religious view, if you like, be allowed, as you say, to be free of subdivisions 1, 2 and 3—get rid of them; they are just exercises in state coercion of church institutions and that is all they are—but keep subdivision 4 whereby those entities will let people know clearly that ‘it is not available, so please do not come here if that is what you want’.

CHAIR: We had the Uniting Church appear and unfortunately you were not here with them. Reverend Gunton said that they would support a practitioner in their institutions. I note that you said ‘not government’, because they indicated that their hospitals and 60 residential and aged-care places were funded generally by the federal and state governments. There is a mix.

Dr van Gend: But the ethos of care was created by that church community. Again, you guys have all the power. You can trample on them if you want or there can be that goodwill I spoke of. This can be getting this initiative into law, which we oppose, but if you get it into law at least you could have the civility, the peace-building capacity, of not crushing the conscience of individuals or church based institutions. That would be a far lesser evil than the present proposal. We ask for that.

CHAIR: I thank representatives from Cherish Life Queensland, the Australian Christian Lobby and Right to Life Australia for your contributions today. We will move to the final group of witnesses, representatives from Health Professionals Say No!

BEST, Associate Professor Megan, Associate Professor of Bioethics, Institute for Ethics and Society, University of Notre Dame Australia; Health Professionals Say No! (via teleconference)

CIGOLINI, Associate Professor Maria, National Coordinator, Health Professionals Say No! (via teleconference)

McENIERY, Dr Judith, Queensland Representative, Health Professionals Say No!

CHAIR: Judith, would you like to start with an opening statement?

Dr McEniery: Thank you for this opportunity. I realise it is the end of the day and everyone is tired. I also acknowledge that much of what I am about to say has inevitably been covered today but I think we can all relax and review it. It is important.

Health Professionals Say No! is an independent secular network of over 850 doctors, nurses and other health professionals who are deeply concerned about the proposed VAD legislation for medical and social reasons. Personally, I have worked for over a quarter of a century with the chronically ill, aged, disabled and dying in every mode of palliative care provision for patients with an extensive range of cancer and other non-malignant conditions. I have been involved with providing dignified care for thousands approaching death and supporting the associated families through the experience.

In introduction, we would like to emphasise the following: VAD legislation has around it a great deal of public misinformation, falsely creating an illusion and promise to relieve suffering. This sidelines the real societal and healthcare actions required to compassionately address the causes of the suffering. For example, the legislation as framed is for a prognosis of up to 12 months, well before a person is actually dying, while community palliative care service provision—palliative care being the evidence based standard of care to improve quality of life and dying—is only funded by this government for the last three months of life. Making VAD legal without reforming the palliative care sector—and again I refer to the postcode lottery—that fosters dignity and eases suffering means there is no choice, especially for those anxious and under duress about their care.

I have a further point about suffering. Grief when someone close to us dies is always a source of suffering and even those whose loved ones go through assisted suicide or euthanasia will know the serious suffering of grief, as has been experienced overseas, warranting care and support. We have heard about the inquiries into aged care, disabilities and the National Suicide Prevention Strategy, and those have all confirmed fears surrounding high rates of abuse, risks of coercion and a crisis currently among vulnerable social groups such as First Nations people and those in regional areas who may be subject to the inherent lack of safety in VAD legislation in general and specifically that proposed in Queensland.

I give some examples of that in this law. There are deficiencies in the assessment process by allowing non-specialist determination of prognosis and suitability for VAD rather than appropriate specialist referral for best practice care. Giving prognosis is notoriously an inexact science. How many people here know of someone given a specific number of weeks or months to live who has then gone on to prove the prognosticator wrong? Even experienced clinicians find that very difficult.

The inappropriate use of federal telehealth initiatives could further increase the risk of inaccuracies. Allowing the beneficiary of a will to collect lethal drugs poses an obvious danger of misuse, especially in the presence of a fluctuating mental competence. Finally there is falsification of death certificates, eroding the powers of the coroner to investigate possible abuses.

How can this government allow such unsafe practices to become legal before addressing strategies such as adequate palliative care, suggested by these national inquiries? Good laws make it easier to do right and harder to do wrong. Others have spoken of wrongful deaths. The suggested VAD legislation makes mistakes, abuse and coercion more likely without addressing and protecting the real needs of vulnerable individuals.

VAD is not a medical treatment. It is not part of evidence based health care and introducing it creates an ambiguous environment leading to moral distress among patients, healthcare and other service providers and families. Reports of the distress among staff and patients in Victorian hospitals and the exit of many doctors and nurses from Canadian hospitals and hospices since VAD was introduced—or MAID, as they call it—support this. Health professionals and institutions should not be forced by VAD legislation to act against their ethical standards.

