



**LEGISLATIVE ASSEMBLY FOR THE
AUSTRALIAN CAPITAL TERRITORY**

**SELECT COMMITTEE ON THE VOLUNTARY ASSISTED
DYING BILL 2023**

(Reference: [Inquiry into the Voluntary Assisted Dying Bill 2023](#))

Members:

**MS S ORR (Chair)
MS L CASTLEY (Deputy Chair)
MR E COCKS
DR M PATERSON
MR A BRADDOCK**

TRANSCRIPT OF EVIDENCE

CANBERRA

MONDAY, 29 JANUARY 2024

**Secretary to the committee:
Ms K de Kleuver (Ph: 620 70524)**

By authority of the Legislative Assembly for the Australian Capital Territory

Submissions, answers to questions on notice and other documents, including requests for clarification of the transcript of evidence, relevant to this inquiry that have been authorised for publication by the committee may be obtained from the Legislative Assembly website.

WITNESSES

BARAKOVSKA, MS IZABELA , Chair, ACT Ministerial Advisory Council for Multiculturalism	63
BLACKER, MR SIMON , Branch President, ACT branch, Pharmacy Guild of Australia.....	8
BOESEN, MR MICHAEL THOMAS , Member, ACT Policy Advisory Group, National Seniors Australia, ACT Branch	25
FERRINGTON, MS SANDRA , Committee member, ACT branch, Pharmacy Guild of Australia	8
WONG, MRS KUI FOON , Council Member, ACT Ministerial Advisory Council for Multiculturalism	63
GORMAN, MS KATE , Deputy Director, Health Care Consumers Association	17
JOHNSON, MISS JESSICA , Policy Officer, Carers ACT.....	40
KELLY, MS LISA , Chief Executive Officer, Carers ACT	40
McARDLE, DR PATRICK , Chancellor, Archdiocese of Canberra and Goulburn	70
PROWSE, MOST REVEREND DR CHRISTOPHER , Catholic Archbishop of Canberra and Goulburn.....	70
REDDY CHINTALAPHANI, DR SHANTI , Co-Chair, ACT Ministerial Advisory Council for Multiculturalism.....	63
ROBERTS, MR TROY , Media and Government Relations Manager, Australian Federal Police Association	1
ROWE, MR JOSHUA , Acting State Director NSW/ACT, Australian Christian Lobby	70
SHORT, THE RIGHT REVEREND DR MARK , Bishop, Anglican Diocese of Canberra and Goulburn.....	70
STEVENS, DR ADELE , Consumer representative, Health Care Consumers Association.....	17
TORRESI, MS KYM , Senior Adviser, Aged Care, Speech Pathology Australia.....	49
WALLACE, MR CRAIG , Head of Policy, Advocacy for Inclusion	55
WARD, ADJUNCT PROFESSOR KYLIE , CEO, Australian College of Nursing	32
YATES, PROFESSOR PATSY , Executive Dean, Faculty of Health, Queensland University of Technology	32

Privilege statement

The Assembly has authorised the recording, broadcasting and re-broadcasting of these proceedings.

All witnesses making submissions or giving evidence to committees of the Legislative Assembly for the ACT are protected by parliamentary privilege.

“Parliamentary privilege” means the special rights and immunities which belong to the Assembly, its committees and its members. These rights and immunities enable committees to operate effectively, and enable those involved in committee processes to do so without obstruction, or fear of prosecution.

Witnesses must tell the truth: giving false or misleading evidence will be treated as a serious matter, and may be considered a contempt of the Assembly.

While the committee prefers to hear all evidence in public, it may take evidence in-camera if requested. Confidential evidence will be recorded and kept securely. It is within the power of the committee at a later date to publish or present all or part of that evidence to the Assembly; but any decision to publish or present in-camera evidence will not be taken without consulting with the person who gave the evidence.

Amended 20 May 2013

The committee met at 10.01 am.

ROBERTS, MR TROY, Media and Government Relations Manager, Australian Federal Police Association

THE CHAIR: Good morning and welcome to this public hearing of the Select Committee on the Voluntary Assisted Dying Bill 2023, in its inquiry into the bill. The committee will today hear from a wide range of witnesses who made submissions to the inquiry.

The committee wishes to acknowledge the traditional custodians of the land that we are meeting on, the Ngunnawal people. The committee wishes to acknowledge and respect their continuing culture and the contribution they make to the life of this city and this region. We would also like to acknowledge and welcome all Aboriginal or Torres Strait Islander people who may be attending today's event.

The proceedings today are being recorded and transcribed by Hansard and will be published. The proceedings are also being broadcast and webstreamed live. When taking questions on notice, it would be useful if witnesses used these words: "I will take that question on notice." This will help the committee and witnesses to confirm questions taken on notice from the transcript.

Voluntary assisted dying is a sensitive topic. The secretariat has information on support organisations available for witnesses or other people attending this public hearing who are impacted by the issues raised during the hearing.

Our first witness today is from the Australian Federal Police Association. I remind witnesses of the protections and obligations afforded by parliamentary privilege and draw their attention to the privilege statement. I believe this would have been forwarded to you, Troy. Witnesses must tell the truth. Giving false or misleading evidence will be treated as a serious matter and may be considered contempt of the Assembly. Please confirm that you have understood the implications of the statement and that you agree to comply with it.

Mr Roberts: Yes, Chair. I understand the statement and I agree to comply with it.

THE CHAIR: Thank you. We are not inviting opening statements, but if you have one you are welcome to table it. We will now proceed to questions. Your submission discusses the trauma, the mental and physical toll, that attending and investigating a suicide scene has on police officers, staff and other first responders. How do you anticipate that the introduction of voluntary assisted dying legislation in the ACT will improve workforce wellbeing in this regard?

Mr Roberts: Thanks for the question, Chair. It is a really valuable question because we in the police already see too many traumatic deaths. We go to homicides; we go to suicides and fatal car crashes. It is an aspect of the job which we cannot avoid. We need to do it. We understand that we need to do it, but it has a significant impact on the mental health of police officers, not only in the ACT but Australia wide.

It is not a huge occurrence but has happened a couple of times in my career, over 20

years in ACT Policing, that I have attended a suicide and then we commence the investigation and we find out that the person has recently been diagnosed with a terminal illness. We normally find out via a suicide note or, once we engage with the GP as part of that investigation, it comes out that they were recently told about their terminal illness.

At times, they have not told the family, so it is very traumatic for everyone. We are hoping that with the VAD legislation—as cold as this sounds—it becomes a process for people. They can go through the process, they understand the process, there are safeguards in place which make sure that the process cannot be misused or abused and then, come that time where someone does choose to take the drugs as part of the VAD program, their death is done in a peaceful way.

Quite often with suicides they are traumatic, especially where someone—and I hate saying it—hangs themselves in their backyard by the tree or they gas themselves, in the old days in a motor vehicle. Some poor person—and that is normally a family member—has to find that person and then notify us. Then we attend and the officers obviously have to try and give first aid.

As part of my experience as a police officer, I have had to climb a tree to cut the rope to lower someone to the ground. And it still haunts me today that we have to do that. As I said, it is your role as a police officer. You accept it and you get on with the job. But it all adds up to the accumulated PTSD issue that a lot of police officers are facing today.

THE CHAIR: Following on from that, you noted in the submission—and I think you made reference to it in the answer that you gave—that you have had cases where you have attended a suicide and it has been for medical reasons. You have subsequently found out that that is the indicator. If the bill were not passed, would it be your expectation then that you would continue to see suicides for health reasons?

Mr Roberts: Most definitely. As I said in our submission, we are not going to see a huge decrease in suicide. If someone wants to commit suicide, they are still going to commit suicide. This just gives people a voluntary option so that they can take their own life with their own hand, under their own power and their own mindset, and have some dignity at the end.

THE CHAIR: Thank you.

MR BRADDOCK: In your submission you talk about an average of 34 deaths by suicide per year. What proportion of those would you think are suicide due to health reasons?

Mr Roberts: To be honest, it would be a complete guess. I do not know what that number would be. I am hesitant to actually put a number on it. I would not want to mislead or throw out furphy stats to the committee.

MR BRADDOCK: Okay. Thank you.

MS CASTLEY: You note in your submission that the Voluntary Assisted Dying Bill

will not introduce a predicted time of death for applicants and that this is inconsistent. Can you talk about your concerns with regard to that?

Mr Roberts: Yes. It is a good question. Basically, I have a better understanding now, after review, in relation to that time frame. One thing that I did not consider when we did the proposal was dementia and stuff like that, which I think is really important because circumstances can change. Medical conditions can change very, very quickly. I have had personal experience with a very close friend who suffers from dementia. Their dementia took hold in weeks. At the beginning of the month they were the person that I remembered from the past 25 years. At the end of the month they could not remember me. It was like those 25 years of friendship never existed.

MS CASTLEY: So has your position changed from your submission?

Mr Roberts: I would like to see more data about it. It gets back to what we say about the review period. It probably needs to be something that is looked at on a more consistent basis, rather than waiting three years for a review, as under the original legislation. It is a difficult question to ask, because we are talking about medical opinion on terminal illnesses here. I am a police officer; I am not a medical expert in the medical circle. I cannot tell you how long it would take for someone to die of natural causes with cancer, compared to undergoing the VAD program.

MR BRADDOCK: Currently, how many welfare checks do you believe have been undertaken in relation to those who are at risk of suicide due to medical reasons, and would that also be a reduction of the burden on the AFP?

Mr Roberts: That is a hard number to come up with, because, if it is a medical check on welfare, police may not go to that. That may be an ACT Ambulance response. It would probably be a question that ACT Policing may be in a better position to answer. I am not sure if they are appearing, but they may have more data about how many check-welfares police actually go to purely for medical reasons. But you would hope that some of those stats would not be recorded by police and they would actually be recorded by the ACT Ambulance Service.

MR BRADDOCK: Okay. Thank you.

DR PATERSON: Your submission states that the bill is “solid and considered legislation” with appropriate safeguards in place, but one of the recommendations that you make is for a review every year for the first three years and then every two years after the first three years. If you believe that the bill is solid and evidence based, what is the logic for such a significant review process?

Mr Roberts: That review process will be quite resource intensive, I am guessing, and also quite stringent. I think that, given the nature of the legislation, it is important that, if issues or loopholes are identified early, they actually get jumped on early and looked at. If that is a job for the committee or if that is a job for the health department, I am not sure. I am not sure that we should wait three years for a loophole to be closed.

I think it is valuable that we start having a look at that review process as early as we can. It may be a simple review: “There are no issues. Okay. Let’s move forward.” But

if there are issues then, due to the community debate about this conversation, we feel that three years is probably a little bit too long. Maybe one year is too short, but we definitely thought that three years was too long for a review.

DR PATERSON: Do you think there might be a better way, rather than having a substantive legislated review for the first three years of the process? Looking at some of the other jurisdictions, the updates to voluntary assisted dying have been very small. I wonder if there might be a more proactive, reactive or instant way of alerting the government to any loopholes or problems that may exist with the legislation, rather than, like you said, having a really resource-intensive review every three years.

Mr Roberts: Yes. Sure. I am guessing it is going to be an ACT Health-led initiative, and it could be part of their annual report. They could report annually, like police do with the surveillance device legislation. Each year, they are required to submit an annual report telling you how many applications, how many rejections, how many approvals, and stuff like that. There could also be a portal on the Health website. If people do come across issues with the legislation, then they can report it to the government via that portal.

DR PATERSON: Great. Thank you.

MR COCKS: Let me start by saying thank you for what I think was a very well-considered submission. I would really like to acknowledge that cumulative trauma that you were talking about for AFP members who have to deal with suicide. I would really like to understand a bit more about the impact. Your submission seemed heavily grounded in the mental and emotional impact for police officers on attending suicides, and the impact through the investigation, paperwork and reporting stages. Can you help us understand what that process involves and how that affects your members?

Mr Roberts: Yes. The police prepare a report on the behalf of the coroner. We work for the coroner in relation to a death here in the ACT. Firstly, we would attend the scene. That normally starts as a check-welfare in most cases. The police go. Sometimes the house is locked up and, if it is inside a premises, we have to break in if we have concerns for the person inside.

At other times a member of the public can find someone; a family member can find someone. That is a huge amount of trauma for that person. At least with us, as police officers, we have had some training in relation to attending those types of jobs. You will never take away the trauma of it, but you can take away the surprise element of it. As you are driving to the job you are sort of preparing in your head that you may find something that is not pleasant.

Once we attend a job, obviously we need to determine what it is. Is it a crime scene? Is it a suicide? Is it a homicide? You treat the scene as a crime scene, which, especially if it is a suicide in a house and family is still present, can seem a little odd and a little impersonal. You are there to do a job. You are there to secure the scene. So you are asking people to not go in that room, to at times leave the house, depending on where the body is. It can be quite an impersonal experience for the family, which adds to their trauma. They are already traumatised enough.

Once we have identified that, yes, we believe it is a suicide, then we call in the forensic medical officer. They come in and say, “Yes, this person is deceased and we believe it was at this time.” Then you have to undergo a coronial brief, which is a lot of work for police officers. You get the medical records. You go back and interview family and friends. You are trying to tell the coroner what exactly happened and how the evidence leads to how this person ended up deceased, and that can take years. The full coronial process can take a long, long time, which at times can leave family with many unanswered questions. As police, all we can do is follow the evidence that is in front of us, and that is what we report to the coroner.

MR COCKS: Thank you. A lot of that is going to continue for those suicides that are not redefined as assisted dying. Are there things that can happen to reduce those mental health impacts and emotional impacts that are outside, or in addition to, this legislation?

Mr Roberts: That is probably something that I would have to consider. I would probably need a bit of time to consider that. If I may, Chair, I might take that one on notice and come back with a better answer than I could give right now.

THE CHAIR: That is fine.

MR COCKS: Thank you. I am happy with that.

MR BRADDOCK: How much time and effort would you predict goes into preparing a report for the coroner and working with them?

Mr Roberts: A coronial brief can take months. Sometimes they can be quick. If a doctor or a GP is happy to sign off on a person’s cause of death quite quickly, then it can be quite a simple process. Where we have a complex process—and we see it especially with overdoses—we need to speak to doctors, subpoena information, try to find a local chemist and get details from them, and speak to family and friends. Back to the process, especially given the trauma that sometimes a family goes through, sometimes people are just not ready to talk at a specific time. So, to answer that question: how long is a piece of string? They can be quite big processes. They can take three, six, nine or 12 months.

MR BRADDOCK: Thank you.

THE CHAIR: You have noted in your submission:

If emotion, personal views, and beliefs are removed, the Bill is solid and considered legislation, with appropriate safeguards to ensure that the legislation isn’t abused or misused.

Can you elaborate on how you formed that view and why you also feel it is important to note that taking emotion, personal views and beliefs out of looking at the bill is important?

Mr Roberts: Yes. It is a highly charged debate, this one about voluntary assisted

death. Depending on your background and how you were brought up, and your religious beliefs and your personal beliefs, that can influence where you may sit in relation to this legislation. We are not here to discuss philosophy or anything like that. We base our views and opinions purely on the words written in the bill. We wanted to take away all that other stuff which will complicate this legislation. At the end of the day, we all revert back to our personal beliefs, but in this case, as I said, we parked them and we focused purely on the words in the bill and the legislation at hand. That is all our response is in relation to. We are not the moral police. We are not here to judge people on what their beliefs are. We are here to discuss the bill and voluntarily assisting dying as part of that bill.

THE CHAIR: Thank you.

MR COCKS: Just to be completely clear: it sounds like what you are saying is that the submission seeks to take the personal beliefs out of the position of the AFPA, noting that personal beliefs and those other issues are valid in the broader discussion of the bill.

Mr Roberts: Yes; they are valid and they are going to come into play. We do not dispute that, but, as I said, we are not the moral police. In this legislation is the word “voluntary”. I think the Victorian model highlights that a decent percentage of people who do have approval for that actually do not use the drugs or medication that comes along with it. As I said, we just want to take the emotion out of it. For assisted suicide and stuff like that, we turned it back to the legislation in front of us. We think it is sound and solid and has enough safeguards in there to stop it from being misused or abused.

THE CHAIR: Mr Roberts, just so that I can make sure I have understood correctly, is it fair to say, in summary, that what you are saying is you are not looking at the policy debate and the substantive question of whether one does or does not agree with voluntary assisted dying; you are looking at the functioning of the bill and how it works?

Mr Roberts: One hundred per cent correct.

MS CASTLEY: I have a question following on from that. Does the AFP have any concerns or view around policing the possible misuse of the proposed laws? A few of the submissions have talked about concerns about coercion and things like that. I am just wondering: have you considered the flow-on of what happens if there has been some misuse?

Mr Roberts: Yes; we have considered it, and, if we did not pass legislation because someone was going to misuse it or abuse it, then we would have no legislation.

MS CASTLEY: Of course. No. That is not my suggestion. I am just wondering what your thoughts are on how you will proceed. Obviously, it will come out in a coronial inquest or whatever. I am just wondering what you guys have thought about that so far.

Mr Roberts: We will be directed by the coroner. If the coroner says, “Look, there is

something here that needs to be looked at,” or “I believe there could be charges,” the coroner can make that referral and police will pick up that in an investigation.

MS CASTLEY: Great. Thanks.

THE CHAIR: Mr Roberts, is there anything you want to add before we finish?

Mr Roberts: No. Thank you for the time. This is going to be a well-debated hearing, I think.

THE CHAIR: Great. Thank you for your time and thank you for your testimony today. There will be a proof transcript sent to you, so you will be able to check that. Keep an eye out for that. You have a couple of days to respond. You did take one question on notice, I believe, so the secretariat will follow up with you about getting that information to the committee. Once again, thank you very much for appearing.

Mr Roberts: No worries. Thank you, Chair. Thanks, committee.

BLACKER, MR SIMON, Branch President, ACT branch, Pharmacy Guild of Australia

FERRINGTON, MS SANDRA, Committee member, ACT branch, Pharmacy Guild of Australia

THE CHAIR: We now welcome witnesses from the Pharmacy Guild of Australia, ACT branch. Do you have anything to add regarding the capacity in which you appear today?

Mr Blacker: I am a community pharmacist in Canberra.

Ms Ferrington: I am a community pharmacist in Canberra.

THE CHAIR: I would like to remind witnesses of the protections and obligations afforded by parliamentary privilege and draw your attention to the privilege statement that is on the table. Witnesses must tell the truth. Giving false or misleading evidence will be treated as a serious matter and may be considered to be a contempt of the Assembly. Please confirm that you understand the implications of the statement and that you agree to comply with it.

Mr Blacker: I agree.

Ms Ferrington: I agree.

THE CHAIR: Thank you. As we are not inviting opening statements, we will proceed straight to questions. I will go first. Your submission notes that you interpret clause 52(2) of the bill as indicating that a pharmacist could initiate a conversation about VAD with an individual, and that clarity is required if pharmacists are permitted to do so. What is it about clause 52(2) that remains unclear and what kind of wording would assist with a more confident interpretation of that clause?

Mr Blacker: In terms of the statement, the word “pharmacist” is not mentioned. We note that “relevant health professional” is the term. From our perspective, we expect that community pharmacists will receive questions, if they have not already, very early in the piece, in regard to the ACT community becoming familiar with how this will work, where they may gather more information, what questions they may have and even whether a pharmacist has an opinion on it. From the Pharmacy Guild’s perspective, on behalf of community pharmacies, we want clarity to ensure that what pharmacists can and do say is what is expected and that we are giving the right information and the right advice when we are asked.

I am sure that, at some stage, a pharmacist may see an opportunity to introduce a conversation, but to start with it will largely involve people wanting our opinion, given that we are involved in caring for people as they age in the home, and towards end of life and into end of life care. Having transparency and clarity for community pharmacists is something that pharmacists on the ground would want to see.

THE CHAIR: Mr Blacker, is it fair to say that the clarity you are seeking is not solely about the application of that clause and an official role, necessarily, within the

system; it is also about someone approaching you and what the appropriate response is, what is the right place to point them to and what you can and cannot do under the legislation—that general information, as well as the specific roles that are part of the scheme that pharmacists take on?

Mr Blacker: We acknowledge that Canberra Health Services, the Canberra Hospital and a specific part of the pharmacy department will have carriage of the role that pharmacists will play through VAD. From our perspective, it is about making sure that we can assist, because the queries will come our way. We do not want to do the wrong thing. We want to provide the right information and advice when we are asked. Sandra, you have talked about that as well. We had examples through COVID where we were asked questions early in the piece.

Ms Ferrington: Yes. Often clients will come into the pharmacy—we are very accessible, as community pharmacists—and we need to know where to direct them so that they will get help. If we do not have the information, if we are not included in the clinical process, we need to know where to direct them to. If the care navigator system is where they need to go, community pharmacists need to be aware of that. They need to know what conversations they can have and make sure they are being directed to the right place.

I feel that we need to be listed as part of the primary healthcare team, along with doctors and nurses. We need to know how to collaborate with the hospital, the doctors and nurses, and the GPs that are looking after the patients that we continue to look after. I think that is really important, so that we can assist them and direct them, because they do not want to be directed wrongly when it is such a significant time for them.

THE CHAIR: What input have you had so far into the development of the scheme and what consultation and engagement have you received through the development?

Mr Blacker: Obviously, we have put in a submission. Beyond that, I cannot recall being involved in any conversation. There may have been an information session that one of our representatives attended. To date, it has been minimal. That is not a criticism; it is more about flagging that we will field questions and we would like to be involved at the appropriate time.

When I say “we”, I am referring to the Pharmacy Guild of Australia, as well as the Pharmaceutical Society of Australia. I have spoken with the ACT PSA president, Olivia Collenette, who is a community pharmacist. Certainly, we would see both of our organisations having a role at the right time, in terms of providing input when and where it is required.

DR PATERSON: People might seek advice from their doctor and from other medical professionals in the community. They might then come to their local pharmacist and get their views and opinions, particularly about very serious, life-changing or altering processes such as voluntary assisted dying. Can you outline the role that pharmacists play in that ecosystem of healthcare support for people in our community?

Mr Blacker: We care for people as they age in the home. Some pharmacies also

continue to have involvement with aged-care facilities and the like. We are dealing with patients; we are dealing with patients' families. We are dealing with the hospital, on occasions, when people go in and out of the hospital, and we are dealing with their GPs—hopefully, they have a regular GP—all the time.

From our perspective, collaborative care is critical. We see our role as being part of a primary healthcare team, and working closely with other health professionals for that patient's benefit, in the way that that patient wants. One of my first questions, if I was asked by a patient about voluntary assisted dying, would be, "Who have you had conversations with and have you spoken to your regular GP?" That would be the first thing I would ask. It would not be about jumping ahead of anyone else; it would be about finding out where they are at with their own care and how they are handling it.

Ms Ferrington: The difficulty is in access to the other healthcare providers. Sometimes they will have rung their GP and they cannot get an appointment for a couple of weeks. They just have that question and they can walk in and talk to a pharmacist. We do field a lot of those inquiries.

We also coordinate the provision of medication for a lot of palliative care patients who choose to be at home. Because we are coordinating that with the GPs, we will often know that they need a certain amount of medication to keep the syringe drivers going or whatever. We need to make sure that we have that in time. If they are also looking at or choosing VAD, we need to link that in with providing the medication; otherwise there will be wasted medications in the home.

It is very much about having collaborative care, but we do field a lot of questions because people can just walk in. They can walk in at any time, such as over the weekend, when the doctors' surgeries are closed. It is really important that we know what the guidelines are and that we are involved in that process so that we can, as Simon said, ask, "Who have you spoken to? If you can't get in contact with your GP, who is the next person you can speak to about this?" With respect to whether we have an opinion on it or not, it is partly about that, but it is about getting them into the right stream of the healthcare system.

MR BRADDOCK: By way of clarification, is it your position that you would like to see pharmacists as part of the list who can initiate the discussion about the idea?

Mr Blacker: Yes, but the scenario for you to wonder about is: how many people will you list? I take it that "relevant health professional" might be an attempt to encompass anyone else. Whilst we might not have much involvement now, who can predict what could happen in the future? From our perspective, if we could have a pharmacist listed, we would support that. But I understand that the term "relevant health professional" might be there to capture all others.

Ms Ferrington: For our members, clarity is really important, regarding what they can and cannot say. We want them to know what is the right thing to say, and whether they can initiate it or not. We need to have that made fairly clear so that members do the right thing. Community pharmacists should know whether they can suggest it at all, and whether they can discuss it; otherwise they might say, "No, we can't do anything for you," and that person will not get the help they need. I think it is

important, for our members, that what they can do is made really clear.

Mr Blacker: With an evolving scope of practice, that is a journey, but it is harder to know what things will look like in five years; hence, we are trying to pre-empt that at the moment.

MR COCKS: I want to follow on from the discussion about how you would communicate in the pharmacy. If someone approached a pharmacist and asked questions that indicated they were considering using pharmaceuticals for suicide, how would you currently manage that?

Mr Blacker: We would be looking to take them somewhere else so that we could have a slightly longer conversation than could occur while standing at the back counter of a community pharmacy. We would be looking to ascertain exactly what they were asking about, in terms of what is the intent of the questions. These things can happen from time to time. Our intent is to do no harm and to look after people. Trying to ascertain exactly what they are asking about would be my first priority, and wondering who else they have spoken to about it, so that I can choose the right referral pathway and, with the patient's permission, involve a family member, their GP or somebody else.

It would be about understanding what their mindset is at that moment. We see people regularly. When people are quite unwell, we may not see them in person so much. Community pharmacies deliver to people ageing in the home. We pack medications and deliver to many people ageing in the home. Sometimes it is not face-to-face contact; these conversations could be via the phone, potentially. I would be confident that a pharmacist would have their radar up and would think, "This is a very serious question; what is the intent? What is the patient actually asking? How do we provide the right advice and direct them to the right person so that they can get more information and not harm themselves?"

MR COCKS: Would there be any sort of referral on, if you considered that someone was at immediate risk of suicide?

Mr Blacker: Personally, I would be looking to retain them in the pharmacy until I could find a way forward—find someone to refer to who can take care of the patient and provide some level of care that carries on from the moment they walk outside the four walls of the pharmacy, so that we knew we had referred and kept them safe.

MS CASTLEY: You said that it would be good to have pharmacists listed as someone who can have the conversation. The Law Society, I think, raised concerns about conscientious objection and the strict limit of the two-day time frame turnaround. What are your thoughts on that? Will that work for the pharmacy cohort?

Ms Ferrington: There is a recognition of conscientious objection. In pharmacies quite often there are several pharmacists, so if a particular one may not wish to have that conversation it could be passed immediately on to another. In pharmacies that may not have that option, we would usually have a buddy pharmacy that we refer them on to straightaway, because we already have that issue with the morning-after pill and some of those things. We are already set up for that, and we acknowledge that.

With the pharmacists on our team that have that, we are very aware of who is able and who is not able. The community pharmacy network is very strong, and we would refer to our neighbouring pharmacists or refer the client on straightaway.

MS CASTLEY: So there are no concerns with the time frame.

Ms Ferrington: And it would be someone who was open at the same time.

MS CASTLEY: In your submission you raised issues about the drugs being returned. Can you talk to me about that? Is it your hope that pharmacies would be able to gather that medication?

Mr Blacker: Ms Castley, with regard to that, what we often see when someone passes away is that some family members are quite keen to wrap things up, from a medication point of view, and they will return unwanted medicines to community pharmacies, which all pharmacies accept. That can happen quite quickly, or it can be done months later.

Without knowing exactly how the process will work and how the hospital will liaise with a patient and a patient's family, in the event of voluntary assisted dying happening and if there was leftover medication, it is about how that would be disposed of. Because of the easy access to a community pharmacy, we are a natural access point, but without knowing what drugs will be used and how they may need to be stored, there might be implications for the community pharmacy, if they were to receive them, in having to store them safely or having someone witness having them disposed of.

That is where pharmacies can play a role, but it takes time. If a pharmacy is not involved in the process before that point, they may not know what to do with that medication. With leftover medicines, in that regard, how will the hospital handle them and what will the instruction be to the family? It is something that pharmacies are used to dealing with, but it will be a new sphere, if you like. From our perspective, we do not want it to be onerous for a community pharmacy. It is something that we do not charge for; it is something that we do in our own time. We keep them under lock and key, generally.

MS CASTLEY: It sounds like there needs to be more consultation so that pharmacies are clearer about it.

Mr Blacker: Yes.

Ms Ferrington: The idea is that the hospital pharmacy will come and pick them up; that is what I read in the guidelines. That is fine, as long as the family do not suddenly want to get rid of all of those medications, which are quite potent, from their family homes, so that other people cannot access them. If they all come in a bundle to the pharmacy, there needs to be a requirement of and accountability for the hospital to take them back. There is a bit of a gap in the system if it does not go back. It depends on what the medication is scheduled as. If they are S8s then we have quite an administrative burden in actually disposing of them. It is also about accountability. Will the hospital be trying to find out which community pharmacy actually received it

and try to retrieve it? It is a bit open-ended. Do the community pharmacies know what they are getting, and how to dispose of it?

MR COCKS: How dangerous are these products if they remain in the community?

Mr Blacker: They are certainly not medications that you would leave lying around. There are quite a number of medications that could be dangerous for the wrong person, where they are not appropriate. With respect to safety of medicines, medication misadventure is something that we all hope to avoid. I would assume that they are potent and need to be securely stored. Once the process is complete, what is the next step? From the hospital's perspective, would they be collecting them? What is the disposal process? Certainly, these are things that are dangerous to the wrong person, and you want to keep them safe.

MR COCKS: It sounds like it is important that there is a really solid handling procedure and really clear guidance and regulation around how that is handled at the disposal end, as well as how it is handled in the community.

Mr Blacker: Yes. Sandra mentioned scheduling. Controlled drugs are schedule 8. Pharmacies are expected to account for every tablet, mil or ampoule itemised and have a register. From our perspective, we take that incredibly seriously. We are expected to do so, and we do. You would want to account for everything. We keep those under lock and key and have a register to record balances and transactions or dispensing. I imagine that the medications we are talking about with voluntary assisted dying would fall into that area, in some capacity.

MR BRADDOCK: Are any changes to the legislation required to allow community pharmacists to handle this unwanted, unused medication, or is it more in the regulation and process sphere?

Mr Blacker: No changes will be required. We already handle controlled drugs in schedule 8, so we are capable of doing that.

DR PATERSON: Would you like in the future to see community pharmacists be able to deliver the voluntary assisted dying medications themselves?

Mr Blacker: As a community pharmacy, it is hard to predict what would happen in the future. As the scope of practice evolves, it is not inconceivable to think that there would be pharmacists who could. Sitting here, it is hard to find the scenario where we would do it in the near future. I think that pharmacists may play a role. Obviously, pharmacists in the Canberra Health Services will be playing a role.

It is hard to predict what will happen with primary health care and access to healthcare professionals. We are talking about the ACT, which is a city state, which brings certain conveniences. In other states and territories there may be a role to play. What invariably happens for pharmacists, when you see the scope of practice change in a different state or territory, is that there are inquisitive, talented pharmacists who want to do more. There would undoubtedly be pharmacists who would see a role for themselves in the future in this space.

Ms Ferrington: It is definitely something that we would look at in the future. We are the medication experts. We are looking after patients all the way through. I have been a community pharmacist for 17 years in Canberra, and you see your patients go from being very well, healthy people to having whatever diagnosis and people caring for them at home—their carers. To be able to assist them with their full journey is something that is quite important for me—the health outcomes. It is about being able to support them in this, and for them not necessarily having to, in a time of grief, go somewhere that is unfamiliar or to someone that they do not know and have these conversations. You have that relationship and that rapport.

As Simon said, it is definitely something that has to be done in collaboration with the right training and with the right structure and guidelines around it, which is why we are here early on—to make sure that the guidelines are there to protect the client and the healthcare providers, and to make sure that that process is something that is very clear and available to whoever needs it.

DR PATERSON: You speak about end of life care and pharmacists' role in palliative care. Do pharmacists go to the home? Is it mostly in-home care? Do family members pick up medications currently? Can you describe the role of the pharmacists in palliative care, and what is the ideal role in voluntary assisted dying?

Ms Ferrington: We have a combination. Initially, family members will come in and pick them up. A lot of people do not have a lot of family in Canberra, so that is sometimes really hard, and they do not want to leave their loved one. We have a couple of pharmacies that are involved in palliative care delivery. There was some funding given to a couple of pharmacies so that they could be available to keep the right stock at the right time and deliver it after hours as needed, because it is a need that is there.

At this stage the funding has stopped. Some of the pharmacies still try to provide that service, and we will deliver where we can. I think that the funding needs to be there to enable people to have that, because a lot of people want to be looked after in their homes. We have a good palliative care team here, The pharmacists are very heavily involved in making sure that we have the medication that either the nurse practitioner or the GP looking after them wants them to have. There are quite a range of medications, and having them in at the right time and not having them out of date is a challenge. We are very much involved in that process at the moment, and supporting and delivering, so it is a bit of an extension from that.

Mr Blacker: With the challenges, at times, in accessing palliative care services, we would certainly hope that there would be no reduction in the services provided. Regardless of what happens with voluntary assisted dying, we think that demand will be there. It is obviously a sensitive time. It needs to be timely. Community pharmacists will play a role in that space. We certainly do not want any reduction in funding in that space.

MR COCKS: I want to go back to the issue around pharmacists initiating conversations on voluntary assisted dying. Can you see any risks if pharmacists were to initiate conversations with individuals who may not actually want voluntary assisted dying?

Mr Blacker: Pharmacists are very good at following protocols and procedures. That is one of the ways we are trained. We have said several times today that we would like to be involved in the creation of guidelines. By having input at that level, we would cover, hopefully, every eventuality, and an inappropriate conversation would not happen. If the pharmacists know what they can and cannot say and how they should refer, we would cover all bases, I would like to think.

MR COCKS: In particular, I am thinking of the very stringent criminal offences in the legislation around coercion, which can be coercing in either direction—issues that could arise for a pharmacist initiating those conversations, and whether there are particular risks that you see for your members.

Ms Ferrington: I would hope that the conversations were only initiated with people that you were looking after and very familiar with, not a random person who walks in to your pharmacy. We deal with different customers all the time. That is a very good reason why we need to be involved and know exactly what is around those coercion laws. We are very careful with conversations and whether or not we would be following up that they had had those conversations with GPs and their support team, and what sorts of conversations they have had. We do not necessarily have access to all of their diagnoses. We do have a lot of information, but we would need to make sure that those conversations were had with people that we were familiar with, and as part of that collaborative care team. I do think you have to be careful, but we usually are.

THE CHAIR: I have assumed within the hearing today that, if someone approaches a pharmacist—it is my reading of the legislation, too—access to the voluntary assisted dying scheme has to be initiated by the person wanting to access it, not by a healthcare professional saying, “I think you would be a good recipient of this.” Can I check that we are working to that assumption, and that everything you have provided today in your testimony is on the assumption that someone approaches you, and you as a pharmacist would like to know how to appropriately respond, as opposed to a pharmacist being in a position of recommending this as a course?

Mr Blacker: I would not see a pharmacist recommending that, for clarity.

THE CHAIR: I just wanted to double-check.

Mr Blacker: Mr Cocks, in terms of your question about how a pharmacist would handle an unusual query, in the role we play with medicines and the different schedules—and controlled drugs, particularly—if someone comes in that you do not know and they ask questions about certain types of medications, from a professional practice standard perspective you would immediately think, “I don’t know this person and they’re asking questions about strong medications.” You would be very cautious, because you do not know their background, their medical history, whether they have taken it before et cetera.

Straightaway, there are many questions that come to mind for a pharmacist when they are dealing with someone who is asking about certain health conditions or certain medications where there is no history, if you like, and particularly if they do not have

a prescription in front of them. We are trained to be very aware in those moments of saying, “I have no information at hand, and to handle your query I need a lot more information.” We are trained to ask questions, gather information and refer as appropriate. Pharmacists will be capable of doing that; it is what we do.

Ms Ferrington: We would phone the GP before we said anything. We would look at their network and contact the other health professional before we went any further with that client, definitely.

THE CHAIR: We are almost out of time, unfortunately. In the minute we have left, is there anything that you want to add that might not have been covered today?

Mr Blacker: In terms of the cultural diversity of the ACT, we are very supportive of the care navigator service. We hope that it will cater for every need, because not every pharmacy has language capability in certain cultures. In terms of adequate protections for healthcare professionals, which comes back to process, understanding how this works, how we refer and the role we play, it would make pharmacists more comfortable in referring. If there are uncertainties, there will be some pharmacists who do not want to be involved in the conversation for fear of saying something wrong.

THE CHAIR: We will wrap up there. Thank you for appearing today and for your testimony. I do not believe that you took any questions on notice, so we will not need to follow anything up. A copy of the proof transcript will be sent to you, and you can suggest transcription corrections.

STEVENS, DR ADELE, Consumer representative, Health Care Consumers Association

GORMAN, MS KATE, Deputy Director, Health Care Consumers Association

THE CHAIR: We welcome witnesses from the Health Care Consumers Association. Witnesses must tell the truth. Giving false or misleading evidence will be treated as a serious matter and may be considered contempt of the Assembly. Please confirm that you understand the implications of the privilege statement, which is on the pink card on the desk in front of you, and that you agree to comply with the privilege statement. You are welcome to take a minute to read it if you need to.

Dr Stevens: I do not need time to read it. I have appeared before a committee before. I do not think it has changed. Yes.

THE CHAIR: You both agree to comply?

Ms Gorman: Yes. Absolutely. I have read it.

THE CHAIR: Great. Thanks. We will jump straight to questions today. You have an opening statement. You are welcome to table that, but we will start with Mr Braddock on questions.

MR BRADDOCK: Thank you. In your submission you state that you are keen for the ACT government to revisit the potential for the inclusion of people with dementia, via a planning process. Can you please describe what that might look like in action, noting that the ACT government has also stated in its submission that it is receiving feedback that the decision to administer an approved substance to an individual who lacks capacity is highly subjective and ethically challenging. I am trying to reconcile these two points and come up with a way through.

Dr Stevens: I will start. Our members have clearly stated to us—and, also, I am a member of U3A and move a lot with older people—that they would not like to be excluded if they get dementia. That means that if someone has, say, unbearable suffering and has dementia, they are not eligible. They want to be able to write in their advanced care plan that they would like to make use of voluntary assisted dying. The Netherlands has a clause that says:

For some people, the prospect of ever suffering from dementia may be sufficient reason to make an advance directive (living will). This can either be drawn up independently ...

And then it says:

A physician can perform euthanasia on a patient with dementia only if ... a directive exists, if statutory care is taken and if, in his opinion, the patient is experiencing unbearable suffering with no prospect of improvement.

That is the kind of thing we are looking at, and what has happened in other countries. There are quite a few countries that do allow—

MR BRADDOCK: This country has also dealt with the ethical challenge of how you administer a VAD substance to someone who lacks the capacity at that point in time—

Dr Stevens: At that point, because they do not—

MR BRADDOCK: They had previously given a directive.

Dr Stevens: They had previously put it in writing under these conditions. The physician then says, “This patient has unbearable suffering”—that kind of thing. It is about exploring that kind of extra dimension of the bill. I have to say that I am really pleased with the work that the Assembly has done. I am, on the whole, pleased with the bill. I think we need to move forward on this issue and I recognise that we have a small minority that are vocal in opposing it. This bill kind of goes to the middle path, where they are trying to get this through. Although we would really like to have these people included, if it would hold up the bill for everybody that is a problem. It is really good that we are moving to have this in the ACT, as in every other jurisdiction, except the Northern Territory. We would like more, but we will accept it.

MR BRADDOCK: Understood. The Netherlands model is one that you would recommend we aspire to?

Dr Stevens: Yes. I think it is worth looking at.

MR BRADDOCK: Thank you.

DR PATERSON: I am interested in the governance part of your submission, where you refer to processes in ACAT, the Civil and Administrative Tribunal, to address that you would like to see a consumer member as part of the Voluntary Assisted Dying Oversight Board. Can you speak to that recommendation?

Dr Stevens: Would you like to do that, Kate?

Ms Gorman: Yes; I am happy to. Our concern around the ACAT review process is that it is essential that there is the ability for a consumer requesting VAD to have a non-favourable decision reviewed at any point. We are also concerned that people may face vexatious interference with their decisions. At the moment, the bill talks about any interested party being able to seek a review. There is a really important and fine line between allowing and supporting review and protecting the decisions of people seeking voluntary assisted dying. We see that consumer representation in these kinds of decision-making and review processes is completely essential in being able to bring the lived experience and the broader consumer perspective into the decision-making process. We see that as a really critical part of the expertise that is necessary to come to a position on those kinds of significant decisions.

DR PATERSON: And you would like to see a consumer member as part of the oversight board?

Ms Gorman: Absolutely—somebody whose primary intent in being there is to be a voice for the people who are seeking to access it and support the people accessing

voluntary assisted dying.

DR PATERSON: Thank you.

Dr Stevens: It is part of our consumer view: nothing about us without us.

Ms Gorman: And the idea that other people on that board will be there to perhaps represent what it is like to be the medical practitioner, the pharmacist and the care facility. There will be other people with other views that have a primary reason for being there. Somebody needs to be on that board whose primary reason is to take care of the people and their families who are seeking VAD.

DR PATERSON: Thank you.

MR COCKS: How would someone be selected to be a lived experience representative for voluntary assisted dying?

THE CHAIR: That is a fair question.

Ms Gorman: If I used the term “lived experience”, that was probably not quite the right term. I think what you would be after on that board is someone who has a deep and coalface understanding of what it is like to be in that voluntary assisted dying space. Obviously, if somebody has been through the process they are probably not still with us. You would want a member with a community perspective, somebody who has perhaps been part of a community or a family, or a support person or somebody who may, in future, want to access it themselves; somebody who has had exposure to the broad perspectives of community members and their understanding of voluntary assisted dying so that they can speak from, potentially, a broad community view of understanding voluntary assisted dying, bringing their own experiences with community members but also a bigger picture community perspective.

MR COCKS: Can you see a risk that someone with those attributes might be ideologically driven in one particular direction?

Ms Gorman: That is always a risk, but I think that is a risk for any member of the board. I do not think that is necessarily specific to a consumer member.

THE CHAIR: Ms Gorman, Carers ACT put in a submission and mentioned quite a bit about the need to have the carers, the family and the close friends involved in anyone’s decision to undertake VAD—an oversight process to make sure that supports are in place for those supporting the person making this decision. Is this the type of situation that you would be referring to when you talk about the kind of expertise—

Ms Gorman: A consumer member?

THE CHAIR: Yes.

Ms Gorman: Yes. We would support that view too—that such a person could be a family member or a carer, a support person for somebody who wants to access—

Dr Stevens: I can give you an example. There is a senator from the Liberal Party in Victoria and she voted against voluntary assisted dying, but then they implemented it in Victoria and she experienced it with her mother and changed her mind. She had actual experience of seeing how that was useful for her family and her mother, so she changed her mind in the Senate and changed her vote.

Ms Gorman: Briefly going back to the original question about ideologically driven issues, a selection process for a person who can see a broad view and understand different perspectives is something that our organisation goes through every day with community members sitting at various levels of governance for all sorts of projects. It is entirely possible to find a person who can see balanced views.

Dr Stevens: Healthcare consumers would want not somebody who would be just speaking about their own experience but somebody who has mixed with other consumers who have similar experiences.