In conclusion, there is a huge amount of misinformation about this topic. Through this inquiry you have heard of very emotional cases where high-quality care was not given. This emotion can blur how we as a society provide compassionate care to those facing the end of their lives. The Queensland government should aim for the compassionate equitable provision of health care, improving the quality of life for all of its citizens, caring for the suffering and protecting vulnerable Queenslanders.

CHAIR: Thank you, Dr McEniery. We now have on the line Associate Professor Maria Cigolini. Maria, would you like to make a brief opening statement?

Prof. Cigolini: I accept Judith was speaking for us all. We were hoping to expand on the things that we feel are contradictions within the legislation, around the framing of eligibility and the concept of choice in regards to the services and the timings of the enactment of the bill, if it were to exist. I also point out that, even though we represent 850 independent medical and other healthcare professionals, what we are stating is evidenced by surveys of much larger groups of health professionals where VAD already exists, for example, or is due to exist soon.

CHAIR: Thank you, Maria. Megan, did you want to comment?

Prof. Best: Judith has spoken for the three of us. We collaborated on her opening statement and fully endorse what she said.

CHAIR: I have a brief question before I open it up to the rest of the committee. I have two points to note. We have heard from medical specialists and specialist palliative care providers, including Will Cairns, who is very well known in North Queensland. We thank everyone who does this amazing work in palliative care. They were in favour, and have come before the committee and given graphic evidence in previous hearings of people suffering. They believed—as did the nurse practitioner of 27 years experience yesterday in Rockhampton, plus the many providers that came before us in the former inquiry—that some people should have choice and not all pain can be alleviated. What do you say to those other health professionals who might be diametrically opposed to your views?

Dr McEniery: That is fairly complicated. I will make some comments and let the others comment as well. Very few of them are 'diametrically opposed'. Some of them do see VAD as co-existing with palliative care. I do not agree with that. Will Cairns, in particular, has followed that line and he does quote some challenging scenarios. David van Gend alluded to the fact that we are not about eliminating all suffering. There is a hell of a lot of suffering in the world that is not removable and that is because a lot of the suffering is not pain, is not physical. It is existential—their mental and emotional wellbeing. It is very complicated what leads up to that, and it feeds into their illnesses.

Every one of us can think of situations. Will quotes the example of a person with a very advanced extensive facial lesion, yet, from my point of view, one of the most dramatic patients that I dealt with through my career had exactly that. His courage and spirit were absolutely exemplary. He gave more than we gave to him. He had an eroding tumour—and I will not go into the details, because it was really quite ugly and challenging to look at—yet, in his final days at hospice, he gave much joy. When he lost his eyesight because of this tumour he said, 'When I was 16 I played the drums.' He obtained a practice drum kit and he learned the drums again, as he was visually impaired.

I quote that as an example of someone living well until they die. I think that is one of the goals of palliative care. Pain is sometimes physical—and we can talk more about the relief of that—and we do have means, as David alluded to, which sometimes do come to the person dying during that process.

Prof. Cigolini: If we are looking more generally at the information we have available through benchmarking data of palliative care and the quality provision of palliative care—in particular the PCOC data, or Palliative Care Outcomes Collaboration data—it shows that when appropriate care is given, both psychosocially and physically, the vast majority of patients are well controlled in their last days of life, in terms of their symptoms and their families being well supported.

I have been practising for 38 years, 20 of those in palliative care and in the last 10 years in very acute hospice situations as well. A lot of people come fearing the unknown, but when they are provided with appropriate quality palliative care and supported and their relatives and families or carers supported, they find they are able to cope again. That time can provide a degree of closure, or even a time for making family memories that are a legacy, rather than a truncated experience.

Even though the occasional case exists where symptoms have not been controlled, the majority experience is that it is controlled. When symptoms cannot be fully controlled—sometimes due to the choice of the patient not wanting sedation, or wanting to be present to their relatives or their experience for other reasons—they can be supported and appropriately accompanied through it, which is what we call 'dignified care'.

Prof. Best: We are concerned that in the government's efforts to make euthanasia available to all people in Queensland you are failing to provide options for those who find it threatening. The three of us have worked in palliative care and we know that support in palliative care populations for this legislation is much lower than in the general public, because our patients know what care is available. Many of them have expressed concern that if there are no institutions where VAD is not practised they will not have anywhere to go where they feel protected from this legislation.