Ms Gorman: When you are one person who is speaking as a consumer representative, you may be there to speak to a view that is not your view or speak to an experience that is not your experience. You may be there to say, “We need translation services for multicultural communities. I am not a multicultural community member.” You need somebody who can recognise the different needs that are there or may be there, and not just their own. That is part of the selection process for that person.

THE CHAIR: Picking up on that note, the AFPA put in their submission—and they talked about it this morning—the need to take the emotion and the personal views out of discussions on the bill and to look at the substance of it. Is that essentially what you are getting to in your response, Ms Gorman: that you would want a representative who is not necessarily there for a particular personal view or an emotional view but can look more critically at the information and the evidence before it?

Ms Gorman: Yes; absolutely. That is exactly what I am getting at. People usually put their hand up for these things because they have a personal interest and they care about it. For a consumer representative in something like this, in a governance sense, it is a collaborative role in doing the work of supporting the community. In that sense, your lived experience is not as important as your ability to work with others for the best outcome for the people that the bill serves.

MR COCKS: I note that the discussion around the AFPA submission was specifically in relation to the way they presented their submission, rather than what should be considered about this bill in general. Your submission takes the stance that eligibility for assisted dying in the ACT should be broad and flexible, and to prioritise access over safeguards, relieving the burden of red tape and facilitating more efficient access. I was hoping you could elaborate on the areas in which this bill is closer to that objective, compared with other jurisdictions.

Dr Stevens: I can start on that. Not having the time lines that we have in some other jurisdictions is a benefit. “Unbearable suffering” is a better way of dealing with it. What happens is that those time lines cut out people with some neurological conditions. It may be motor neurone disease. That time line is not so clear. The

majority of people, when you have those time lines, are people dying of cancer, who are eligible, whereas people with neurodegenerative diseases are harder to be accepted. We have done a good thing in the ACT in not having those time lines.

Ms Gorman: Or the time lines around how long the request process takes. I think that is good too.

Dr Stevens: Yes. Something that I would like to add, because I am hearing it from a number of people, is that the bill has three requests and we feel that is much too bureaucratic. If you go through two requests, what you want is quite clear. The third request could be when people are very close to dying and are quite sick. Two requests, we would argue, is quite sufficient. That is one thing I would really like to see changed—having it reduced from three to two requests. It is okay to go with not bringing in dementia. I think we need to get this up and running.

The talk at the beginning was about having teenagers in the bill. I am co-chair of the Consumer Reference Group for End of Life and Palliative Care for the ACT government. My co-chair is someone who had a child with a terminal illness. She spoke very convincingly and strongly in the beginning, when the inquiry did some interviews with groups, about her experience with her son. She said that at 14 he was right across his illness. He knew and he made decisions. She said that if VAD had been around when he was so sick, she would have liked him to have the option of using that. He died a week after he was 18. She spoke very convincingly. I was quite taken aback by her evidence. It was quite useful. Of course, we have people—I think they are a small but vocal minority—who are arguing against this kind of thing, but I would argue that, just like dementia, this is an issue that we need to address in the future.

MR COCKS: In relation to the issue of younger people, I am very keen to understand how you would draw that line. I think the submission reflects that the age should be reduced to 14-year-olds, and I understand that is intended to be actively considered in the future by the government. What is it about being 14 years old that makes that an appropriate age, compared to, say, 15 or 12, as in other suggestions?

Dr Stevens: Already, under medical law, people who are over 15 have the right to have a say in their medical care. That is why we have taken that age—because it is already there with medical care.

MS CASTLEY: Fifteen or 14?

Dr Stevens: I think it is over the age of 14. I would have to talk to Alarna, who is my co-chair. She is really across it all.

MR COCKS: I would be keen to understand what it is that makes that the line.

THE CHAIR: Dr Stevens, maybe that is something you could take on notice, just to confirm why.

Dr Stevens: Yes.

THE CHAIR: If I understand what you are saying now, as you have looked into this matter, it is consistent with what other medical provisions allow for choice of care.

Ms Gorman: That is correct, but probably a bit more information would be useful. Certainly, from the age of 14, children can start to access their own record, they can have independent medical care and they can have some decision-making—maybe not all decision-making but some about what happens. Perhaps it would be a graduated—

THE CHAIR: Thank you for that. If you are happy to provide any more information on notice, that would be much appreciated.

Ms Gorman: Yes.

DR PATERSON: Mr Cocks's question was basically summarising your submission—that you prefer access over safeguards. Would you see that as an appropriate assessment of your submission?

Dr Stevens: One could argue that perhaps three interviews are safeguards. We would argue that it is just bureaucratic.

DR PATERSON: Do you think that having two interviews is an appropriate safeguard?

Dr Stevens: I think that is an appropriate safeguard. Some people want more safeguards. We want to allow consumers to have access to this service without too much trouble near the end of their life.

Ms Gorman: But we do recognise the need for them to be safe while that happens.

MS CASTLEY: I would like to talk about the three-year review period. You have raised concerns that three years is too long. Perhaps you could talk about that.

Dr Stevens: Yes. It is because of our feeling that this bill is not answering all consumers' needs. We would like to see it start, but the sooner we can improve it the better.

Ms Gorman: That has come from our members who anticipate wanting to request voluntary assisted dying and fear that they will be too late. There are a lot of community members who have waited a long time to see this and they are hopeful that it will include dementia in the not too distant future.

Dr Stevens: Yes. I chair the Health Care Consumers Health of Older People Consumer Reference Group and that view has been expressed in that group. We have a member of that group who now has dementia. Two years ago, she would have been eligible and now she is not.

MR COCKS: Very quickly, just to clarify, it sounds like you would like to see the way this operates moving further sooner than the legislation currently provides.

Dr Stevens: Yes.

MR COCKS: Thank you.

THE CHAIR: Dr Stevens, just to clarify, were you saying that the person you are referring to is no longer eligible because she has dementia, whereas previously other conditions would have made her eligible if she did not have dementia?

Dr Stevens: No. I am saying that, if she had other conditions at the time that made her eligible, she would have been eligible.

THE CHAIR: I just wanted to clarify to make sure we are on the same page. It is interesting that there are a range of views on how far the legislation should or should not go, and you have come in with, I think, one of the views that is more towards less regulation and more access. I think those are your own words, to be fair. On balance, though, given that there are a range of views out there in our community as to how to best have a system that has the safeguards in place but also provides access without a lot of bureaucracy, do you think that we have the starting point correct?

Ms Gorman: We are pretty pleased with it.

Dr Stevens: We are pleased that we are going ahead. If it means that the Assembly has much more trouble getting it through by having the other things that we think are important in there then we are prepared to let them go.

Ms Gorman: We saw that this was an opportunity to take the experience of other jurisdictions and other countries and create a system for the ACT that tries to meet some of the needs that are perhaps the more challenging ones. We recognise that most of what people asked for is in this bill, but, to us, there are still a couple of important outstanding things that need review.

THE CHAIR: Dr Stevens or Ms Gorman, is there anything you would like to add before we finish up today?

Ms Gorman: I just want to have a quick word about the care navigator service. I heard the pharmacist before us mention it too. We see that as an incredibly important part of this working, in terms of the community understanding and being supported to use this process. Also, as the pharmacist was saying, medical practitioners are going to need support as well. At the moment, the bill gives the impression that the care navigator service is there for when there are barriers or breakdowns in the process. We think a care navigator service needs to be widely promoted and widely available, whether you need it this much or that much, as a support, not just for people using voluntary assisted dying for themselves but also for the carer and family support part and also medical practitioner support. What I am asking for is a plea for its importance to be recognised and for it to be fully funded and supported. Almost everyone who goes down this path will need some degree of support.

THE CHAIR: You are welcome to take this on notice if you need to provide more information. You have taken the position to make the scheme as accessible and open to everyone as possible, including people who would be considered quite vulnerable: people with dementia and younger people. There are a range of views out there that

we should be protecting the most vulnerable and that the safeguards are not making these things accessible to them. I want to get a better idea of how you see the balance and how making the scheme accessible to those who would be considered quite vulnerable is not actually working against their protection.

Ms Gorman: In the end, we value people having choice and control over the major decisions of their own lives. We see person-centred care as people being given all the information and having all access so that they can make those choices when they are able to do so. People may need support to make those choices and, in some cases, they may not be able to make those choices. We recognise that too. We think that good care puts people at the centre and puts as much control as possible into people's own hands about decisions about their health and their wellbeing.

We see that some young adults, older children, are potentially getting into the space where they can make some of those decisions about the level of suffering that is tolerable to them and how life is for them. It is not necessarily the case that they are too young or depressed or cogitatively impaired. Sometimes people can make those decisions even though they may be considered quite young or they may have some level of cognitive impairment. We fall on the side of allowing more choice but with the safeguards of good support, good information and the involvement of support people to provide safety for those decisions to be made.

THE CHAIR: Thanks. We will need to finish there. Thank you very much for your attendance today. On behalf of the committee, I would like to thank you. One question about age was taken on notice. The secretariat will liaise with you on that one. You will also be sent an uncorrected proof transcript for you to look over in the coming days. Thank you again for your testimony today. We will now move on to our next session.

Dr Stevens: Thank you.

Ms Gorman: Thank you very much.

BOESEN, MR MICHAEL THOMAS, Member, ACT Policy Advisory Group, National Seniors Australia, ACT Branch

THE CHAIR: I would now like to welcome our next witness, Mr Michael Boesen, from National Seniors Australia, ACT Branch. I remind you of the protections and obligations afforded by parliamentary privilege and I draw your attention to the pink statement on the desk, which is the privilege statement. Witnesses must tell the truth. Giving false or misleading evidence will be treated as a serious matter and may be considered contempt of the Assembly. Can you please confirm that you understand the implications of the statement and that you agree to comply with it?

Mr Boesen: Yes; I understand the implications of the statement and accept the requirements.

THE CHAIR: Thank you very much. I note with thanks that you have provided the committee with a copy of your submission to the government discussion papers, and we have also received your written opening statement. Thank you very much for both of those. We will now proceed to questions, and I will ask Ms Castley to go first.

MS CASTLEY: Thank you for your very comprehensive submission. I have a question—I think it is in the formal submission and not the additional documentation—where you say, “In place of the restricted criteria of the patient’s condition being advanced, progressive and expected to cause the person’s death,” you would like less restrictive relevant conditions. If access to voluntary assisted dying were to be extended to those of advanced age suffering intolerable quality of life, what considerations do you think should be given to ensure that there is no pressure on individuals to use voluntary assisted dying—for example, if they feel that they may be a burden to family? Can you talk about that for me?

Mr Boesen: Yes. I could suggest procedures which would lead to such a bad situation occurring, but I will not try to do that because I am not totally familiar with the procedures that are used in other jurisdictions. There are a number of jurisdictions, particularly the Netherlands, Belgium, Luxenberg and Switzerland, where the same question would have been asked and answered by the practices that have been implemented in those jurisdictions. I would encourage the government to have a look at those procedures that are enforced in those other jurisdictions, some of which have been going since 2000 and have been reviewed on many an occasion. I would be confident that their procedures would avoid the problem that you have referred to. Otherwise, if it had not, it would have been picked up before this.

MS CASTLEY: Thank you.

MR BRADDOCK: I have a question on those who have lost their decision-making capacity—and you are encouraging that this bill should be expanded to incorporate that. I am wondering how the other international jurisdictions have dealt with some of the ethical challenges in terms of the person not being able to provide their consent at the time of the administering of the substance.

Mr Boesen: I would encourage the government to have a look at how it is done in

other jurisdictions. I gave you as a late handout a copy of the Netherlands' information. If you read that, it goes into a lot of detail about what they do in order to ensure that what is being done meets the overall guidelines of the act. The Netherlands' system is a model that we would propose as giving excellent procedures which, as I said before, have withstood the test of time. I will not elaborate on that. If you read what happens in the Netherlands, that will give you a good model of what might be done here.

MR BRADDOCK: Thank you.

DR PATERSON: Thank you very much for your submission. At the end of your submission you talk about the ACT branch of your organisation, with approximately 250 adults. I was wondering if you could speak to the overall views of your membership in terms of their support and the main reasons that they support this bill.

Mr Boesen: Support for?

DR PATERSON: The bill.

Mr Boesen: We have not undertaken any recent survey which would answer your question directly. But, based on the 2019 and a more recent survey undertaken, the types of needs that were identified by people lead to the proposition we have made in our submission that, for some of the people who have a need for VAD, their needs will not be met by the legislation. Our membership has indicated, as we have indicated before, that the bill will address the needs of people who are at death's door, who are in extremis, have a terminal illness and have only a short time left to live but that there are also other people who are not in such a grievous position as that. Our members quite clearly, through surveys and through associated discussions, feel that there is also a type of person who is not terminally ill, does not have a short time left to live but has a serious physical or psychological condition or constellation of conditions. My hearing is going and I do not sleep well at night now, but I can only imagine that, as time goes by, I will develop other problems. There are people who have a number of problems, none of which might be defined in terms that the government has used.

The government starts with a different approach to, say, the Netherlands. The Netherlands focuses on the fact that a person has their views about their situation—that they are in a parlous situation, and that that is the starting point. So the suffering that they are experiencing is the first focus of, say, the Netherlands and other legislation. The focus in the government's legislation is—as was originally implemented in Victoria—that you have to have a progressive advanced disease that is expected to cause death. So they are focusing on the condition, whereas other jurisdictions are focusing on the suffering of the person involved. Did I answer your question or have I drifted off the point?

DR PATERSON: No; you are right. It was very interesting. Thank you.

MR COCKS: Let me start by thanking you for the work that National Seniors Australia, the ACT branch and nationally, has been doing in researching this subject over a long period of time. I did go back and look at the 2019 research and the 2021

National Seniors survey. I assume that is the other piece of research you were referring to.

Mr Boesen: Yes.

MR COCKS: In your submissions to the bill development and the inquiry, you indicated that assisted dying should be available to a broader range of people than the current bill makes provision for. I would like to understand that a bit more. You have suggested that assisted dying should be available to people with an intolerable serious physical or psychological condition.

Mr Boesen: Yes.

MR COCKS: Could you expand on that? What would constitute, for example, an intolerable serious psychological condition? Would you envision any restrictions for that group?

THE CHAIR: Mr Cocks, is there a reference for what you just spoke about which would help me find the page number?

MR COCKS: I do not have the page number.

MR BRADDOCK: I believe I have it. It is on page 3 of your submission, Mr Boesen.

Mr Boesen: I could not identify specific illnesses, but throughout other systems—and, in fact, in the system the government is proposing—a person can have a condition that is referred to in, say, the Netherlands as a somatic or physical condition or a psychiatric condition. There is also, for people who are simply aged and worn out, as it were, what is referred to in the Netherlands as a multiple geriatric syndrome. As you get older, you have sight impairments, hearing impairments, osteoporosis, osteoarthritis, balance problems or weak bones, and those sorts of conditions then pose an insufferable burden on the person involved. I cannot say what specific psychiatric conditions might be appropriate, because I do not know enough about the systems in other countries, except to say that they refer to those conditions as being ones that should be addressed through the legislation for people who are suffering intolerably.

MR COCKS: The other group, as I think you have alluded to, is those of advanced age who do not have a terminal illness or a serious condition but whose quality of life is intolerable.

Mr Boesen: Yes.

MR COCKS: In your 2019 survey of 93 of your members, you seem to have been pretty specific that that is people aged 90 or possibly 80 or older.

Mr Boesen: Yes.

MR COCKS: Could you help me understand what the basis is of that line around a particular age and what quality of life factors would be considered in that?

Mr Boesen: In one of the handouts, there are other questions which you indicated you have looked at. In the survey undertaken in 2019, we tried to portray a scenario where you have a person who is fully informed about the voluntary assisted dying process and have rationally evaluated their life expectancy and health and illnesses, but they have conditions, diseases or illnesses which they find intolerable. We posed a scenario to that effect and then said to the respondents who answered the questions—this is question 12—“Should access to voluntary assisted dying be allowed for such people if they are older than 90?” That is where we get 71 per cent of people saying, “Yes, such people should be allowed access to consideration for access to voluntary assisted dying.” Then we went a step further: “What if they are only 81 to 90?” We again got 61 per cent saying yes. “What about 71 to 80?” There was a lesser percentage there—52 per cent.

We broke up the age spectrum into 10-year groups, and what we were looking for was: how old do you have to be before the respondents would say, “Yes, they should have access to voluntary assisted dying”? Our approach on that is possibly even less restricted than, say, the Netherlands. But then we can have a look at what they say—and I read out the multiple geriatric syndrome. That describes the sort of situation in which elderly people would be suffering intolerably. These are the people whose needs we think should be addressed.

MR COCKS: Would that include the factors in the 2021 national survey, where there was a series of individual responses—for example, the ones that were pretty strongly on very broad access to assisted dying? One was: “I very strongly agree that VAD should be legally available in Australia for everyone who wants to make use of this service.” That person went on to say that, if they ever felt that they were going to become a burden on their family and friends, they would not hesitate to make the decision to end their life. They seemed to be very much leaning towards the position that there should be no age limit.

Mr Boesen: No age limit? I do not quite understand that.

MR COCKS: For older people. Reading through those positions, it seems to be that there is an argument amongst some of the respondents to that survey that there should be no age limit; that you must be over 70 or 80 to access services because of intolerable conditions or quality of life.

Mr Boesen: No; I think our focus is on the person’s feelings about their life. Are they suffering intolerably? It is not really an age issue, but we do of course know that, as people get older, some of the conditions become less and less tolerable as they go along.

MR COCKS: It is about suffering.

Mr Boesen: Our focus—as is the case in, say, the Netherlands—is on the feeling of intolerable suffering; people who are suffering intolerably, where there is no acceptable treatment, where they understand their condition and they understand what the alternatives are should have access to voluntary assisted dying. If there is no alternative that they, in conjunction with their physician, see as being there, then such

people should have access to voluntary assisted dying.

THE CHAIR: All right. I am winding up on this line of inquiry now. If you have any other questions about the survey, Mr Cocks, you can put them on notice.

THE CHAIR: Do you have a supplementary, Dr Paterson?

DR PATERSON: Just a thought on intolerable suffering.

THE CHAIR: Is it a question or a thought?

DR PATERSON: I just would like to—

THE CHAIR: While you think about that, I will ask my supplementary. Mr Boesen, if I have understood you correctly, you are saying that you would like the scheme expanded to include consideration of broader eligibility criteria.

Mr Boesen: Yes.

THE CHAIR: Our last witness had a similar view. They also put to us that they would not want to see discussion on expansion of the scheme holding up what is currently before the parliament. Hopefully I am characterising this correctly, but it was a sentiment of, on balance, that they are happy with the bill where it is, but they want to be able to continue the conversation in the future around expansion of eligibility. Is that a position you could get behind?

Mr Boesen: No; it is not. The government have made the proposition that the systems and safeguards in the bill are comprehensive and they have been developed and informed by research, evidence, and community views on what is fair and appropriate. I do not think the government have done what they claim to have done. For example, if they say the community views support a model of legislation which is essentially based on the Victorian model, then we do not have evidence that they would agree to that as against a less restrictive model.

The government have not asked the questions that they should have asked. We have, for a long time, suggested to the government that they undertake comprehensive research to find out what the community's views really are—in justifying the position the government refer to, for example, feedback obtained in the YourSay panel. However, I do not think that the facts of the matter agree with what the government are really saying about it.

THE CHAIR: Mr Boesen, can I clarify that? When you say that the scheme before us in the legislation is too restrictive and that the community would like a less restrictive scheme, where is the disconnect?

Mr Boesen: We have not done a survey saying, “Here is the government's criteria for admission to voluntary assisted dying. To what extent do you agree or disagree with that?” What we have asked the community is: “What are the types of symptoms and problems that we should be addressing in the legislation?” When I say that the government has not asked the right questions, I must also say that I do not think the

government will change its point of view, because it has had a long commitment to implementing models which are consistent with the models implemented in the states. The government is very firmly committed to that.

To give you an example, the YourSay panel members—I think there are about 29,037 people—contributed responses to some questions which the government asked at the end of the process. The key question was: “Which of the following eligibility criteria would you expect to be in place as part of the introduction of voluntary assisted dying in the ACT?” What the heck does “would you expect to be in place” mean? That is not the same as saying “would you like to be in place”. So they have an inane question: “What eligibility criteria would you expect to be in place?”

My expectation is that “the advanced progression can cause death” requirement would be in place. I do not want that, though, because I think it is too restrictive. Even allowing for misinterpretation of the question, “The person must have an eligible illness, condition or disease that is advanced, progressive or will cause death,” only 48 per cent of the YourSay panel said they expect that to be in place. Does that mean that half of the respondents would not like it to be in place? I do not know. The questions that the government have asked are really deficient, and they do not have a clear understanding of what the community requirements and community desires are.

THE CHAIR: Mr Boesen, I must say I am a little bit confused. In reading through the submission from the seniors association, it was quite clear that they thought the requirements were too restrictive as they stand and that they would like to see those expanded. Listening to your testimony today, it seems that you are going far stronger than that, and I am not really quite sure where the National Seniors actually stand.

Mr Boesen: When you say that I am going more stronger than that, what do you mean?

THE CHAIR: It is clear that you think that there should be fewer restrictions within the bill. My question was: “With what is there, on balance, is that a reasonable starting point or are you very much of the view that the restrictions are too much and they should just be loosened?” To be honest, I am not sure I can articulate you a clear question, because I have become confused by the many different points within your answers.

MR COCKS: Perhaps I can ask a supplementary to try and clarify. It sounds like what your saying is that, currently, the government has not undertaken the necessary research to properly understand the full and broad community positions on what is in this bill.

Mr Boesen: Yes. I do not think that is in question.

THE CHAIR: Mr Boesen, I guess my question is: are you saying that in the sense that you think the question of whether voluntary assisted dying should be permissible is the question you are thinking of or is it the case that you think that the community has a greater appetite for fewer restrictions and that has not been tested by the government?

Mr Boesen: Yes. For example, if you look at the National Seniors national survey, question 43 is:

VAD also should be legally accessible to adult Australians—

and I will get back to “adult” in a minute—

with decision making capacity—

and I will get back to that too—

who have a non-terminal illness causing them unacceptable suffering, provided they meet all other eligibility criteria listed above.

And part of that, of course, is unbearable suffering.

The government’s position is that the first cab off the rank in eligibility requirements is “relevant condition, advanced, progressive and expected to cause death”. After that, they then go to the position that “the individual must be suffering intolerably in relation to their relevant conditions”. So they are looking at it from the point of view of conditions, medical terminology, and things like that. For us, the first cab off the rank is that the person has an unbearable condition and unbearable suffering.

THE CHAIR: All right; I think I have got where you are going. So, if I am correct in understanding, to summarise and to succinctly say what you have been putting forward, you think there is more work needed to better understand the community wish or want as far as removing restrictions to access the scheme is concerned and that has not been done.

Mr Boesen: Absolutely.

THE CHAIR: Okay; I think I have got that. Thank you, and thank you, Mr Cocks, for helping me.

Mr Boesen: I think that is a very perceptive observation.

THE CHAIR: On that note, we will finish because we have gone a little bit over time. Thank you for appearing today. You will be sent an uncorrected proof of the *Hansard* from the committee secretariat, so please check that for any factual errors. Again, thank you for your time and your submission to the committee inquiry.

Short suspension.

WARD, ADJUNCT PROFESSOR KYLIE, CEO, Australian College of Nursing
YATES, PROFESSOR PATSY, Executive Dean, Faculty of Health, Queensland University of Technology

THE CHAIR: We will now welcome our witnesses from the Australian College of Nursing. For the *Hansard*, could I please ask you, one at a time, to state the capacity in which you are appearing today.

Adjunct Prof Ward: I am Chief Executive Officer of the Australian College of Nursing, and I am also a Fellow of the Australian College of Nursing.

Prof Yates: I am a Professor of Nursing at Queensland University of Technology in Brisbane, but I am here today in my capacity as the current Chair of the End-of-Life Faculty for the Australian College of Nursing. I am also a Fellow of the Australian College of Nursing.

THE CHAIR: I would like to remind you of the protections and obligations afforded by parliamentary privilege and draw your attention to the privilege statement that should have been sent to you. Witnesses must tell the truth. Giving false or misleading evidence will be treated as a serious matter and may be considered contempt of the Assembly. Please confirm that you understand the implications of the statement and that you agree to comply with it.

Adjunct Prof Ward: Yes, I fully understand.

Prof Yates: Yes, I confirm that I understand and agree.

THE CHAIR: We are not inviting opening statements, but you are welcome to provide something for us to table; that is fine. We will proceed to questions.

MS CASTLEY: Thanks for joining us today. I have a question about the differences in the bill from other jurisdictions. Do you have any thoughts on the ACT bill being slightly different to other jurisdictions, given that we are an island in New South Wales? Do you have any concerns, or your members' thoughts, on that?

Prof Yates: I have worked with some colleagues of mine here in the Australian Centre for Health Law Research at QUT on looking at some analyses of the different legislation. While the differences reflect a number of important lessons we have learnt along the way as legislation has been implemented, I think it is understandable that there will be variations in a country like Australia. I think the most important consideration would be that there is real clarity for health professionals involved as to what is different so that we are not putting any health professional at any risk; that just really goes to the importance of education.

We have recently—and if it is possible, I am happy to submit this—published a paper in *Collegian*, which is the journal of the College of Nursing, where we presented an analysis of the legislation of the states at the time and where we have summarised the differences and the implications for nursing. It was published last year, so we obviously did not have information for ACT. I think that would be a good base to start

in terms of how we might look to educate nurses across the country, but, in particular, in the ACT, as it is implemented.

MS CASTLEY: That would be great, thank you.

Adjunct Prof Ward: I will add to complement Patsy's comment, because Patsy and I, and others, have been working on this from the very early days of the Victorian legislation, and we have worked with each jurisdiction as they have considered it. The other important factor that I would like to impart to this inquiry is that we bring knowledge that has now been tried and tested, and some of the learnings. I think the ACT is well positioned because we can contribute what our colleagues in nursing, in medicine and in this industry have been experiencing to support the consumers that will be involved.

MR BRADDOCK: I have a question about the application of VAD to those who have lost decision-making capacity, which your submission supports but the ACT government submission says is highly subjective and ethically challenging. I would be curious as to your views as to, ethically, how it is appropriate in terms of applying a VAD substance to someone who cannot give consent at that time because they have lost the capacity, and whether it is subjective or not.

Adjunct Prof Ward: The first thing I am going to say is that the whole philosophy of nursing care from the undergraduate curriculum and all through our careers—and I have had over 30 years experience as a registered nurse—is a holistic approach to care. We are always deeply embedded in ethical issues, so having ethical considerations is not new to us and neither is having patients, residents, clients or consumers—however we wish to consider them—in cognitive decline in a palliative care state or in an end-of-life state, whether that is in deliria, dementia or any other state, when we are managing, assessing and caring for the people that we serve.

For us, there is always ethics and there is consideration of the individual and the family. This will not be new to the nursing profession. You will never get a black and white line, even between the under-18 or over-18 age bracket, for example. As we have progressed into this century, we have needed to think about dying with dignity, and we do need to think about individualised care and people's right to choose. There is guardianship and many other factors that come into place that would also be factored into these decisions. Patsy, you might like to extend on that.

Prof Yates: No, I do not have anything else to add. I am just looking at the ACN's submission; I think it also does acknowledge that it might be something that needs to be revisited over time. Kylie has pointed out that there are enormous challenges in this area, as you quite rightly point out, so I think we need to be thoughtful and think that through before legislation is able to safely accommodate that. That is where I think the ACN's submission has noted that it might be something that is reconsidered over time as we develop our understanding further, and using some of the other mechanisms that might be possible there in terms of things like advanced care planning and those sorts of things—advanced directives—as we go forward.

MR BRADDOCK: We heard from a couple of submitters this morning referencing the Netherlands model. You refer to the Canadian model in terms of a way of

addressing that loss of decision-making capacity. Is that a model you would recommend the committee look at? The Canadian one, I mean.

Prof Yates: I think we need to learn from any of the models that are out there. I would not necessarily say that there is any one model, given the complex nature of this, that is going to be perfect for any situation, so I think learning from other jurisdictions is something that we should all be doing.

THE CHAIR: In the discussion it comes up, and it is a tenet within the submission as well, to look at voluntary assisted dying as health care and part of the healthcare journey and a healthcare intervention—I think they are the words you used in your submission. Is that the sentiment that is shaping your views on further consideration of people under 18 and people with, say, dementia or other cognitive issues? If it is, can you help me to understand a little bit more the rationale behind this idea that it is part of the healthcare journey and how you arrived at that position?

Adjunct Prof Ward: I am going to say in preface that we are going back to 2022 and where we were at that point in time when we made this submission. We are now in 2024 and we are 14 months along. What we did was consult with our members. I think it is really important here that we have given you that collection. For the previous question, we are not endorsing the Canadian system. We are saying, “Let’s look globally and bring that back locally, because ACT are looking to do things a little bit differently.”

Voluntary assisted dying, when Patsy was leading us, and it was a term first introduced in Victoria, had a little bit of emotion and it was viewed very differently. We absolutely advocate on behalf of our members that this should be considered as a healthcare intervention. We have strongly advocated in every jurisdiction, and we will continue to, that a second practitioner be an expert registered nurse or nurse practitioner, for the best interests of the consumers. But there is no nurse that would be involved in this area—we are very confident with our medical colleagues—that would not be taking a very therapeutic and considered approach in consultation and collaboration with the person who is experiencing great discomfort and at the end of their life.

From our perspective, this should be considered a healthcare intervention as part of the holistic approach to health care. Especially in very remote, rural and isolated areas, which ACT does not really suffer from, we really encourage that it is part of the healthcare discussion so that the nursing professional is well positioned and can be educated and supported to engage in a dialogue with those that need to have a greater understanding and have the discussion, and it is treated as part of a therapeutic intervention.

THE CHAIR: Professor Yates, did you want to add anything?

Prof Yates: The only thing I would add is probably that the important thing for me is that nurses and health professionals are really at the frontline of voluntary assisted dying; so, I suppose, whether we call it a healthcare intervention or not, the important thing is that this is considered as something health professionals will face and be asked to deal with. Therefore, it needs to be understood as part of healthcare

professional training and practice; however, recognising that those healthcare professionals will have different views, and I note the conscientious objection processes you have. That is the main point: this is actually part of the healthcare system now, and therefore we need health professionals to be adequately prepared to deal with it.

DR PATERSON: Given all the work you have done in other jurisdictions around Australia, is there anything that really stands out to you that this bill is missing, or that other jurisdictions have advanced that we have not here?

Prof Yates: In the work we have done, a key issue people keep coming up with is this: who can have conversations? I think you have attempted to have some clarity there. That will always be challenging because conversations are not always structured in a way that makes it really clear, but I think there is an attempt to deal with that. The second issue is really about the role of different health professionals, and I think that there is an attempt to have some clarity about that in the legislation. The third key issue is about conscientious objections. They seem to be some of the most challenging aspects, particularly for nurses, and none are ever going to be black and white, but I think that there has been an effort to address them and provide clarity in the legislation.

Adjunct Prof Ward: The only thing that I would add is that the Australian College of Nursing has been committed, for many years now, in leading work for the nursing profession in this space for both nurse practitioners and registered nurses. We offer education. If there is more education needed, as the college providing the largest number of postgraduate certificates in the country, we will continue to do that.

In echoing Patsy's very sound three areas that are highlighted in every jurisdiction we speak to, I would like to reinforce the knowledge and the expertise and the commitment that nurses who are experts in this area of specialty in their careers bring. The ACT is really blessed with some outstanding nurse practitioners and registered nurses, who may be clinical nurse consultants or advanced practice nurses and very, very experienced. That should never be underestimated in the consideration of legislation and how the expertise of the profession value-adds to the communities we are all interested in serving.

MR COCKS: Just to clarify: those areas that you have identified there sound like areas that are challenging and need to be worked through, rather than areas where there is a more progressed position in other jurisdictions. Is that correct?

Prof Yates: Yes, correct.

MR COCKS: Thank you for your submission. The ACN seems to be pretty happy with the overall greater involvement of nurses in the administration of assisted dying compared with other jurisdictions, but I wanted to get your views on an issue that your organisation has not touched on as much as the Australian Nursing and Midwifery Association. The bill introduces, I think, 34 strict liability offences, and those offences would mean health practitioners, including nurses, could be found guilty of a criminal offence without proof of knowledge or intent. Has your organisation considered those elements of the bill, and do you have a view on whether

those strict liability offences could have any impacts on nurses, given there is a two-day time frame associated with some of these things?

Prof Yates: I cannot talk specifically about those particular liability clauses, but what I would say is that nurses' understanding of their legal obligations is really critical to the implementation of voluntary assisted dying. I think the legislation will be impacted if people do not understand the requirements, and so if there are particular understandings, or particular things, which might make healthcare professionals more reticent, then we need to be making sure that people understand how they navigate those particular clauses. As I said, I cannot talk specifically about those clauses but, again, I would go back to the importance of people having to understand what their obligations are; that is a given. There has to be really important, strong, thorough education so that we are clear that people understand what their obligations are.

MR COCKS: Given the workloads and sometimes inefficient systems our nurses have to contend with, do you think a two-day maximum time frame is always going to be feasible for nurses?

Adjunct Prof Ward: I am with Patsy. I cannot speak on behalf of every individual one of those 34, and I do not know that as a faculty we have looked at them or that as an organisation we have looked at them. What I can say is that two days in the life of a nurse is very different than two days in the life of society, because we work 24/7.

We are regulated; we are accredited; and we govern our own practice. There is a legal, ethical and moral responsibility for the nursing profession to practice within the scope and guidelines. Having said that, there is also a responsibility to protect the public. So, I actually think that two days might seem reasonable but without going into the detail—if you are on Friday night and somebody is in need, there might be a little bit of latitude in that, because nursing is 24/7. We are the only profession that provides the type of care around the clock; there is no other profession that is anywhere close to providing the coverage in the health system that nursing does.

The other thing that I would add in complement is that this is a very niche, particular area and specialty of nursing. This should not be rushed and should be considered by expert nurses. This is not a type of front-up to ED experience; this needs to be expert clinicians working with the individual and family and loved ones to get the best outcomes for the individual in a very planned approach in line with legislation.

THE CHAIR: I want to pick up on a couple of the comments you made that you are a representative organisation and you have a lot of nurses within your membership. I think you made the comment, and correct me if I am wrong, that there are a range of views around voluntary assisted dying within your membership, but your focus is on looking at it as a part of the healthcare system and having a system that is useable and meets the needs of consumers and practitioners. Can I get your view on whether you think the system that is in the ACT legislation meets the expectations and the needs of your membership?

Prof Yates: Kylie is the CEO; I can speak to the membership more broadly. What I will say is that I think the important thing about ACN's position is that it does, as you say, acknowledge that our members will have very different views. That is where it is

important, if this is going to be part of healthcare practice, that that is supported—those different views and that people are helped to work in a safe way while also, as you say, protecting the public and giving the public the choice. So I think, overall, I would say that the legislation, with the mechanisms that are in there, acknowledges there are different views about that, but Kylie can speak as the CEO to the broader membership and how the college is responding to that.

Adjunct Prof Ward: We get overwhelming support from our members, and our membership represents over 160,000 nurses across the country. We have overwhelming support for voluntary assisted dying in every jurisdiction around the country from our membership: both those who work specifically in this area of specialty, and those generally. So it may well be in the nuances, but some of the things that we are very committed to—Patsy said it beautifully.

We are not going to fall on our sword around language around healthcare intervention, but it is that therapeutic intervention. Definitely our membership are very strong advocates and champions around the adoption of the role nurses have in terms of the authorised practitioner and being able to assist our medical colleagues in the discussion and decision-making and support. There are some things that I would say the membership are very passionate about and committed to in the language, and that is in the role of the nursing, and then others where there is a little bit more discussion and debate but, generally, the support is fully there. There is no-one in our membership that has been against voluntary assisted dying.

THE CHAIR: And more specifically towards the ACT legislation, considering your members are the ones who are going to have to apply the legislation—

Adjunct Prof Ward: Correct.

THE CHAIR: Is there anything that you see there that from day one would not work appropriately or that needs further consideration? Or do you think on balance what is proposed in the bill is a reasonable starting point?

Adjunct Prof Ward: Yes, I think it is a reasonable starting point. I know we have started in other jurisdictions where we are fighting to get nursing, so I think this, from my perspective, is considered and reasonable.

Prof Yates: Up until implementation, in the pre-implementation, there is time to really prepare the workforce to understand what their obligations are, what the requirements are and how the system will work. I think it is going to be critical that there is some pre-implementation phase.

MS CASTLEY: My question is about clarity about what the bill says and does and goes back to Ed's initial question about the two days. In the ACT, if a nurse does conscientiously object, they have two days to get that referred to somebody else. I am wondering—as you said Kylie, 24 hours, or two days, in a nurse's world is very different to everybody else. Is two days enough? Noting that they could be facing criminal charges if they do not get it done in that time. I am just wondering what you, from the nursing fraternity, think about that?

Adjunct Prof Ward: I would give nurses more time. I think that if a nurse is conscientiously objecting, they will know. And we have had very extensive discussions around abortion legislation and all sorts, so we do get an understanding of our membership and our profession, but, particularly in this area, nurses will need time to refer—it is in the referral and the access to referral. I feel they would understand themselves; it would be rare to be morally comprised at this point. We could manage that in the health system but not the referrals.

MS CASTLEY: Yes, so the admin side of things.

Adjunct Prof Ward: Correct.

Prof Yates: I agree. I think that you are quite right when you say the system is not always lined up in ways and for all sorts of reasons; so, as you say, given the potential consequences, there absolutely needs to be a reasonable time to manage that.

MR COCKS: I just want to clarify, Adjunct Professor Ward: you made the comment that no-one in your membership opposes voluntary assisted dying. Is it that no-one would have an objection to it, or have you done research with all of your members to say no-one objects?

Adjunct Prof Ward: I would definitely not call it research. I have Distinguished Professor Patsy sitting with me, the renowned researcher. But I can say that as we have extensively gone to the membership and the profession to consult and to gather responses to inform the submission we put forward, there is general consensus. I am not going to say that there is not a nurse who does not disagree, but they are not coming forward when we are putting consultation papers out. We have a faculty of end-of-life care. We have been leading the discussions professionally for many years now, probably back to 2017 when we did our first position assessment on voluntary assisted dying. We are more inclined to get nurses asking us to support them with education. In fact, some of the webinars we have done in jurisdictions where we are educating on voluntary assisted dying are some of the most highly sought after information sessions—around the law, the effects and the practice of voluntary assisted dying. So we have had more curiosity and learning and wanting to understand this than we have ever had any objection.

Prof Yates: Adding to Kylie very quickly; I know time is limited. I think it is important to say, as Kylie said, that it is probably the people who responded to the college, but I am sure there would be nurses out there—because in some cases it is a very private matter—who will not be expressing their views, so it is really important that the legislation includes those conscientious objection processes.

THE CHAIR: If two days are not enough, it does beg the question: what is enough time? Is there any guidance you could provide as to what would be reasonable for a nurse to provide the notice that a request has been made—I think that is the way we classify it in the legislation. Bearing in mind, obviously, that it is quite a sensitive topic and people will not necessarily be wanting to wait weeks for a referral to start the conversation.

Adjunct Prof Ward: Patsy, do you have a best practice model with this?

Prof Yates: No. I wish I could say how our system works, but I really would not want to say.

Adjunct Prof Ward: I think there are two factors that I would like to consider, and I think the ACT is well positioned to lead in this space. I reside in the ACT. We are small in geography; we are small in population and even in the nursing workforce. Considering we are a border town, sometimes that does bring about challenges. Who would you refer to if there is a skills workforce shortage? Where do you refer when depending on the waiting lists and the services? I think that, rather than a mandate of 48 hours it would be best practice within a week. But if somebody is on annual leave or if something else is happening, I do not want somebody to be criminally or professionally affected—have their license affected—because the system does not have the supports in place, and then to be morally compromised around conscientious objection. So what we would be looking at would be the government’s offerings of services.

THE CHAIR: Adjunct Professor Ward, is it fair to say you are drawing a distinction between someone who, for whatever reason, might not feel comfortable participating in the system at all and does not want to participate, as opposed to someone who, through extenuating circumstances outside of their control—say, the person they could refer to is on leave—cannot refer?

Adjunct Prof Ward: Correct.

THE CHAIR: So, it is looking at that nuance—that is what you would like further consideration of.

Adjunct Prof Ward: If a nurse was inhibiting a person’s right to choose, I would be the first to support prosecution of that; that goes against the whole nursing philosophy. But if it is around access to referrals, I would not want to see a nurse affected professionally or morally because of access, and around the country there are more access issues and workforce issues than we would ever want there to be in this situation. We are actually seeing global and national trends of those issues exacerbating by 2030 and not improving.

THE CHAIR: We have to wrap up there. I thank all members for their questions and all witnesses for appearing today. I do not believe we had any questions taken on notice, so there is no follow-up for that. But you will be sent an uncorrected proof transcript, so please make sure you have a look at that. Patsy will be forwarding through a document for us, so we will keep a look out for it. If you would liaise with the secretariat, they will be able to help you out with that.

Adjunct Prof Ward: Thank you for the opportunity.

THE CHAIR: Thank you again for appearing today.

Prof Yates: Thank you.

Hearing suspended from 12.35 pm to 1.30 pm

KELLY, MS LISA, Chief Executive Officer, Carers ACT
JOHNSON, MISS JESSICA, Policy Officer, Carers ACT

THE CHAIR: Everyone, welcome back to the public hearing for the committee's inquiry into the Voluntary Assisted Dying Bill 2023. The proceedings today are being recorded and transcribed by Hansard and will be published. The proceedings are also being broadcast and webstreamed live.

When taking a question on notice, it would be very helpful if witnesses used the words: "I will take that question on notice." This will help the committee and witnesses to confirm questions taken on notice from the transcript.

Voluntary assisted dying is a sensitive topic. The secretariat has information on support organisations available for witnesses or other people attending this hearing, or who are listening to this hearing, who are impacted by issues raised in this hearing.

We now welcome witnesses from Carers ACT. I would like to remind you both of the protections and obligations afforded by parliamentary privilege and draw your attention to the privilege statement. Witnesses must tell the truth. Giving false or misleading evidence will be treated as a serious matter and may be considered contempt of the Assembly. Please confirm that you understand the implications of the statement and that you agree to comply with it.

Ms Kelly: I understand and agree.

Miss Johnson: I understand and agree.

THE CHAIR: Thank you very much. We are not inviting opening statements; however, you are welcome to table one with the secretariat if you have one. We will proceed straight to questions.

MR BRADDOCK: My question is related to those who have lost decision-making capacity, which, whilst not covered under the bill, you have mentioned in the hope that it will be incorporated at some point in the future. What would be the role that you would see for carers, particularly for those individuals who have lost that capacity?

Ms Kelly: We know very clearly from carers that they are looking for the provision for people to indicate a desire for voluntary assisted dying while they still have capacity, for that to be administered at a point in the journey that is defined, but that that point in the journey may be at a time when that person has lost capacity. The carer would be the holder of that wish and desire, through a power of attorney or a legally endorsed statement that would say, "This was the wish and desire of the person, and I am upholding their wish and desire now that they have lost their competency to do so."