We need to remember the responsibility of the government to provide security for the vulnerable people in our community. Your sole responsibility is not to provide access to this legislation for those who are requesting it, as your only consideration. We feel that the debate has been unbalanced, because so many of the vulnerable people in our palliative care communities are not well enough to engage in the public debate.

CHAIR: The former iteration of this committee reported on palliative care and aged care in Queensland and made 77 recommendations. I wanted to point that out. A fair bit of work has gone on already and it has resulted in additional funding, but we certainly take your point.

Prof. Best: Patients are only eligible for full palliative care services when they have a prognosis of three months. They will be eligible for VAD when they have a prognosis of 12 months, so that is a difference of nine months where they cannot access palliative care services fully in the home.

Prof. Cigolini: That in itself creates coercion, because if you have fears or you are not supported you have no choice, but you are still offering that as a choice when the services are not available or accessible. In fact, a survey of more than 1,500 medical practitioners conducted by the Western Australian branch of the AMA found that all of the doctors were concerned about lack of safeguards in the bill, particularly around lack of equitable access to palliative care across the state.

More than 90 per cent of those doctors surveyed considered it crucial that there be demonstrable, equitable access to palliative care for patients at the same time, if voluntary assisted dying were offered. That answer was the same whether the doctor was personally opposed or supportive of VAD. It was further confirmed by 2,000 Western Australian residents. That survey demonstrated that 75 per cent would want government to address palliative care service provision and regional access ahead of VAD. At the moment, even though I commend health and the government putting forward and starting on recommendations and staged action, the issue is that the VAD legislation is premature and will be for a long time to come.

Dr ROBINSON: How does palliative care relieve extreme or intolerable pain compared to VAD treatment? The legislation is supposed to be about relief of suffering of those with a terminal condition who are also in intolerable pain. How do both treatment regimes achieve that?

Dr McEniery: I am not sure how many of you are familiar with how VAD is actually administered. There are two options that are offered to people who are seeking assistance in their dying. The first is an oral—they call them 'medication', but they are not; they are drugs. They are substances that are provided to the person or to their delegated agent. It consists of three substances. One is a relaxant; one is an antiemetic, which stops you from being sick; and the third is basically a sedative. There is no pain relief currently in Victoria's system. The major substance has an action of diminishing your awareness and your nervous system until you stop breathing and functioning at all. In other countries, there are alternative medications.

The second option is for a doctor—they also allow nurse practitioners—to administer intravenously. That is actually as a push. Sometimes that is given as a sedative and then somebody is given a relaxant. By the way, this is supposed to be secret, but it is on the internet if anybody is interested—how to commit suicide and how it is done as euthanasia.

It is basically a decision that somebody makes, having already applied and when they feel that it is right for them. If, in the rare instance they are doing it for severe pain, there are a lot of other options of giving real pain relief that really should be offered and accessed before that. How does palliative care do it? When we see a patient first up, we spend considerable time getting the whole scenario of that person's illness. Someone said before that we do not always know the person. You get to know them.

The first consultation would be rarely under an hour and basically talking through, 'What are your concerns today? How can I help you with those?' We would ascertain if they had symptoms like pain or vomiting or if they had not passed their bowels. They may talk about something distressing, like they feel rejected by their family or they are going to be a burden. Sometimes you go through their whole medical and social history—their life story, really—and it can unearth lots of different factors that are contributing to their distress. Each one of those concerns is addressed with expertise.

Sometimes it is not the doctor that does everything. Sometimes we will call upon a counsellor, or a nurse might come over separately. A social worker might be involved. A lot of it is medication. It is a matter of saying, 'What have you tried already for this pain? What's it like?' and tailoring an appropriate, carefully worked out regime to that particular person.

If pain does become an escalating scenario, then drastic situations require drastic measures. There is proportionality in addressing the degree of the distress by the degree of the doses that are used, and it is reviewed frequently. Sometimes a person in that scenario has severe end-of-life distress; the person is already dying. They might be reviewed three times in 24 hours by a specialist palliative care service and have their approach adjusted. This will mostly deliver a situation of calm, of the person being minimally aware or not aware.

David had the situation where someone woke up. I have rarely had that situation, because most of those really terrible, challenging scenarios that I have encountered have been right at the end of life, often in young people who have missed the opportunity to have their real distress addressed.