Carers told us very strongly, in consultations, that they were concerned that the current legislation, as it is written, prohibits people with Parkinson's, motor neurone disease or any sort of degenerative disorder that affects cognition from being able to

apply for voluntary assisted dying. That has changed slightly. That was in the draft legislation, where there was the six-month time frame. With the removal of the six months, that has allowed some more scope there, but people are still concerned that, if the person themselves has to be competent at the time of asking, and that time is close to the administration, that would prohibit people from being able to use voluntary assisted dying.

MR BRADDOCK: Thank you.

DR PATERSON: Could you detail the role that carers play in the decision-making. In your submission you speak in depth about that, about carers being included and being front and centre of that decision-making process. Can you speak to that role and where you see that the bill needs to strengthen that articulation?

Ms Kelly: Yes. No surprise: we represent carers and that is who our primary target is. One of our concerns is that, in drafting the Voluntary Assisted Dying Bill and even in the conversations that were occurring around it, there was a huge amount of focus on the person who is dying—quite rightly. However, our concern is for the people who are left behind at the end of that process, and for what happens to carers in their grief and in their exposure to complex grief if the process to that death has not been a good process and a process that involved and engaged carers all the way along.

What we are looking for is provision to enable facilitated conversations to happen between the carer and the person who is dying, prior to that death, so that both people have had a chance to express their view on what is happening, to have heard each other, to ideally have come to a resolution together, as a couple, as a relationship, as a dyad, that this is the desire the person has and that they have come to peace with that.

The carer can then support the decision, with the aim that, once the person has died, we are not left with a carer who has very complex grief or very mixed feelings about what happened in the death—particularly if it was not their decision too. There has been a lot of air time about coercion in voluntary assisted dying. What we are not hearing is about what happens when the person who wants to die wants to die, but the carer does not want them to. To walk that journey beside someone and be left at the end is really challenging. What we are looking at is provisions around how we ensure that carers have an opportunity to discuss that in ways that are supportive, that are not about one person winning an argument over the other but in way that both people can be heard.

We want the process itself to recognise the Carers Recognition Act and the rights of carers to have their view heard in the space. At the moment, in the way the act is written, there is no provision that allows for or requires the carer's view to be heard. It is not that the carer's view should be heard more than that of the person dying, but it is not okay that I sit beside somebody as they are going through that journey and they make this final decision about their life and my voice is not heard at all in that. There is no-one providing me with the support that I need to come to peace with that decision and make the death a good death, and a death that we both want.

THE CHAIR: Ms Kelly, just picking up on this, you made the comment that there has been quite a bit of discussion about coercion. Some people could potentially say

that involving another person in the decision could start to resemble coercion. How would you respond to anyone who says that the inclusion of a carer could amount to coercion and therefore cannot be done?

Ms Kelly: I think that I would respond by saying facilitating good relationship discussions is not coercion. We have still got enough protections in the act so that the person who wants to die is the person who is making that statement. We have professionals and health professionals involved along the way who should have the skill to discern in a facilitative conversation whether somebody is being coerced.

I guess I would also say: are we going to cut out 99.9 per cent of carers because we might have a case of coercion at some point, and is that case of coercion not going to be picked up through the other mechanisms and the other safeguards that have been put in place, to the point that we cut out people from the conversation in order to protect against it? Our research has shown that there have not been very many cases at all that have shown that there has been coercion involved.

What we are seeking is that, particularly at the start of the journey, when it is first raised, the health professional involved suggests that there is a family conversation or a conversation between the carer and the person who is choosing to die to ensure that everybody is feeling okay about it. If not, the health professional's role is to continue to abide by the wish of the person who is dying, but we may also refer the carer to some counselling and support of their own so that they can work through their processes and what is happening for them in that process as well. As you would be aware, the Carers Recognition Act does not say that the voice of the carer outweighs the person; it simply states that they have a right to be heard.

THE CHAIR: I will just put on the record that I moved that act as a private member's bill, just so that there is no difficulty. I am very familiar with that clause.

MR COCKS: I just want to clarify this question of coercion. At the moment, the bill provides that a person commits an offence if the person dishonestly or by coercion induces an individual into making a request for access to voluntary assisted dying. The converse is essentially persuading someone to revoke a request for access to voluntary assisted dying. Do you see any risks for carers in that space?

Ms Kelly: I actually think there are lots of risks in the act at the moment for carers, and we probably need to heighten some safeguards for carers within the act. Some of that is around what happens when the person changes their mind. How do we not see that as coercion and how do we patrol and manage the conversations that happen in private spaces? I do not know that we can.

I guess I trust that there are trained professionals involved along the way, and they should be trained and capable and competent in uncovering the whys people present to them. They should be confident and we should trust them to ask the right questions and to have the depth of conversation where you can be assured that the people who are involved are coming to the conversation and to the decision of their own accord.

When we talk about carers and sometimes we talk about carers' coercion and about people who have health conditions or disability as victims or vulnerable, we take

away the actual relationship that exists between the two people. We forget that, despite them being a carer and somebody who is dying, they are spouses, they are parents and children, and they are brothers and sisters. There is a whole range of other relationships that happen within that space as well. We have to be able to trust in relationships, and we have to be able to trust in health professionals.

The more regulation we put in, the harder I think it becomes for people to access what it is they want or to enact the decision. We are concerned that there are lots of safeguards in protecting the person who is vulnerable at the moment; there is not as much protection of the person who is caring. What happens if the person changes their mind? Is that seen as coercion, when in fact the person just changed their mind? Either way—did not want it, now does; wanted it, now does not—is that just about somebody changing their mind? As a health professional, should we not at that point be saying, “Let’s talk about that. What’s changed to make that decision change for you?”

I am not 100 per cent sure what it would need to look like at this point. I am sorry, but I am a little bit concerned about whether, if the carer is administering or has any contact with the drug or is involved in any way, they are running a risk at some point—that somebody else in the family is then going to charge them with something or raise an issue with that. Sorry; law is not my background, but there is a concern I have around how we ensure that we protect the carer through the journey and after the journey. When there is any question raised, how is that carer going to be protected, to show that they were not coercive in any way, shape or form in the process?

Miss Johnson: We did, in our submission, mention that we wanted a protection statement for carers included in the legislation. I think Lisa hit the nail on the head: carers are going to be involved in the process regardless. If you are unwell enough to be seeking VAD then you are probably going to have somebody caring for you. It is about the training of those health professionals and their understanding of the importance of carers in that supported decision-making as well. That way they will know that it is not that there is a person there trying to coerce them, but they are a carer and they should be part of that journey as well.

Ms Kelly: That in itself adds a protection. If I am a health professional, I am a doctor or I am a psychologist—whoever it is that is charged with it—and I have had a conversation with both people, that in itself is some protection because then there is a witness to: “This is what was happening. This is what was going on. No, actually this was not me coercing; this was me participating in a conversation and supporting this person to enact their wish and desire.” It actually builds an argument for the inclusion because it does provide a protection around the carer.

MR COCKS: I think it touches on the same issues, to a large extent, around how we protect carers and look after carers, and the people left behind in the care dyad, as you state. I am interested in what more we can do to look after people. You raised specific concerns around the societal judgement of carers who advocate one way or the other. What can we do to look after people in that situation?

Ms Kelly: I think the societal judgement stuff is a big question. I do not know that I have got a solution on that, other than we continue to work with people around what

good dying looks like and what palliative care looks like, and continue to have good palliative care and good access to palliative care.

At no point do we want to be seen at all to be saying that VAD is the alternative to good palliative care. VAD should be an option and a decision people have the right to make, but it should not replace us investing in good palliative care. We need to have more public conversations about dying. It is something that is going to happen to all of us at some point. It affects all of us, in all of our days, in lots and lots of ways and yet it is the biggest taboo topic we have.

I think the removal of stigma comes from having better, open conversations about dying, right from the start. We protect children from conversations about dying, yet it is their parents that die sometimes. How do we have these conversations that just make dying part of life—and good dying being the desire we all have? I think that would help with the stigma end of it.

From the support end, we would really like to see that it is legislated so that it does not actually go away, so that it is not a budget decision and so that it is not on a whim. We want to see that there is post-death support available and it is built in and it is a requirement that carers who have been supporting somebody through a voluntary assisted dying process are provided with six sessions, or whatever it might be, of good grief counselling at the end of that process.

As callous as it might sound, I am concerned about the people who are living. I am concerned about somebody having a good death, but I am concerned about the people that are left after that good death. How do we make sure that they have also had a good death and that that death does not take over the rest of their life? Counselling within the process, I think, is really important. I think counselling for carers within that process is fundamental. We do not do enough of that and we do not offer enough of that, and then compulsory counselling after it is also fundamental.

MR COCKS: And it sounds like—

Miss Johnson: VAD-specific as well. I just wanted to point out Grieffline. Their submission had a lot of information about the barriers to carers and family members accessing specific bereavement supports, because a lot of the mainstream supports have so much stigma attached to that.

MR COCKS: Yes, and it sounds, from the submission, like that stigma can apply equally if someone did not support the decision for assisted dying.

Ms Kelly: Yes. I think carers are stuck between a rock and a hard place in this. Unless you have a family situation and a friend situation and a neighbourhood situation where everybody is agreed that, yes, that this is the way we are going to die and this is the end point, then someone is always going to be annoyed by what happened. Unfortunately, it is human nature for us to then turn around and look at who we can blame. Our concern is that that will end up being the carer: “They did not do enough. They should have cared more.” What we hear a lot is: “The carer must be relieved the person is dead.” Regardless of VAD or not, no-one is relieved that someone is dead, so why is it that we see that as a response that is appropriate or suitable? Our concern

is that, in VAD in particular, those internal moral and value-based reactions will come forward and they will come forward as verbal commentary about the person who was closest—often that being the carer.

MR COCKS: Yes.

DR PATERSON: It must come up very regularly, though: conflicts or different points of view on the medical treatment of the person who is being cared for.

Ms Kelly: Yes.

DR PATERSON: I imagine that there is a lot of this process. By the time you have got to a voluntary assisted dying situation, they have likely navigated perhaps years of discussions and working to navigate medical care for an individual.

Ms Kelly: I think we assume that. If the act was working beautifully and wonderfully, yes, I would agree. However, there are GPs that say, “I don’t speak to the carer. They are not the patient. The Medicare bill is going to the person who has the health condition, not the carer, so why would I speak to them?” We see that oncology and those sort of places work quite well because they are used to having lots of people involved, but in lots of other areas of health, no; we are not there yet.

We still see people prescribed medication and the carers not necessarily being engaged in what is the impact of that on them, what is the change of that medication going to do to them and to their daily life. I have seen examples where the administration of medication is changed from oral to injection, and the carers have gone to pick up the prescription and nobody has actually explained to them how to do that—what to do, how to administer it or whether they are okay about administering or not administering. Until we have a better sense of inclusion with carers in health all the way through, I think we cannot assume that they have always been fully involved.

I remember doing some work with palliative doctors. Part of that was role-playing the engagement of carers in conversations around palliative care, and particularly when medical interventions were coming to an end. Those doctors, who are brilliant—they are brilliant doctors and I do not want to take away from them—really struggled to know what to do with the carer in these role-plays, because they are not their client, and they are not their patient. They could not understand why we were saying, “The more the person with the health condition is declining, the more you actually need to engage the carer and ask, ‘What are you doing about yourself? What are you doing to look after you?’” They really struggled because that is not what they are trained to do. They are trained to diagnose, medicate and move on. That emotional support stuff is often not part of that.

MS CASTLEY: My question is around carers that conscientiously object. What do you think the legislation should do to deal with such a scenario? If we are saying carers need something a bit more stringent in the bill, if that is the case and they are conscientiously objecting, what do you think that should look like?

Ms Kelly: At that point, whether they are conscientiously objecting or objecting generally, I would say that the decision still needs to come from the person who is

dying. They need to be the voice that we follow. The support that I would then want to put in place is making sure that the carer has some counselling, to say, “How are you going to cope with this?” If you are sitting over here saying, “No way; never,” and this person you care for in life is saying, “Yes,” how do I help you reconcile that so that on the deathbed, for want of a better term, we are not fighting? How can I come to a resolution with your decision so that we can end together in a nice way? For me, that is again about preventing the complex grief: how do we keep doing anything we can in that space?

MS CASTLEY: Yes, which is back to your point about taking care of them.

Ms Kelly: Yes. I want to be on record and be really clear because I think carers have copped a little bit of stigma in this discussion. We are not advocating that the carer has the right to make a decision. We are definitely not advocating that. We are advocating that the person who is dying is the only person who has the right to make that decision.

THE CHAIR: Ms Kelly, can I just clarify? Recommendation 13 in your submission says:

Ensure the Bill upholds the rights of carers to have their social wellbeing and health recognised in matters relating to the care relationship, in accordance with the *Carers Recognition Act 2021* (ACT).

That, to me, seems like a summary of what you have been saying. It is not about the person who is making the decision; they have their rights under the bill and that is to be respected. It is just about making sure that this other person with a significant relationship to them has those additional supports—

Ms Kelly: Is seen—yes.

THE CHAIR: to get through the process.

Ms Kelly: Yes; absolutely—and that the act is balanced in terms of seeing the carer not just as a source of coercion but actually as a source of support.

THE CHAIR: There are two parts to it, if I understand correctly. The first is making sure that the needs of the carer are maintained throughout what is quite an emotionally charged process. The second one is making sure, if I have understood correctly your evidence, that the bill does not inadvertently create a legal liability on a carer.

Ms Kelly: Yes, or a stigma—both parts of that, I think.

THE CHAIR: Thank you. We have spoken quite a bit about the first issue, but in the few minutes we have left could you run us through some of the main issues you see there, as to where there might be, say, a legal liability imposed on a carer that is inadvertent?

Ms Kelly: Yes. Do you want to start?

Miss Johnson: Sure. I think that we can all assume that when self-administration has been chosen as the process for VAD, the carer is most likely to be the contact person. As a contact person there are a lot of liability offences that go with that. I think that that is a very, very big one. The objectives of the act talk about protecting medical professionals engaged in that but do not mention anything about protections for contact people or carers. I think that is the main thing there.

Ms Kelly: Yes. I would agree with that. In the legislation, where those protections are provided to health professionals, we advocate that they extend to unpaid family carers as well and that those protections are in place there.

THE CHAIR: Great. That definitely met the brief within the few minutes we have left, so thank you.

Ms Kelly: Perfect.

MR COCKS: It sounds like one of the big concerns around those offences is the strict liability aspect that says that offences do not depend on actual negligence or intent to harm.

Ms Kelly: Yes.

MR COCKS: Is that a significant concern?

Miss Johnson: For me, I think it is the two days to notify of a death happening, and the liability offences that go with coming outside of that two days. That is my biggest concern.

THE CHAIR: So it is about seeking further clarification on how that would be applied in the instance of a carer having a role in the process?

Ms Kelly: In the administration, yes, and then protecting that carer from any action, even civil action that might be taken by another person who disputes that.

THE CHAIR: Yes—where you could have two children who are of different views, for example?

Ms Kelly: Yes.

THE CHAIR: Yes; okay. In the minute we have left, is there anything that either of you would like to add that we might not have covered today?

Ms Kelly: Probably the thing we would stress the most is that there need to be provisions for people who have cognitive decline and who may not be competent at the time that they wish to administer VAD. Otherwise, we have ruled out a range of people that carers have been asking for a long time for VAD to apply to, and we have narrowed the field down to a point where it is questionable about who this would benefit in the long run. We also think that the process is onerous. We think that three asks, in that way, is a long and drawn-out process to prevent coercion. We would encourage a rethink about whether it could be a more simplified process than that.

THE CHAIR: Great. Thank you very much. On behalf of the committee, I thank you for your attendance today. I do not believe there were any questions taken on notice. You will be sent an uncorrected proof transcript for you to read over. Thank you again for your attendance.

Ms Kelly: Thank you for the invitation.

Short suspension.

TORRESI, MS KYM, Senior Adviser, Aged Care, Speech Pathology Australia

THE CHAIR: I now welcome our witness from Speech Pathology Australia, Ms Kym Torresi. I would like to remind you of the protections and obligations afforded by parliamentary privilege and draw your attention to the privilege statement. Witnesses must tell the truth. Giving false or misleading evidence will be treated as a serious matter and may be considered contempt of the Assembly. Please confirm that you understand the implications of the statement and that you agree to comply with it.

Ms Torresi: I understand and I agree to comply.

THE CHAIR: Thank you very much. We are not inviting opening statements; however, you are welcome to either table it or provide it to the secretariat if you have one. We will jump straight into questions. We will lead off with Ms Castley.

MS CASTLEY: Thank you for your submission. I want to jump straight to your concern about the need for speech pathologists to be listed in the list of relevant health professionals. Are you wanting to make that more formal or is it just that you want clarification that they are part of that cohort?

Ms Torresi: From a Speech Pathology Australia perspective, having more formal clarification within the bill would be of great assistance. Under the section that that was referring to, section 152, specifically in relation to who can initiate conversations around voluntary assisted dying, at the moment the bill talks to health practitioners and then it also identifies counsellors and social workers as potential groups of people who are able to be part of that.

In our submission we talked a little bit about the background of speech pathology and why we are quite intricately involved in both the conversations a lot of the time with our cohort but also in providing the support for that person to access the first request process. As speech pathologists, we often work really closely with those cohorts of people, such as those with neurodegenerative conditions like motor neurone disease or brain tumours et cetera who have communication and swallowing difficulties as part of their presentation.

As a speech pathologist, what often happens is that, because I am there providing those supports, strategies and assistance, clients have often divulged things to me as part of that process because I am providing those strategies that they need to get their message across. At the moment, in the bill, the requirements that you have set out do not apply to speech pathologists per se in relation to making sure that you notify them to speak to their treating doctor and provide them with information that there are a variety of choices but also the opportunity to support that person. Typically, if we are then supporting that person with a communication aid, for example, it is the speech pathologist who needs to program the vocabulary into the communication device. Without that communication device, the person may not be able to clearly make their wishes known to the medical practitioner to seek voluntary assisted dying.

So it is more the sense that that could be perceived, under the bill, as initiating the vocabulary associated with voluntary assisted dying. For that reason, we have found

in other jurisdictions that we are not really adequately incorporated or protected under the bill. We would suggest that, in that case, just as counsellors and social workers and self-regulated professionals are stipulated, speech pathology as a self-regulating allied health professional should also be stipulated in that section.

MS CASTLEY: I am happy to be corrected on this, but my understanding would be that speech pathologists would then be taken up into that strict liability. If you had a speech pathologist that is a conscientious objector and says no, they then have two days to make the referral; otherwise there is that strict liability. Have you considered that for your speech pathology group and do you believe that that two days is an appropriate amount of time?

Ms Torresi: My understanding of the bill currently is that it does talk to health service providers also having the capacity to conscientiously object and, according to the current definitions, that is where speech pathology sits. I am not necessarily suggesting that we specifically be elevated into the health practitioner general conversation but just that, in that specific clause under section 152 where it says, “health practitioner or counsellor or social worker”, that be added as an “or”. I am not sure if that means that you are saying that that does take us up to the strict liability. If so, I think Speech Pathology Australia would support the notion that we would also have that duty to connect our clients to the supports for them. It is part of our code of ethics to do that sort of process anyway. We will take your comments on notice about the two days, but, yes, I guess that would be something that we could support in terms of the process.

MR BRADDOCK: In your submission, where you are talking about communication aids and strategies, you make a link to the South Australian legislation. I have that in front of me. It says that “a person may make the request verbally or by gestures or other means of communication available to that person”. Is that the sort of language you are looking for?

Ms Torresi: In the submission, we were specifically commending that you have included those alternative ways of communication through lots of the stages of the bill. The only place that we were suggesting that that could be strengthened was particularly in the section around capacity assessment, because it is often overlooked, even at that stage, that somebody will still need access to the right sorts of communication supports to demonstrate their capacity. Often it is assumed that, if somebody has little or no speech, they may not have the capacity to make their own decisions. So that person, at that stage, needs to be given the opportunity to have access to the aids. Our submission was really referring to that capacity stage. As you say, that is an example from the South Australian bill that could be used in that case.

MR BRADDOCK: Another section of that South Australian bill talks about the decision-making capacity and also talks about using modified language, visual aids or any other means.

Ms Torresi: Yes; that is right. It has that additional level of support to people around thinking about that point.

DR PATERSON: I thought it was very interesting that, in your submission, you were

talking about people automatically assuming that, because you do not have speech, you have impaired decision-making capacity. Are there issues that have come up, given that voluntary assisted dying has been implemented in other jurisdictions, that you think would be important for us to be aware of here in the ACT?

Ms Torresi: From our perspective, a key point is to ensure that communication accessibility message, such that somebody with little or no speech is not disadvantaged in terms of their access—that they are going to be able to have equitable access to the scheme at whatever point. I think the bill is generally trying to do a really good job at considering that point. On the ground, it would be that point that you have just made about getting that message into practice around acknowledging that people may have capacity. That is why I have particularly spoken to the examples in the capacity assessment in that previous point.

For us, the only other main issue that we are seeing is the concern, particularly in the states, where it has been quite specific that the person must use certain vocabulary as part of their request and where that has been challenging for speech pathologists to be involved in supporting electronic communication aids and speech-generating devices that need that specific vocabulary put into it for the person to be able to ask for it in the first place. Once the person has asked for it, we can be involved in it as part of our usual process of supporting the person's communication along the way and supporting the medical practitioner to understand how best to communicate with a person. It has been that sticking point in terms of that initial access, really.

MR COCKS: Thank you for taking us through the role of speech pathologists. I have to admit that it was something I was struggling to understand before you took us through it. It sounds like the legislation as it currently stands does not adequately account for adjunct-type roles, roles that are not the primary healthcare providers but, as in your case, sit alongside those discussions. Do you think there is potential to have specific provisions that would provide for and protect speech pathologists and similar professions that are not exactly the same as those that you would expect for a GP or other medical professional?