There are lots of case stories. The one I remember most clearly was a man in our Ipswich palliative care service who was so restless and distressed he was being nursed on the floor—on a mattress but on the floor—because he was a danger of falling out of bed. Medication was proving very, very challenging. What we did was approach his wife, because he was not in a state to be coherently communicating, and she said he has not spoken to his son for four years and we said, 'Do you know what is behind that?' She did not know what was behind it. 'Where is the son?' He was on an Army base or on an exercise somewhere near Townsville and supposedly uncontactable. We managed to get special access to contact him. He knew what was going on. He spoke to his father—even though his father was incoherent and not communicating well—for about five minutes. We do not know what the son said on that telephone call, but thereafter the patient himself was calm. It was a really poignant example of the distress at end of life not being a medication issue but being a relationship turmoil, and so often that is never addressed.

Dr ROBINSON: In short, is there a difference in terms of contrast in terms of the purpose or the intent of the two different treatments?

Dr McEniery: With VAD the purpose is to end that person's life.

Dr ROBINSON: What treatment?

Dr McEniery: Sorry, the VAD. Whether you take the substance orally or the person is having it administered by a doctor or nurse, the intention is that the life is terminated; the person is killed. With respect to the palliative care scenario, all of the time we are addressing the symptom or the problem that is at hand. We are using sometimes very powerful medications in combination: strong pain relief like hydromorphone, powerful sedatives such as midazolam, a calmativ agent, an antiemetic such as haloperidol, often in combination, sometimes in very large and increasing doses that surprisingly people tolerate, but we are not killing the person. The person is dying and we are treating their symptoms.

Mr ANDREW: Unfinished business is very important.

Dr McEniery: Exactly. That is a nice term: unfinished business—the matters of life, the spiritual distress that comes at end of life when relationships have not been healed.

Mr ANDREW: Are there any other inadequacies that you see going forward if the bill is introduced?

Dr McEniery: I think the possibility that the wrong people will access, that there will be unrecognised coercion. If any of you have not seen the short film *The Mother Situation*, I suggest that you google it and spend seven minutes watching it. It plays into that whole coercion, beneficiary of will type scenario—the possibility that people will feel that they have a duty to access because of the pressure of their families and not wanting to be a burden. I think some of those have been mentioned earlier. Megan and Maria, do you want to add anything?

Prof. Best: One of the big problems with the bill that we recognise is the lack of institutional and individual conscientious objection. We would like to refer to a poll of over 5,000 Victorian doctors in 2019 which found that only 20 per cent of doctors wanted to be involved in the practice of VAD. There needs to be some opportunity within the bill for those individuals and institutions who do not want to engage in this practice to perform medicine according to their own ethical values. We see this as a great shortcoming of the bill.

There is also the lack of expertise of the doctors who are asked to be involved in the evaluation of patients. Particularly as palliative care specialists, we are aware of how poorly understood by generalists are the therapeutic options that we have, and we do not think patients will be properly informed of their options if a palliative care staff member is not involved. Thank you very much for listening to our views.

Prof. Cigolini: I would like to make a further statement along the lines of what Megan has said and just add a little bit further to the Victorian experience. In regard to residential aged care, I specifically would say that many of the people in residential aged care would be quite distressed to know that residents were being able to access VAD within the institution, particularly if residents find out. We find that for a lot of the carers, whose goals of care are to foster and allow flourishing of life in those institutions, it will create moral distress and ambiguity around messaging around what care to expect in those institutions. We have seen in Oregon where people are afraid to come forward to palliative care because they feel that in aged-care facilities where it does exist they may be offered VAD instead.

Lastly, we can look at the figures from the death certification of the State Coroner which was defective and was initially provided as evidence for VAD by the pro-VAD groups. What that evidence actually showed was that those who did seek suicide in their last year or so of life did so mainly because they had a lack of access to high-quality specialist palliative care in that these people mainly had not been exposed to palliative care, had not had their symptoms managed and had not been referred for appropriate care at that time. Many of them were likely to have undiagnosed mental conditions, including severe anxiety, depression or demoralisation, which may have just been put down to, 'Well, what would you expect? They have cancer.' I think these situations are much more subtle than expressed and also they are issues which can cause continual problems when there is not equal access, as demonstrated by the Western Australian surveys.

Lastly, if I may, I would like to read a letter that I have received. I am sure you have listened to many letters from the Dying with Dignity and Go Gentle group, but this is the type of letter that we actually receive.

Dr McEniery: Just a short version, Maria, because we are out of time.

Prof. Cigolini: This is a very short letter.

Dr McEniery: I think, Maria, you are going to need to send it because we are over time.

CHAIR: Maria, we are over time. We would love to read that letter if you could send that to the committee, please. We are well and truly past our finishing time. We appreciate all of you giving time this afternoon. Your observations certainly help the committee. Thank you very much. I now declare this public hearing closed.

The committee adjourned at 5.23 pm.