Ms Torresi: That is a really good point. It is something that we have been really grappling with as we have looked through all of the different legislations, because speech pathologists are part of that multidisciplinary team that wraps around this person. Communication and swallowing are both really critical elements to the voluntary assisted dying process, both in terms of being able to communicate your decision and your wishes as well as being assured that we have got an understanding that you are going to be able to safely swallow the medication, for example, for those people who have swallowing disorders. Often our role in providing that swallowing assessment assists the medical practitioner to determine the root of administration. As you say, we are not the first line of coordinating consulting practitioners, but we are inputting information into that process. It is an important thing to recognise.

I would say that the ACT bill does not present us with as many concerns in that way as some bills that have talked about registered health professions across all of the areas of liability, protection from liability, conscientious objection et cetera; it is only registered health professionals, and that is of concern to us. Wherever there are those aspects of registered health professionals, we are just asking for that to also

acknowledge the self-regulating health professions like speech pathology within that context. It seemed, from our understanding, looking at the draft bill, that most of those areas had enough provision for us potentially. It was potentially just in initiating the conversation that we could not quite see ourselves. If that is the case, if it is a matter of being able to include us specifically in there, hopefully that means that we will be included throughout those core aspects without necessarily needing a separate section.

MR COCKS: In parallel with the specific role that the speech pathologists undertake, are there particular training elements that would be unique in how to deal with voluntary assisted dying that would need to apply to anyone who was going to work as a speech pathologist engaging with these issues?

Ms Torresi: As a self-regulated profession, we have the certified practising speech pathology credential. That is the credential that Speech Pathology Australia oversees, and we do the auditing of somebody meeting those requirements. Those requirements mirror the Ahpra registration process. Those requirements include things like insurance, that somebody has the appropriate qualifications, that they have got the right level of recent practice, that they are doing the specified number of hours of professional development et cetera—all of those requirements that you get under the registered professions.

From Speech Pathology Australia's perspective, we would say that the certified practice and speech pathology credential should be embedded as part of the regulations to ensure that you have that robust governance process over the speech pathologist engaging in that process of supporting voluntary assisted dying. As part of that, Speech Pathology Australia would be undertaking those audits et cetera where somebody is identifying appropriate professional development in areas. For example, augmentative communication might be one of those things that we might see working with somebody with little or no speech.

MR COCKS: Do those credential requirements include how to deal with the ethical considerations that would come up with respect to assisted dying?

Ms Torresi: Good question. We would say that speech pathologists all have a base level of skills and competencies to be able to meet the clinical needs of this cohort of clients. In terms of the additional considerations that you mentioned—ethical considerations et cetera—and, in thinking about what the specificities are in terms of our role, Speech Pathology Australia is engaging in providing a number of different professional development opportunities for our members. We have provided written information; we have run workshops at our national conference and so on. That would be something that we would see is available to those members.

MR COCKS: Just to confirm: it is not in the credentialing at the moment?

Ms Torresi: The credential of a certified practising speech pathologist just refers to those same requirements as a registered health professional. It is not a credential around the voluntary assisted dying practice per se or a clinical area of practice. So, no, it does not have that specificity to say that a person has a credential in that area. That would be part of their development plan. We have, as part of our categories, the option for somebody to identify that they would be supporting people undertaking

voluntary assisted dying, and then there would be the expectation as part of that auditing to see that they are undertaking professional development that relates to that area of practice. There is nothing mandatory, if that makes sense.

MR COCKS: Thank you.

THE CHAIR: A little bit earlier, we had the pharmacists in, and it was quite interesting hearing from them. I think they characterised it as: they liked protocols, and they just wanted to be very clear on what their role was and how to meet their obligations and not to put themselves in a situation where they inadvertently did something incorrectly because they were not aware of the process or the limitations that they had to work within. In reading your submission, I was struck that there are a few of the same core issues there in acknowledging that speech pathologists will have a role in the process that is quite specific, and just wanting that clarity around how to operate within the role so that they are meeting the obligations and expectations placed on them.

Ms Torresi: That would be something that we would really welcome, yes. Our crossovers with pharmacists are often also around the swallowing aspect, where somebody does have a swallowing difficulty. We would welcome the opportunity for that clarity that we try to get out there to members—for example, it is not our role to be determining the route of administration, but it is our role to provide an assessment of swallowing and provide that information that then can be used by the consulting and coordinating practitioners to work towards deciding that route of administration. So clarity around things like that would be welcomed. Perhaps some further guidance materials as well would be really useful.

THE CHAIR: Would that cover off on the main considerations that you have raised in your submission—having that clarity about the role of speech pathologists in the process around what their responsibilities are and where their obligations do and do not extend to?

Ms Torresi: I think that it would support a number of the issues. There is also the issue of protection around the initiating conversations, because the vocabulary on the communication devices is still a bit of a live issue in terms of legislation, and ensuring that we are recognised there by being protected from any civic prosecution or whatever.

MS CASTLEY: My last question is around the differences in the bill for the ACT, compared to, say, the New South Wales jurisdiction. Do you see any concerns with that? A few people, in their submissions, have said they should be a bit more aligned to other jurisdictions. What are your thoughts? We might have an ACT person seeing a New South Wales speech pathologist and vice versa.

Ms Torresi: That is a really good point. Because of that closeness, that is a really good point. There is certainly an argument to be made for having that aligned as much as possible. Certainly, in the New South Wales legislation we have the opportunity to be involved in that initiating conversations bit. We do not have those same concerns with that legislation. It would be something that would be quite different and it would impact the way somebody practises quite markedly to have those differences in the

bill. I agree that there would be great benefit in having alignment there.

THE CHAIR: We have a few minutes left. Is there anything that you would like to add that might not have been covered?

Ms Torresi: I think that we have covered the key points in our submission really well. There were three core areas of recommendations, and we have probably talked to all of those so far. We really appreciate the opportunity to speak to you and to put forward this area, because it is often an area that is not necessarily very well known, but it carries a lot of significance for those people who do have speech and communication difficulties to feel as though they might be losing the opportunity to access voluntary assisted dying. That is something that we have heard some feedback on—that people do not realise that there is that capacity within the bill to enable that. There is a little bit of fear for those people to think that they must get in really early or they are going to miss out because their speech is impaired. It is a great opportunity that that has been recognised and to ensure access for that cohort. Speech Pathology Australia would really thank you for that opportunity.

THE CHAIR: Thank you. On behalf of the committee, we thank you for your submission and your attendance today. If you have taken any questions on notice—and I believe you have taken one question on notice—we would ask that we get that back as quickly as possible. The committee secretariat can help with the time lines and the processes.

Ms Torresi: That would be great.

THE CHAIR: It will be five business days upon receiving the uncorrected proof, which will be sent to you. If you do have any questions, if it is a bit of a new process for you, feel free to reach out to the secretariat. I am sure they are happy to provide guidance. Once again, thank you very much for your submission and your testimony today.

Ms Torresi: Thank you so much.

Short suspension.

WALLACE, MR CRAIG, Head of Policy, Advocacy for Inclusion

THE CHAIR: We now welcome the witness from Advocacy for Inclusion. I remind you of the protections and obligations afforded by parliamentary privilege and draw your attention to the privilege statement. Witnesses must tell the truth. Giving false or misleading evidence will be treated as a serious matter and may be considered a contempt of the Assembly. Please confirm that you understand the implications of the statement and that you agree to comply with it.

Mr Wallace: I confirm that I understand the implications of the statement and I agree to comply.

THE CHAIR: We are not inviting opening statements. However, you are welcome to table one or provide it to the committee secretariat. We will proceed straight to questions. Ms Castley will ask the first question.

MS CASTLEY: Thank you for joining us. My question is on eligibility. I note that in your submission you say that AFI does not support access to voluntary assisted dying being expanded beyond the scope of the Victorian legislation. Can you expand on that for me, please?

Mr Wallace: Yes. The Victorian legislation has a time frame requirement that a person needs to be within six months of their expected death. The ACT's does not, but the ACT's does have a requirement that on paper excludes disability from voluntary assisted dying. But if you take the time frame requirement away, there is nothing that distinguishes the meaning of disability within the ACT Discrimination Act—which is cited within the draft bill—from the eligible conditions that might be brought into scope for voluntary assisted dying. I am happy to expand on that, if you like.

MS CASTLEY: Yes, please.

Mr Wallace: Within the Discrimination Act, disability means something like, for instance, total or partial loss of a bodily or mental function, a part of the body, a progressive disease, disease-causing organisms, or a malfunction, malformation or disfigurement of a part of the body. All of these things, in the real world, involve some level of real or anticipated suffering. Most of them are not treatable. Most of them shorten the life span over time.

We would argue that the bill, as it stands, does not, in any meaningful way, exclude disability from being eligible for voluntary assisted dying because it does not have the time frame requirement. There is no formal definition that I have been able to locate that distinguishes a terminal illness from a degenerative disability that is likely to lead to death.

My disability will shorten my life span, but do I have a terminal illness that I would want to address by seeking voluntary assisted dying? At this point, no. But there were times when that disability might have been intolerable to me and, if this legislation had been present, I might have sought voluntary assisted dying, and I would not be giving evidence to you today. That is where our problems with this lie.

THE CHAIR: I want to clarify a few things, because it is an important line of investigation. Your proposition is that the bill, as it stands, means that if you have a disability that in itself can count as a reason to access the voluntary assisted dying scheme. Have I understood that correctly?

Mr Wallace: In the real world, yes. On paper, the draft bill says that if you just have a disability within the meaning of the act—which is an anti-discrimination offence; it is not a diagnostic tool—you are not eligible. In reality, for most disabilities that people have, not having the time frame requirement brings many within the scope of the act.

THE CHAIR: Part of the reason for my line of questioning, and what I am trying to get my head around, is that we have heard from a lot of people that they do not actually support having the time line there. I can appreciate that you have a very different view. Are there safeguards or checks and balances that you believe could be in place that do not involve a time line?

Mr Wallace: Yes; we have outlined a range of those in our submission. We acknowledge that the bill is likely to be passed, and there is likely to be VAD in the ACT. We do not actually have a position on whether the bill should be passed or not, but we do think there are conditions, supports and circumstances which would mean that it was far less likely to have unintended outcomes for the people that we care about and represent.

The major one would probably be that we think anybody that is considering voluntary assisted dying should be asked whether there are any disability, mental health, psychosocial supports or suicide counselling assistance that might avert that decision. If they answer yes, they should be offered, and the offer of those should be mandated within the bill, and the maintenance of a fund to ensure that people do have those emergency supports should be provided for in the bill. We also think there are a range of other supports and measures that should be taken by government to rule out unintended consequences here.

THE CHAIR: The unintended consequences that you reference are the ones in your submission that go to, I think it is fair to say, what is so far anecdotal evidence coming out of the Canadian scheme. Is that what we are looking at here or is there something more?

Mr Wallace: It is not anecdotal. People have actually been offered medically assisted dying in Canada instead of disability support. In Canada, people have gone along to their disability or healthcare provider and said, “I need a pressure-based water bed”—I think that was one of the cases—“and I need some housing modifications and a wheelchair that is sculpted in such a way that I’m not in pain all the time.” The provider has said, “We can’t provide that, but here’s some information about medically assisted dying. Why don’t you consider doing that?” I say that should be illegal. We should create an offence around a provider actually doing that, and we should do everything possible to ensure that people get supports and are not softly coerced into voluntary assisted dying.

THE CHAIR: You say this is not anecdotal. You say there is evidence of this. Are

you able to provide copies of any of the reports or reporting that go to this matter so that the committee has reference to these examples?

Mr Wallace: Yes. There may be some things in my earlier submissions. I am happy to do that. They will be media reports, but that is enough for us.

THE CHAIR: That is fine; so that we have it handy.

Mr Wallace: People with disabilities in our community talk about it.

THE CHAIR: You noted coercion, and soft coercion, that you do not want to see occur. I am trying to test your view on this, because you are talking about how it would be applied in practice. One way of reading the bill is that, because the person has to initiate the conversation on voluntary assisted dying—the person who wants to undertake it—if a health practitioner put it forward as an option, that would already be a transgression under the bill. Because coercion is an offence, if it was going down that path there are liabilities and avenues within the bill to deal with that.

My question to you is: how do those checks and balances that are already in there assist or not assist with the scenarios that you are currently putting forward and advocating to have better precautions against?

Mr Wallace: My general thoughts on this would be: if a disability provider is having a conversation about the range of supports that are available to a person, and the limits on those supports, and provides information or talks about voluntary assisted dying being available, does that meet the test of coercion? I was not confident about that, because it kind of does.

THE CHAIR: That is the question that you are putting to the committee and asking us to test—whether that is a scenario that would be able to be prosecuted under the definitions of coercion.

Mr Wallace: Yes. I am not convinced, from my reading of the bill, regarding what I am calling soft coercion. You can imagine being in a conversation where you have acquired a disability, you are in pain, the world looks really grim, and you are looking to get your house modified so that you can move back in and rebuild some quality of life. They say, “No,” and then they say to you, “By the way, there is this other option, which is ending your life.” You might take it. That is what I am wanting to avert.

THE CHAIR: I do not think anyone would say that that is unreasonable. My reading of the situation, though, is that service providers could not then come back and say, “Here’s another option you might want to consider,” and that it needs to be instigated by the individual. But I am happy to put the question to the government and see how they would approach this situation.

MR BRADDOCK: Continuing on that theme, your submission states that you prefer a direct prohibition being made around this issue. The direct prohibition would be around those providers who offer VAD in place of other disability supports; is that what you are seeking?

Mr Wallace: I do not think any disability service provider should be able to initiate or talk about voluntary assisted dying with a person that they are providing supports for. It should be an offence.

MR BRADDOCK: I wanted to clarify that and make sure I understand what you are seeking there.

DR PATERSON: The Disability Health Strategy and the ACT Disability Strategy form a large part of your submission, in terms of the lack of progress in the ACT. Can you speak to how important you see that being, going forward, in terms of having these discussions with the disability sector around important issues like voluntary assisted dying?

Mr Wallace: We bring this into scope in our submission because the reality is that, for many people with disabilities, we are in the path of conditions that are avoidable, like cancer, because we cannot screen for them or be treated for them. I can personally attest to this. At the moment I would need to do an overnight stay in the Canberra Hospital for some serious possible conditions, and the environment there is not acceptable. I cannot get on the bed; I would not be able to use the shower. The toilet would be difficult for me to use, and there would be a reasonable likelihood that I might sustain a serious injury.

The issue is that people with disabilities are unable to access screening. They did a survey—I can provide this to the committee—of up to a thousand doctors' examination beds around Australia and found that only a relatively small number of them were accessible to people with disabilities. The bowel cancer screening kits that people are offered cannot be used by blind people because the instructions are inaccessible and they have sharp bits that people with sight impairments cannot use. There is a stack of poor health practices that mean we wind up with things like cancer, that are clearly in the remit of the bill, at a greater rate than other people. Because of that, we need a health strategy.

We also need a health strategy to overcome some of the attitudes that health professionals have. One of the things that we said in our submission is that all of the health practitioners who are prescribing voluntary assisted dying should have some training on the social model of disability. That is because people with disabilities who go into hospital are often confronted by doctors who believe that they have minimal life chances, and that it is not worth attempting surgery on them because their quality of life is too low. People are offered “do not resuscitate” orders when they have not asked for “do not resuscitate” orders. There is an assumption that someone with a disability will have poor quality of life. If you add that to legalising physician-assisted suicide, we see a danger there, and we see that there needs to be an intense program of work on a disability health strategy before a bill like this is enacted.

MR COCKS: Thank you for your submissions, both this submission and the one you referred us back to—the original substantial submission that was intended to inform development of the bill. Those two submissions combined raise some really insightful points around how the life of a person with a disability is valued, what it takes for assisted dying to be voluntary, and the types of risks that we face with this bill. In your submission to this inquiry, you point out that the bill does not meet the tests that

you set out in the original submission and that it widens eligibility. It seems that one of the big concerns is that those involved in the decision-making process may not appropriately value the life of a person with a disability or appropriately assess quality of life. I was wondering if you could talk to how the inherent power imbalance that can happen in those conversations could influence this, and what risks might arise.

Mr Wallace: I can certainly talk to that. Thank you for the question, Mr Cocks. Imagine that you have just acquired a disability in a serious accident. All of a sudden, you are quite vulnerable, you are in a hospital and you are heavily reliant on the advice of a medical practitioner. That particular practitioner is often, by necessity, an able-bodied person who is relatively well-off. You have suddenly lost your income and you have carers and family around you who might be wondering, “How am I going to take care of this person and support this person through what comes ahead?”

There is a range of assumptions and a range of pressures that bear down on a person in that circumstance and, particularly as we are talking about anticipated suffering in sections of this bill—an anticipated intolerable level of life—which means that those assumptions are really important to us, we would certainly be concerned that those assumptions may mean that people choose voluntary assisted dying. For instance, our experience often is that, if you talk to a person with a disability at the time that they have acquired their disability about what their life might look like, they might say, “I don’t want to be here anymore. I’m not going to be able to put up with this. It’s not going to work for me.” But if you talk to them later, after they have accessible housing, a peer support network, they have recovered so that it is a disability and not a critical health event and they can go back to doing sport and working—albeit it is a different kind of life to the life they had previously—in, say, two years, that person will say, “Thank God someone talked me out of it at the time. I’m glad that I am still here and able to connect with my family and enjoy the things that I have always enjoyed doing.”

I do not feel that I have answered that question very well. I hope I have given you a bit of a sense of where we think some of the pressures are, particularly about what happens at a point in time when a person thinks they are going to lose their income, are in pain and are losing quality of life. Doctors are really awful at some of this stuff, such as the assumptions that they make around some of our people. We have people with paraplegia who go in with a broken leg and the doctor says to them, “Are you sure you want to be resuscitated? Are you sure that you want this treated?” They are assuming that the person has a terrible quality of life. We hear about this in our daily advocacy work all the time. This is a really toxic attitude—an ableist attitude—to people with disabilities, and we are concerned that that is going to play into the operation of VAD if it comes to pass here in the ACT.

MR COCKS: It sounds like it would not matter whether those conversations were well intentioned or not. The raising of VAD simply as an option could be damaging in itself.

Mr Wallace: Somebody is vulnerable when they are looking down the barrel of a disability that they do not understand and when they have not talked to another person with a disability, like me, who can tell them, “Actually, your life is going to be different, mate, but you will have a life. You will recover from this. You will be able

to get around, you might be able to work and you can even have a family.” If that conversation happens at the point at which the person is really vulnerable, yes, I am really concerned about it.

MR COCKS: Are there other complicating factors that can exacerbate that at any other time, other than just when someone is first experiencing disability?

Mr Wallace: Life can be intolerable for people because they are in poverty, they are in bad housing or they do not have any friends, because the friends that they had before they had a disability have dropped away, or they are depressed or have no social supports. It is particularly the case in hospital, let me tell you. I have just spent seven months, and in a lot of advocacy before that, dealing with the Canberra rehabilitation hospital, where most people with a disability go after acquiring a disability. There is no community development and no social support there. It is no wonder people want to “off” themselves. It is such an isolating experience with no support for people. That needs to be in place before we start suddenly offering people an easy but really toxic way out from disability when people could be living good lives.

MR BRADDOCK: We have received a range of submissions. Some groups have been calling for expansion of eligibility to include, for example, those with lost capacity, and more so for reductions in what they call the red tape—for example, going from three requests down to two. Can you please provide your perspective on those calls?

Mr Wallace: I do not have a perspective on the number of requests, but Advocacy for Inclusion does not support making voluntary assisted dying available to people with limited decision-making capacity, children, people with dementia or people with intellectual disabilities where there is no decision-making capacity. To us, that is not something that is responsible, ethical or appropriate. We can imagine that being quite easily abused in the case of those people.

THE CHAIR: Mr Wallace, with respect to some of the testimony that has come up, these are very complex situations to write regulation for. I want to test with you the idea that perhaps it is not necessarily about trying to write the perfect system and that the answer might be that there are certain points where it is not appropriate to discuss this, rather than trying to create a system that allows for discussions to happen at any point. I want to test that idea with you.

You were using examples of when a person, as a result of an accident, first becomes disabled—that it is a lot to deal with emotionally and that their perspectives might change over time. It was in my head that maybe it is a case of saying it is not appropriate to discuss voluntary assisted dying when someone is not in a fit mental state, which, arguably, that would be. That is the sort of thing that we need to explore, rather than saying, “This is when you would discuss it.” Does that make sense? It is a bit of a thought bubble, so it is not the world’s most formed question. Do you understand what I am saying? It is more about saying that we know that there are certain points when people are perhaps emotionally or psychologically not in the right place to make these decisions and that perhaps we need to explore them a little bit more and say they are not appropriate times to have the discussion, as opposed to

looking at other avenues for addressing the concerns that you have raised.

Mr Wallace: Yes. It might also be when a person's condition changes or deteriorates. If you have a disability, a relatively minor change in your functioning can suddenly become really critical. I often wonder what would happen if I broke a finger or a hand, for instance, because I might need to drive, get around and transfer. I think there are specific vulnerabilities. I also think the conversations need to be had at the same time as conversations about what else we can do, which is why we have called for the bill to include a stipulation, a requirement, that people be given a support offer with some alternatives at the same time. If you said to somebody, "What would it take to make your life livable?" it might be that they say, "Nothing; nothing can do it." But other people might say, "Actually, if my housing was stabilised, if I had some additional pain relief, if I could talk to other people with this condition, if I were able to get out once a week, and if I had some hope and some opportunities for joy back in my life, I would not choose this."

Those are supports that are in the remit of disability providers like the NDIS and the new foundational supports that the ACT government is going to put in place, so we would argue that every effort should be made to do that as an alternative to voluntary assisted dying and that there should be a trigger to offer those things at the point at which that is being prescribed and enabled.

DR PATERSON: I am a bit concerned about this discussion. I think the bill clearly outlines relevant conditions. I do not think it can just be a circumstance. You have to demonstrate an advanced condition, a progressive condition that is expected to cause the individual's death. I take your point about what is going on in Canada. There have been some examples of how the legislation has played out there, not just for people with a disability but for people with mental illness as well, that are pretty concerning and that pretty well compare to what our bill here is trying to achieve. In terms of how the bill can be strengthened and improved, there is quite a different context between what is happening in Canada and the ACT bill. Have you engaged with colleagues in other jurisdictions around Australia that have had voluntary assisted dying legislation in place for a while? Have they seen some of the issues that you have outlined occurring in those other jurisdictions?

Mr Wallace: Thanks, Dr Paterson. They have not had it for that long. In Victoria, it is relatively new, so we do not have a lot of intel on that. The key difference is that the ACT is removing the time frame. We would argue for all the tests that show muscular dystrophy, cerebral palsy, spina bifida or Down syndrome are advanced conditions. Down syndrome lessens the lifespan of a person over time. You could argue that is actually a terminal condition. Many disabilities cause suffering that a person might regard as intolerable at a point in time. If you remove the time frame test, in my view, it brings culminating disabilities into scope. I have tested this against the wording in the legislation several times in my head and I am having a lot of trouble ruling out a whole range of disabilities where I know people can lead quality lives if they get the right levels of support and pain relief.

DR PATERSON: There is an oversight body. Do you think that there could be more strengthening or that those sorts of oversight processes could be adjusted to perhaps address some of the concerns that you have, particularly around the time frame issue

around some illnesses?

Mr Wallace: Yes. We think that both the oversight body and the review board should have a person with lived experience. I was listening earlier. They talked about a person with lived experience, which was interesting, but there should be a person with a disability who operates from a social model perspective on both the review board and the oversight body. I am sorry if I am getting those mixed up. I saw some of the earlier evidence that says that the person should have a particular bent towards enabling access. Actually, I think you need someone on there with a critical eye—somebody who can look over this and say, “Actually, that was a person with a disability. If we provided that person with the right interventions at the right time, that might not have been necessary or appropriate for them. What can we do, as we move forward with this, to prevent more adverse outcomes like this?” It needs to be somebody from the disability rights community with a strong understanding of the social model and CRPD who can cast a critical eye over all of them.

THE CHAIR: We will have to wrap up now. Apologies if members have more questions. Mr Wallace, thank you for coming along today. I believe you took one question on notice. The secretariat can follow up with you on that one. We will need it within five business days of receiving the uncorrected proof transcript, which will also be sent to you for checking. Once again, thank you for your attendance today.

Mr Wallace: Thank you.

Hearing suspended from 3.01 to 3.47 pm.

BARAKOVSKA, MS IZABELA, Chair, ACT Ministerial Advisory Council for Multiculturalism

WONG, MRS KUI FOON, Council Member, ACT Ministerial Advisory Council for Multiculturalism

REDDY CHINTALAPHANI, DR SHANTI, Co-Chair, ACT Ministerial Advisory Council for Multiculturalism

THE CHAIR: Welcome back to this public hearing of the committee’s inquiry into the Voluntary Assisted Dying Bill 2023. The proceedings today are being recorded and transcribed by Hansard and will be published. The proceedings are also being broadcast and webstreamed live. When taking a question on notice, it would be useful if witnesses use the words, “I will take that question on notice.” This will help the committee and witnesses to confirm questions taken on notice from the transcript.

Voluntary assisted dying is a sensitive topic. The secretariat has information on support organisations available for witnesses or other people attending this public hearing who are impacted by any of the issues raised.

We will now hear from witnesses from the ACT Ministerial Advisory Council for Multiculturalism. I remind all witnesses of the protections and obligations afforded by parliamentary privilege, and I would like to draw your attention to the privilege statement. For those who are here, it is on the table in front of you; and, Izabela, you should have been sent a copy. Witnesses must tell the truth. Giving false or misleading evidence will be treated as a serious matter and may be considered a contempt of the Assembly. Can you please confirm that you have read and understand the privilege statement?

Mrs Wong: Yes.

Dr Reddy Chintalaphani: Yes, I agree.

Ms Barakovska: I confirm that I have read and understand it.

THE CHAIR: Thank you very much. I note that you have provided the committee with an opening statement. We ask that you do not read your opening statement, but the committee will take that as an exhibit to the proceedings and will read it a little bit later. We will go to questions. To mix it up for the afternoon, we might start with Mr Cocks and work our way to this end of the table.

MR COCKS: Thank you for the opening statement you have provided this morning. I am very interested in the additional complexities that arise in multicultural communities, in particular some of the barriers and considerations you have outlined. Could you talk a bit about the types of cultural stigma and taboo issues, as well as the information and language issues that you have said are highly concentrated in multicultural communities?

Ms Barakovska: I am happy to start and then, if the other members have things to add, they might do that for this question. I apologise for not being able to join in person. I thank you for your question. When we consider barriers unique to the

multicultural community, or perhaps they are more concentrated, intersectionality becomes a really big part of how we look at these questions. I note that the multicultural community is not a unilateral body or one that shares the same experiences and challenges, so the degree to which challenges around language, access and looking at taboos and stigmas impact different groups or subgroups of the multicultural community is different. That is with consideration being given to first, second and third-generation migration, different types of cultures, and the impact of spirituality, faith and values. There are also some more administrative considerations around language and the use of translators and dependency on them. Some of the things that we have specified in our submission are, for example, dependency on translators and the need for them to be independent and impartial, not imposing their personal values or beliefs onto a situation—medical, legal or otherwise.

This can also be complex in a multicultural community when we consider privacy. There are minority languages, and translators are often typically part of the community as well, and that can create some real difficulties with people wanting to have a bit more privacy, a private experience, when they are discussing really personal matters like this—wanting them to stay confidential and not go back to a community. Also, some translators may choose to disengage with a process if they feel that it does not align with their spiritual, religious or traditional values. We see that quite a bit around more sensitive or complicated health cases like, for example, voluntary assisted dying. There is a big difference as well between receiving translated information and receiving it in, for example, easy English formats—the ACT government produces, for example, easy English materials—and receiving it in language as well. There are certain nuances or a particular type of descriptive language that can come across quite differently. That means that sometimes people will understand things very differently in a language, with nuances of particular descriptive words and the like, as opposed to, say, thinking that they understand three-quarters of a sentence. They infer a meaning from it. Those barriers are quite considerable and can stop people confidently being able to engage in the process and have accurate and informed information for decision-making.

To answer the other part of your question around taboos and stigma, the process of living and dying is quite different in multicultural communities. There are a lot of conversations about how we enter the world and how we leave it, and this can be quite different family to family, even within the same cultural, linguistic or spiritual group as well. There are parts of the conversation around VAD that look to the fact that some parts of the community agree with VAD and others do not, and others who wish to engage with it also want to make sure that, if people have particular spiritual or traditional practices that they would like incorporated in that process, they can do it in those ways. It is also about including in the conversation the values and beliefs of our practitioners and facilities, considering the ways that people's personal values and family experiences impact the way that they engage with processes.

MR COCKS: We have had some discussions this afternoon in particular around the risks to vulnerable people and potential power imbalances. I wonder whether there are risks that are exacerbated by communication or language barriers as well.

Mrs Wong: From discussion with the community, at times the understanding of the process or understanding what assisted dying is can be different because of the lack of

clear information due to language barriers or due to misunderstanding of the interpretation. At times, when you say that the multicultural community may be vulnerable, it is not because they are vulnerable; it is because of the lack of information that will allow them to understand the process. That is one thing.

The second thing about communication is that, among multicultural communities or groups in multicultural communities, sometimes we hear, “Now the government says that you can kill yourself.” That sort of language could be a misinterpretation. We are saying that the barrier is that we really need to push for understanding of this bill.

MR COCKS: Do you think the provisions in the bill at the moment appropriately and sufficiently protect people from multicultural backgrounds who experience those language barriers?

Mrs Wong: Initially, this bill protects everybody, but we would really like to see the government or the agencies working harder to make sure that the multicultural community is not disadvantaged because of the language.

THE CHAIR: Mrs Foon Wong, picking up on looking at language and making sure that there is access to information in language that is understandable, given that it is such a complex topic, there is the 18-month implementation period. Is this something you would like the government to focus on during those 18 months? Dr Reddy Chintalaphani, you may want to jump in.

Dr Reddy Chintalaphani: Yes. In fact, that is one of the things I was going to say as well: it is time to look at the implementation and education, as well as the training aspects. We want to give confidence to the community that this whole process is tested and tried, and that there is training for professional practitioners, but there are also educational aspects, including language. Often there is also the legal aspect; it is not just about true translation. The people who are likely to avail themselves of this are likely to be elderly—generally but not always. They lack language skills, particularly on the legal side of the issues. That is where the focus needs to be. It is not just about the translation; it is that you have a right and why, and what is covered under that, and why it is okay to make a decision. It is that aspect.

THE CHAIR: Is it fair to say the concerns that you have raised on language are concerns that can be addressed, and particularly through the opportunity of the 18-month implementation?

Dr Reddy Chintalaphani: Absolutely.

Mrs Wong: Yes; absolutely, especially cultural awareness—not just the meaning of the bill but really understanding culture, because different communities have different cultures and beliefs.

Dr Reddy Chintalaphani: I could add one quick point on the multicultural-specific issues. Often people have extended families overseas and they have a say. This is not uncommon. I can tell you about my own experience in the community. Most of my family is in India. If I am making a decision here, there is usually some influence—at least the need to communicate. It adds another layer of complexity that I want to draw

your attention to when it comes to multicultural communities. It is often a collective decision and the people are spread out. Often people in India have an influence.

THE CHAIR: That is an interesting point.

Dr Reddy Chintalaphani: I have used India as an example, but it applies to anyone, of course.

THE CHAIR: It has come up in other hearings, too. It is an interesting point and I thank you for raising it.

DR PATERSON: I have a question on that issue of collective decision-making. We have heard from Carers ACT. They raised some issues along a similar vein—that the carer be part of the discussion and process. While it might be the individual who is dying, and it is their choice to access voluntary assisted dying or not, the carer, who is often a family member, needs to be involved in that, and discussions need to not be seen as coercion. I am interested in nutting out this point about the dynamics of multicultural communities and how other people’s views and perspectives may come into shaping someone’s decision.

Dr Reddy Chintalaphani: Every case is situational. You need to look at it on a case-by-case basis. In a case where the person is really at the end of life and very ill, and the medical diagnosis is that there is no cure and treatment, it is a very obvious case and the person is able to make the decision; it is straightforward. You would provide the information on the person’s rights, all available information, the resources and help, and what happens during, before and after. I think that would be the case. That is a straightforward case, I would say.

There are situations where it is not very clear. Often the medical recommendation, the practitioner recommendation, is not black and white. It is very hard for professionals—especially in the ACT case, where there is not really a time frame—to say, “Why do you say there is no hope and you want to leave?” That is why we need to provide information without actually driving them down any path.

Mrs Wong: Where care is usually done by family, they are more likely to make sure that their loved one is looked after rather than opting for assisted dying. They want to protect themselves. Especially in a big family, it is not just one person making decisions. From our experience with working with issues like advanced care planning, we always say we need to make sure that the person has the capacity to make decisions. If you are elderly, and sometimes you are ill and already medicated, it is very hard to consider that they have the clear mental capacity to make the decision. That is why, from the multicultural perspective, the family dynamic is very important.

Depending on whether the carer is very close to you or whether your carer has been with you for years—and we have discussed the carer’s involvement in this decision-making process—it is about whether it is appropriate or whether it should be left to someone who is independent, or whether the decision should be made between the professional and the person. That is another way of looking at it.

Ms Barakovska: Some of the dynamics that are unique to or most appropriate in the

multicultural community involve the models of intergenerational living in the same home. When we consider who is involved in the decision-making, as Dr Reddy Chintalaphani said, it is often not just the immediate family members in the home; it can extend to the wider community. When we consider saving face or community reputation as part of those conversations, it becomes a matter not just of the choice for an individual and family but also of how it looks relationally to a community. It adds an extra layer of complexity around the dynamics of conversations around coercion either way—influence towards or against voluntary assisted dying. It links back to those earlier points around the need for education, both for the community and for practitioners and administrators, to understand the context of the conversations that they will be leading as well.

MR BRADDOCK: The mention of saving face brings me to point 6 of your submission, regarding the declaration of death, and death certificates. I want to explore that a little further. You are seeking, for privacy reasons, not to put VAD on the death certificate. Is that the connection that is happening there?

Mrs Wong: Yes.

MR COCKS: What you are saying is that, particularly within multicultural communities, it is not just a personal decision; it can involve the broader community as well as carers or significant others.

Mrs Wong: Yes. If I can give you an example, in Chinese culture, sometimes the family cannot make the decision and they will look for the leader or the doctor; they pass on that responsibility to a person that has the authority.

MS CASTLEY: I know education is crucial for your community. Do you feel that the bill as it stands has enough protections for the person we are talking about—the person that wants to have access to voluntary assisted dying? Do you believe that the bill protects that person enough from being coerced?

Mrs Wong: Personally, from the human rights perspective, there are some protections, but, from the multicultural community perspective, nothing can protect them. We have to be very clear that there is trust, and everything has to be clear that this is not someone trying to tell somebody that you can die. It is very simple.

THE CHAIR: Mrs Foon Wong, on that topic, there are some pretty strong penalties in the bill for coercion.

Mrs Wong: Yes.

THE CHAIR: Picking up on the theme of making sure that the community is aware of the responsibilities and obligations that come with this matter, do you think that, within the multicultural community, with the penalties that are there, provided people are made aware of them and that that education piece is done, that would be enough deterrent or enough to signal to people that this is a very serious matter?

Mrs Wong: With cultural awareness and education about the bill, it needs to be very clear that we have looked, from the multicultural community perspective, at what

assisted dying is. Is it about saying, “I can’t really continue anymore; therefore I just want to go,” or is it that your family see that you are suffering so much and, because you say, “I really want to go because I can’t stand it anymore,” basically, you are helped to go? That is the conflict.

Dr Reddy Chintalaphani: The other thing about the education aspect is giving some real examples. Coercion can be a broad range of things. It can be very subtle. Non-cooperation can be coercion. Obviously, most family members do not encourage them outright. That is generally; I am not saying it is in every case.

There are very straightforward cases and there are some in-between cases. There are some cases where we say, “No, we should really not even think about that.” The family members’ responses will be different. With respect to preparing the training and education material, under the law, a person has a right; however, how you exercise it, what hope there is and what options you have need to be evaluated before you come to that.

All those things need to be packed into education. If I am not encouraging or I stop talking—a family member—is that coercion? I do not know. These are the things that need to be clearly articulated and advice needs to be given. Of course, this goes beyond the multicultural community more broadly—where you draw that line—because these are very difficult issues.

At the end of the day, the individual is responsible; it is their right to choose. We are talking about the surrounding people and how they react to that.

Mrs Wong: We need to stress that it is the culture, the religion and the belief that need to be understood. In some cultures it is acceptable; in some it is not acceptable. For example, there is the favourite son syndrome. Especially in some families, there is a favourite son that always makes the decisions, so everybody will go to that son to make the decision. Sometimes it does not work; then you start having a big argument and somebody has to be blamed for it.

THE CHAIR: Ms Barakovska, do you have anything that you want to add?

Ms Barakovska: In conversations and in training materials, that community understanding needs to be supported. Case studies would probably be really valuable in order to have those more defining parameters of what is coercion, what are the consequences of it, and what that looks like. For quite a lot of people, the concept of VAD is probably going to be quite new. In a lot of multicultural communities, death as a conversation topic is quite out of bounds. It is not considered polite dinner-table conversation, let alone talking about procedures around death, dying and VAD. For a lot of families and communities, it will be quite new or quite foreign. The concept of case studies and that kind of storytelling element of the explainers and the real simplicity of it would be really great. People who are choosing it as a service need to understand the focus of self-advocacy and autonomy; and the surrounding family or community need to understand the rights and responsibilities of that individual, and the people around the individual need to respect that process as well.

MR BRADDOCK: In your submission you talk about the hesitancy in multicultural

communities to access palliative care. I would like to understand a bit more about what might be some of the barriers to doing so. I understand that it is more than just the food. There are definite barriers that I would like to learn about.

Mrs Wong: There are misconceptions about palliative care services. With a lot of multicultural communities who are reluctant, firstly it is because they feel that the family members can look after them better. Secondly, they do not understand that palliative care is a place where they can actually have quality care services.

When we talk about palliative care, the reluctance is mainly because of the fear of going into hospital and never coming out again. Certainly, whether you are ill or not ill, some communities interpret palliative care as being a place where you go to die. In the past, when we have tried to promote palliative care services, we found that we needed the general practitioners' assistance to help encourage them to go to palliative care services.

The other misconception is that people who are diagnosed with a terminal illness in the ACT do not go to palliative care. Therefore, because of that, by the time they are ready to go to palliative care, it means that the doctor has given up treatment for them and they just go to a place where they die. We know that this misconception needs to be changed. Instead we have a hesitance regarding the community taking up palliative care.

Dr Reddy Chintalaphani: Often there is also the perception—it may be the reality or a perception—that in palliative care you are not looked after well. That is often a reason. I know this first hand from my friend's mother, who is actually not well but refuses to go to palliative care or an old-age home. She is at home by herself. It is the perception that “you are not looked after there and you are better off here”. You do not get the care you need, the food, and all of that. A lot goes to that, because multicultural communities are used to certain food types and, when you go to those care services, you get whatever you get from the menu on the day.

THE CHAIR: I will wrap it up there. You did not take any questions on notice. You will be sent a copy of the uncorrected proof transcript. If there are any factual errors, please let us know. Thank you very much for attending today. We very much appreciate your input to the committee's proceedings.

ROWE, MR JOSHUA, Acting State Director NSW/ACT, Australian Christian Lobby

McARDLE, DR PATRICK, Chancellor, Archdiocese of Canberra and Goulburn

PROWSE, MOST REVEREND DR CHRISTOPHER, Catholic Archbishop of Canberra and Goulburn

SHORT, THE RIGHT REVEREND DR MARK, Bishop, Anglican Diocese of Canberra and Goulburn

THE CHAIR: Welcome. Would you like to add anything about the capacity in which you appear?

Archbishop Prowse: After the government, we are the biggest providers of nursing and aged-care facilities in the ACT. Thank you for inviting us.

THE CHAIR: Thank you. I would like to remind all witnesses of the protections and obligations afforded by parliamentary privilege, and I draw your attention to the privilege statement. There is a pink sheet on the table, if you have not had a chance to see it. Witnesses must tell the truth. Giving false or misleading evidence will be treated as a serious matter and may be considered a contempt of the Assembly. Can I please get you all to confirm that you have understood the implications of the statement and that you agree to comply with it? Thank you.

We are not going to have opening statements. However, if you do have an opening statement, you are welcome to provide it to the committee secretariat, who will pass it on to the committee. We will go straight to questions.

MR COCKS: Can I start with commending each of you because, despite the clear fundamental objections you have, as organisations, to assisted dying, each of you has sought to contend with the content of the bill as well. I have to say, I really appreciate that you have taken the time to do so. One of the issues that seem to be pretty broadly shared is that of conscientious objection, at both an individual and an organisational level. I wonder if you might be able to talk to what, from a religious and faith perspective, conscientious objection constitutes, and whether it aligns with what this bill provides for.

Archbishop Prowse: From the Catholic point of view, the word “conscience” has a particular pedigree, something deep within us that gives us an indication—yes or no—that this is a way I would want to go or this is a way I do not want to go. Throughout millennia, conscientious objection has been present in different forms. In regard to the legislation, I find it a very narrow understanding of what conscientious objection is. It does seem to say, “Okay; certain institutions, because of their ethos, may not agree with this, but on the other hand there is the obligation on them to defer or refer the person to other people that may be more sympathetic to accessing that.” Even that, from our Catholic point of view, is not acceptable.

We have talked about formal and informal or direct and indirect cooperation in what we describe as something highly mistaken—even using the word “evil”, which is a word that we would move towards in regard to euthanasia. For a Catholic institution to direct, participate or in any shape or form cooperate, to us, is unacceptable and

would not be seen as a way to go. This is where we have objections to the narrow understanding of conscientious objection in the bill.

Mr Rowe: The Australian Christian Lobby would share the views of the Catholic Archdiocese and Archbishop Christopher. We seek to represent a constituency of Christian people. We have 5,000 here in the ACT and 250,000 nationwide, and those individuals hold that God gives life and that he takes life away. There is a high view of the sanctity of life, and thus people of faith need the right to be able to object to both the administration and being complicit in the referral—as well as faith-based institutions who share that religious ethos. It would be our position that a broader view of conscientious objection, to encompass objection to both administration and referral, would be necessary.

Bishop Short: From the perspective of the Anglican Diocese of Canberra and Goulburn, to build upon what has already been said, we would say that conscience is not the unique perspective of religious people, but all of us have deeply held values that we seek to live out in our personal and professional lives. Many people find themselves working in areas like health or aged care because they want to give expression to those values that animate them as people. We recognise that, in a diverse and pluralistic society, people will have different views on these matters, but I think being part of a diverse and pluralistic society is about allowing people to bring their whole selves to the workplace and ensuring that people are able to conduct their work life consistently with those values in a way that protects them from coercion and allows them to live out those values. It is our concern that the provisions around individual conscientious objection, in particular, are not adequate in that area.

MR COCKS: Very clearly, it sounds like you do not think that the balance between conscientious objection and individuals choosing to access assisted dying has been struck in this bill. Are there other jurisdictions that you think have done better in this space?

Mr Rowe: Yes. I believe that South Australia have done better with their voluntary assisted dying legislation. In section 11 they make provisions for people at an individual level, as well as institutions, to not be complicit in any part of the voluntary assisted dying process.

THE CHAIR: Can I clarify, to make sure I am understanding correctly? In talking about the conscientious objection of individual health practitioners, the issue you take within the bill is that they have to refer. It is not that they are providing the information but that they have to refer to someone who will provide the information. Is that correct? I can see nodding. Assume I know nothing about this topic. Can you please explain to me why that is an issue on the religious grounds that you are representing?

Dr McArdle: If there is a fundamental intellectual moral judgement that this is where I stand and I cannot do it any other way, it seems absurd then to say, “Don’t worry; there is someone else who will do it on your behalf.” If you are saying that I am not being cooperative with this at all, why would you even necessarily know and why would that judgement not extend to saying that I am actually believing this is wrong and therefore it is not just wrong for me; it would be wrong for anybody to be

involved? That does not mean that I am questioning your access to this, just that I do not want to have any part of it. I cannot, because it would be compromising who I am as a human being.

THE CHAIR: Okay. We have heard from a number of witnesses today that there are a range of views. It might be that there are a number of views within organisations, but the position they are taking is to allow people to opt out, still recognising that there is a health service to provide. They have said that they consider voluntary assisted dying to be part of a health service and a consumer-led response. How, then, do you reconcile the want to provide health care and to give individuals wanting to access voluntary assisted dying access to that healthcare provision with the moral choices of the person administering it?

Archbishop Prowse: Possibly on two levels. First of all, perhaps, there is a level of common sense—sometimes uncommon sense. It is simply the fact that you mention that a medical service would include that from the point of view of ethics or philosophy. I cannot agree with that. I do not see that or euthanasia—interesting that the word “euthanasia” is not used much, a gentler term than voluntary assisted dying—as a medical service. There seems to me to be a mistaken assumption here that the health profession, with its whole ethos on healing, would directly involve itself in assisting a person with the poison of the medication that would cause their death. Notwithstanding their terminal illness and their fragility, to me palliative care is just a common-sense response to that, which we could talk about a little bit later, if you so wish.

From a theological point of view—and religious leaders are in front of you—life is given by God. Not everybody is religious, but most people would say there is a certain godliness or transcendence as part of our human being. We are not just atomistic robots; we are human beings. A religious instinct is part of being a human being, and that means that profound respect for life, from conception to natural death, is part of God’s gift to us. God has given us life and we respect that. To bring it to a sudden end deliberately is an offence against God’s gift of life. That is a theological or religious response which may not be accepted by everybody but which would be respected by a very significant majority of people in the ACT.

THE CHAIR: Did you want to say something, Bishop Short?

Bishop Short: I was just going to talk particularly about sections 94 and 95 of the proposed legislation, because that is where we get to the nuts and bolts of the current provisions around individual conscientious objection.

I will make a couple of preparatory remarks about the health and aged-care sector. In the aged-care sector in particular, a lot of the workforce is employed on casual and other non-standard employment bases. I think the most recent statistics are that, for example, only 10 per cent of nurses in the healthcare or aged-care system are employed on a permanent full-time basis. So there are a lot of workers who are in non-standard employment arrangements. There is the fact that in any employment relationship there is an asymmetry of power between the worker and the employer. When you put into the mix the fact that some of those workers—not all but some—will have deeply held convictions around the line already shared that would mean, for

them, it would be compromising those values to be present or participate in the administration of voluntary assisted dying, my concern is that these sections as currently drafted do not take into account the very nature of the employment relationship and the asymmetry of power and the depth of those convictions.

THE CHAIR: I want to pick up on a few of the different points that have been made and put this question to you. I am going to paraphrase. I apologise if I do not quite get it right—and feel free to correct me if you feel I am misrepresenting anyone’s intentions. Essentially, what has been put is that there is this moral and ethical view in a person, and it is so deeply held that, in respecting that, there cannot be an alternative. That has to have some level of primacy, for argument’s sake.

Then we have this want to put in place a health response by other people. I understand that that is contested as a proposition; we will just clarify it that way for the purposes of this discussion. If the belief is so deeply held that there is no alternative, no way to implement it, then to conscientiously object is to say that, as I think Mr Rowe said, you do not have to participate, full stop. This is getting to the crux of my question: is there a way to conscientiously object other than to just not participate?

Archbishop Prowse: I am sure that some people would have a halfway point. To use the well-documented examples, some people who have objected to military service have said, “I can’t participate at all.” Others have said, “I can participate in the medical corps”—for example—“and that doesn’t overly compromise my viewpoint.” I am sure there is a huge spectrum of that.

For example, while there would be a range of things that our respective religious traditions might object to about a whole variety of government policy, we take the view that we participate in health and aged care, and receive government funding largely to do so, because we believe that health and aged care are a fundamental good. We accept, to some extent, the fact that there are limitations around that, or obligations. We just think this is going too far.

People, by and large, who choose to work for religious organisations at one level know what they are signing up for. I accept Bishop Mark’s line about there being an essential asymmetry in the employment relationship. By and large, certainly, we do not leave people ignorant of our ethical stance. That does not mean that we seek to regulate what they do at home or what they do if they are working for someone else. We simply say that our institution will not take part in that. We would accept what their own viewpoints might be, but there is a point at which we need to publicly say, “These are the values that the institution stands for.” Also, the individuals within our institutions need to be protected by us from, for example, the criminal provisions in this legislation.

Mr Rowe: Adding to that, people of faith have a deep conscientious objection when it comes to this principle of “Thou shalt not kill,” and for those individuals, and within those organisations, there would be that strong sense that “I can’t be complicit in the taking of life.” What you would inevitably see is those people, because of that deep moral conviction, stepping away from the health service.

That is already a service in which we need as many workers as possible, and that we

under-resource. You would not want to see a lot of people who are motivated by compassion, and coming into that service and providing good care, actually stepping away from it because they feel that their conscience will be violated. That is where I think the best avenue—as alluded to by Archbishop Christopher—will be the referral into palliative care for people of faith, and more resourcing to palliative care, as opposed to VAD.

MS CASTLEY: Mr Rowe, you said that the South Australian model has done it best with the conscientious objection. What would you like to see changed in this bill for it to be acceptable, if it could be at all?

Mr Rowe: The other members can let me know if I am speaking out of turn, but I think there is a unified objective here which is that, within the legislation, there would be complete provision for conscientious objection for people of faith and institutions that maintain a faith-based ethos to be able to object to any of the processes related to the administration of VAD.

Dr McArdle: Beyond that, there seems to me to be an oddity that there are criminal penalties in this and, on the strict liability basis, it just seems very odd. Listening to some of the evidence this morning, the spouse of somebody who accesses VAD and does everything in their power to dissuade them could well be viewed as coercing the person and subject to criminal liability, when in fact I would think they were motivated because of the nature of the relationship. Similarly, it could work in reverse, but it strikes me as odd that we have gone for the strict liability model and we have made them criminal provisions. It just seems very strange.

THE CHAIR: I think that is a point that has consistently come up today, and it is something that I dare say many of us will be putting to government to get a better understanding of.

Bishop Short: Yes. I draw committee members' attention to the third paragraph on page 4 of our submission. I will start reading from halfway down:

Furthermore, given that under the relevant Act 'health service provider' can refer to a variety of practitioners including nurses and pharmacists one can envisage situations where employees will be asked by their employer to undertake actions that go against their conscience, where there is an inherent power imbalance arising from the nature of the relationship. To avoid such situations, there should be provision in the legislation for health practitioners or health service providers to pro-actively express their conscientious objection ... and an obligation on the part of employers to facilitate such a process and not discriminate against employees on the basis that they have chosen to exercise this right.

Likewise, we would support the removal of the strict liability offence, because our concern is that the requirement under section 95(2) for a health practitioner or health service provider to give the individual, in writing, the reasons for their non-participation, firstly, seems to violate the principle that they should be able to keep their objection confidential. Secondly—and this point was raised in the submission of the Australian Nursing and Midwifery Federation—if VAD has been carried out, it seems difficult to understand how the health service practitioner is to notify the individual. Thirdly, there is a concern that making it a strict liability offence—which

means the prosecution is not required to prove intention, knowledge, recklessness or negligence—puts people, who, as I said earlier, could be in very non-standard employment arrangements, in a particularly vulnerable position. We would suggest that the section be amended along the lines that I have outlined.

MS CASTLEY: I cannot remember which submission it was, but one of them talked about concerns about regulatory creep. Do you remember who put that in their submission?

Dr McArdle: I cannot remember. I think that, by and large, we are of the same view—that a number of the provisions that have been mooted about this have now been indicated as being subject to the review in three years' time. However, at that point there is no suggestion that legislation would be required, for example, to extend the access to minors or those who lack competence. That simply could be done by ministerial regulation, and that would be a concern I have about that.

Archbishop Prowse: Around the world, we found with similar sorts of legislation that the bar level where they start is never heightened; it is only lowered as the years go on. The pending legislation is, as far as I am concerned, at a quite low level. To get lower, I wonder where it would end.

Perhaps I could put it this way: we are all concerned about the terminally ill and the vulnerable. We all share that. The way we respond to that is the question at hand here. To me, the palliative care argument is not only persuasive but overwhelmingly persuasive, because we walk together with the person. It needs to be properly funded, though. I do note that, although promised, the ACT government does not seem to have come forward with the funding at the level where palliative care can increase and become more sophisticated—and particularly outreach to rural areas, which are often very vulnerable to this area.

Wouldn't it be a travesty of humanity if the person who is at that most vulnerable terminal stage receives the "care" package, which they can administer to themselves, in the post? That sounds unbelievably callous, but I could imagine that, if the creep continues, once it is out there and is legal, all of a sudden it will be seen by many as moral and therefore it can just go down a slippery slope which is very offensive to human values.

DR PATERSON: What would you say to residents at the moment, and families who have a terminally ill family member, who are looking at committing suicide because they do not have a medical pathway and there is no pathway for them? They are in extreme pain on a daily basis. They do have a terminal illness—doctors have given them a couple of months to live—and they are considering taking their own life through means that may have adverse consequences? It may be very distressing for the family. It may have legal consequences. What do you say to families who are in that situation when we say we care about the terminally ill and the vulnerable?

Archbishop Prowse: I have been in that situation as a pastor. I have been a priest for 43 years. I have been with people, hundreds of people over the years, who are reaching the end of their life, some because of terminal disease. I do find that they are on a roller-coaster every day. Some days they would say, "This is it. I can't take

anything more. I want the drug or any drug.” On other days, they say, “No; I’ve got other things to do in my life.” So it is a roller-coaster ride, just to be with people—the great grace of proximity, closeness, kindness, on a day-to-day basis, which is all part of palliative care. It is not just about administering drugs; it is also about getting the whole family involved in an attitude that promotes a culture of life, not a culture of death.

Therefore, it is about asking the questions, not just the personal, but the professional: is this person receiving adequate care, medically; is palliative care at the level that it should be? It is about working through things on a day-to-day basis. I think that is a far better way than something that is more abrupt. “My body, my choice” seems to be the way to go, but it is a very lonely argument. In fact, from my experience, personally, it is not what is really happening at the bedside of the person who is dying, and the bedside manner that, as a society, should be maintained with those in the most vulnerable situations.

Mr Rowe: To add to what Archbishop Christopher is saying, from a theological world view as well, at those end-of-life stages, for a lot of people, that is a time when they find reconciliation with family. Long-term breakdown in family is reconciled as well as for some reconciliation with God, conviction of sin, and also the giving of their life to the Lord. That is where it would be the submission of ACL, for example, to the government to increase palliative care funding and options so that people can experience a dignified end of life alongside those they love, where there is minimised pain.

It is worth noting for the record what has happened in New South Wales with the slash of \$150 million in funding for palliative care. That is of great concern to us because we are concerned that the ACT government will also dip into that honey pot to implement VAD, therefore taking more funds away from palliative care to give people a dignified end of life.

THE CHAIR: We have heard from a number of people today that it should not be one or the other, and that both should be put forward. We will add your views to that chorus, shall we say.

Dr McArdle: The only thing in that, Ms Orr, is that palliative care is incredibly expensive and VAD is incredibly cheap, comparatively. Dr Paterson, I acknowledge the tragedy of those situations. I am not a medico, so I have to accept the advice of people like the royal college of palliative care medicine, who simply say that, in all but a very small minority of cases, there are things that can be done, by providing the funding and the access to care as necessary.

There is an existential element to this which might not be about physical pain as well, and I perfectly understand that. That is why we take the view about accompaniment as well as the pain relief.

THE CHAIR: Archbishop Prowse, this question is for you, because your submission says that the bill is contrary to human rights. I want you to expand on what rights you see as being—

Archbishop Prowse: Thank you for that question. I do find in general in the ACT that, when a human rights agenda comes up, it is often mentioned in a very subjective understanding of human rights. I come from a moral theological background, professionally. Human rights and the study of human rights have been part of my academic background. We always go back to the Universal Declaration of Human Rights in 1948 as the mother document. Other commentaries have come up over the years, of course, and even more recently, about how these sorts of situations can be seen as part of human rights. But they are commentaries; they are not declarations that have been signed off by nations over the years.

With respect to the objective aspect of human rights—the duties and the responsibilities of every human right—we have rights, but with rights there is a duty and a responsibility. People have the right to A, B and C, but they also have the duty and the responsibilities attached to that. Human rights, from my understanding of a reading of the bill, are again in that lonely, subjective understanding of human rights. It is not opened up to the fact that the medical people have responsibilities and duties with regard to administering health and healing to those that are sick. Are they to be overridden by a person's human right? The clash of rights is here. Who wins; who is to give way?

If it is so much on “my choice” human rights—“my body, my choice” human rights—it is very subjective. The idea of the human values involved in life, in medicine, in health, in the medical profession and in their oaths regarding protecting life, are often eclipsed. That is the background to my comment there. I hope that is helpful.

THE CHAIR: Yes.

Dr McArdle: I think one of the things here is that there is a fundamental difference between the ACT Human Rights Act and the UN declaration. The UN declaration is based on communal rights. It is a recognition that, because you are a member of the species, you do not have to claim a right; the obligation is on us to make ensure that your rights are met. Under the ACT act, there is an assumption that it is predicated on your individuality and choice and claiming those rights. Hence, in this, you would need to claim access to VAD; whereas we would argue that universal health care is an absolute fundamental right because you are a member of the species, not because you actually asked for it.

THE CHAIR: On that note, Dr McArdle—and I know we already have a point of difference on this—other people have said this is part of the healthcare system. I think it is fair to say that you have expressed your view that you do not consider voluntary assisted dying to be part of a healthcare system. When we are talking about human rights, yes, there are human rights and freedom from and freedom to, but there also seems to be this core difference that—correct me if you feel misled—because of your religious convictions, you just cannot agree with voluntary assisted dying. Other people will not hold those religious convictions. How do you reconcile these different views?

Archbishop Prowse: I would go back to an earlier point. On one level, the religious dimension is not unreasonable. We are not talking about some divine directive that has come down and we passively take it on. It is reasonable. It can be argued that

there is the link between faith and reason and they do fly together. But the theological or the religious dimension gives a vertical or a transcendent dimension that actually enlightens, opens up and gives a broader perspective to basic common sense. I hope there is that understanding that it is not as if religious is over here and reasonable arguments are over there. That is a secularist approach which I think is too sharp. Although there are differences, there is also great commonality.

THE CHAIR: There is. I appreciate that you do not want to draw a line between the two and silo them, and that is not the intention. We have heard from a number of witnesses today who say that they are really supportive of voluntary assisted dying and that it should be accessible. We have also heard from witnesses who say that they want it to be more accessible than what they have got. So we have had a range of views put to the committee. You could almost say that they sit on a spectrum and they cover the whole spectrum.

I think it is fair to say, from the evidence that you provided, that you are at one particular end of the spectrum, and we have other people at the other end and some in the middle. I think that is probably about fair. But, without wanting to pick one view to go for all of them, how do we balance them? I can see that, because of your religious convictions, it is just something you cannot agree with. That is your view. Knowing that not everyone else shares that view, how do we then enact a public health measure where we walk that line and we find that balance?

Dr McArdle: That is where the conscientious objection thing is fundamental. The Chief Minister this morning was asked on radio about things to do with the election and referenced this committee and pointed out that this was a consultative process and that, by and large, we can probably guess from the publicly available submissions and data that about 80 per cent of the ACT at some level are supportive of that. I think he acknowledged he would probably never satisfy us.

I appreciate that the government needs to enact an awful lot of things. I am not a fan of the 40-kilometre speed limit here in Civic, having been caught at it. I do acknowledge that the government has to straddle my objections to that. However, when it comes to something as fundamental as this, the conscientious objection provisions need to be absolute, to allow the minority to say, “I cannot go there.” That is not objecting, ultimately, to the government’s provision of this service for other people who might think that is wrong. That is something we can have an intellectual argument about. But facing—and some of our vulnerable employees are in this situation—criminal liability on the basis that they believe it is fundamentally wrong to engage in this is why conscientious objections need to be absolute. We cannot do anything to prevent other people accessing the service.

THE CHAIR: I think we have covered off on individuals and some of the reasons for conscientious objections with individuals. Institutional objection has also been raised, but I do not think we have explored that quite as much. My question—and I am sorry it is a little blunt, due to time—is: if an institution, say, a hospital run by one of your churches was given the provision of conscientious objection, much like the South Australian one that you have asked for, and did not provide any services, how do you then service the people who come into your health service and do not share the same view that the institution has towards voluntary assisted dying? How will they get

access to the scheme?

Dr McArdle: I do not think anybody accessing a Catholic healthcare service would be surprised that we do not engage in life-ending activity. I just do not believe that would be a surprise to anyone.

THE CHAIR: I can appreciate that and I think it is well on the record. I think it was Archbishop Prowse who said that there is an ethos that sits underneath these things. I guess the point I am going to is that, even within religious practice, there are a range of views. I think it was noted by some of you earlier that you are quite large providers of healthcare services and sometimes people do not have an alternative. It might be a geographical thing or it might be something else. Again, it is coming back to balancing these wants, these rights, these obligations and these responsibilities. For someone who might not have a choice of an alternative service provider but does not necessarily share your views, how do we balance providing for both parties?

Dr McArdle: Then you have to decide, ultimately, whether it is the individual or the community that wins out. It is interesting that, where there has been at least an argument put forward that the minority has to accept the will of the majority in this, we are now turning around and saying that, in a facility owned and operated by a group with an objection, we have to accept the view of the minority.

In our case, we would say those who access our service would be the minority who would share that view, while at the same time absolutely protecting a healthcare practitioner who said, "I am not offering that service." I am not sure that those sorts of rights are commensurable or can be balanced out. There may have to be an acceptance that it cannot be done. The other possibility is that there would be services where we would say that, if that were an absolute requirement, we would have to exit the service, which then goes back to Joshua's comment earlier: "Could you really afford that to happen?"

MR COCKS: It seems to me that this most recent discussion may be based on a bit of a fallacy. In the context of the assisted dying provisions, the penalties I think we are discussing are around referring on to other providers, and the suggestion has just been made that there might not be other providers for the services that you are being asked to provide. Can you think of any services that would not have an alternative or government provider under the VAD legislation?

Dr McArdle: Government is pretty bad at aged care. Everybody—

MR COCKS: But in terms of the—

Dr McArdle: But there would be other providers.

MR BRADDOCK: There is only one hospice in the ACT run by the Catholic Church. The majority of—

Dr McArdle: Government owned and operated.

THE CHAIR: I understand the point that Mr Cocks is making. I put the question, so

give me a chance to sort of wriggle through it. I guess the point I was thinking of was not necessarily that there is not an alternative service. I did say geographically, and I am thinking of a smaller town where there might be one aged-care provider. In another town there might be another aged-care provider that you could move to, but that could be quite disruptive for someone who is in a very vulnerable health state. The point I am getting to is not so much that there would be an alternative but also trying to balance this. There are a range of factors that go into it. Aged care is one, and we do know that religious institutions provide a huge amount of the aged care. It is not a government-provided service for the majority. That is where we start to get into a bit more of these complicated places.

If by circumstance—and you do not always plan that you are going to end up in these places, so you cannot have the foresight of preparing for every eventuality that might happen—you find yourself in one of these places, you could be in a position where you would not necessarily have the ethos. My understanding from the discussion we have had is that organisations run by the churches would be given the opportunity to potentially completely opt out of even providing it. If that is the case and you find yourself there, it is not even going to be a referral to another service; it is just not going to be offered. Is that correct?

Dr McArdle: That is right.

THE CHAIR: I think that is the point I am getting to. Sorry; I have taken a bit of a roundabout way to get there.

Archbishop Prowse: It sounds like an absolute and it is, frankly, but it does not lack true compassion. The word “compassion” means to suffer with someone. I will end where I started. In suffering with someone on the long journey, there are ups and downs—today, yes, and tomorrow, no. It is about being with people there. I have found that rarely do they make a snap decision, although these days there is an encouragement to make it well and truly before and to legislate for that to happen. I think that is a very dangerous path to go down.

With human life being as it is, there is a clash of human rights here and we just have to admit it. It is not as if there is a middle course that is going to be the *via media*, the middle way, that we are all going to accept. There is not; there is a clash of human rights here, and it is a messy road, as indeed terminal illness is with vulnerable people. I think there is a real healing in being with them and talking with them and seeing the fascination of their opinions. That should not be dismissed in a move towards the conclusion too quickly.

THE CHAIR: I think we will need to wind up there. I would like to thank everyone today for their input. You will be sent an uncorrected proof transcript. I would again like to thank everyone. I think this was potentially one of the harder sessions of the hearings, and I would like to thank everyone for staying so respectful throughout the hearing.

The committed adjourned at 5.00 pm.