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

THURSDAY, 1 FEBRUARY 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

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Amended 20 May 2013

The committee met at 1.31 pm.

SWAN, DR LINDA, CEO, Go Gentle

THE ACTING CHAIR (Ms Castley): Good afternoon. Welcome to the public hearings of the Select Committee on the Voluntary Assisted Dying Bill 2023 for 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 and 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 a question on notice, it would be useful if witnesses could use 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 issues raised in this hearing.

We welcome a witness from the Go Gentle group. 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 contempt of the Assembly. Please confirm that you understand the implications of the statement and that you agree to comply with it.

Dr Swan: Yes, I understand and I agree.

THE ACTING CHAIR: We note with thanks that you have provided the committee with your 2023 conference report and a background document. We are not inviting opening statements, but if you wish to table one please provide it to the secretariat. We will now proceed to questions.

DR PATERSON: Thank you so much for your submission. One of the key recommendations and requests that you make is changing the wording in section 26 of the bill, "Referral for further consulting assessment", where you suggest it should be amended to "may" from "must". Can you speak to that and why you think that is important?

Dr Swan: The way the bill is written, when I read that section, I interpret it to mean you have a coordinating practitioner who has presumably determined that the person is eligible for voluntary assisted dying, and then they refer to the consulting practitioner to make a second assessment. If that second person says, "No, I do not think they are eligible", you are in a situation where you have essentially one health practitioner who said, “Yes, they are”, and another health practitioner that says, “No. They are not eligible.” So then you are in a situation where, well, who do you pick? In my mind, it is perfectly fair and reasonable that you must then get a third opinion. So you then must go to someone else to have another opinion about whether the person is eligible or not. That was the context. If you say “may” then you are potentially just left in a bit of limbo about one said yes, and one said no, and if there is no referral, the individual is potentially obstructed from going forward when, if they had a third opinion, they might have gone forward.

MR BRADDOCK: I would like to learn more about your concerns about section 11(4)(c) of the bill, which talks about the individuals in the last stages of their life. What do you foresee being the challenges from such phrasing in the bill?

Dr Swan: My view, and I have spoken to some colleagues and other doctors that work in voluntary assisted dying, is that the phrase is not actually helpful. It is not clear. It is not terminology that is used in medical practice, and if you look at the completeness of the eligibility description, it is actually a bit repetitive. You have another section that already says that the condition must be, at the third dot point, “Expected to cause the person’s death.” So there is this duplication, essentially, where under the definition of “advanced”, you say the individual must be in the last stages of life, and then you have another point that says the condition must be expected to cause the person’s death. So I think it is repetitive.

I can understand why it is put in there to try and add clarity, but the “last stages of their life” is again, very subjective. How do you determine that? What do you mean by a stage? How long is a stage? So I do not think it is adding the clarity that it is intended to. It is just adding complexity and it is already covered by another element of the eligibility criteria. So that is why we were recommending that it be removed.

MR BRADDOCK: From your perspective, if that particular line was removed, would that make any meaningful changes as to how the bill was implemented?

Dr Swan: No. I do not think it would make any meaningful change. It is not about allowing more people to access voluntary assisted dying or changing the eligibility criteria in any significant way. It is just trying to make it clearer and easier for people who are needing to understand the law and to implement the law.

DR PATERSON: Do you think that perhaps may be a reaction to the “there is no six month to live timeframe” in the bill? That it might have been the compromise, having that in there?

Dr Swan: Yes. I think it is still very much covered by that third point that is already there. We are already asking people to determine that the condition they have is advanced, progressive and it is expected to cause the person’s death, and they need to be suffering intolerably. So there are already quite a few hurdles that a person needs to get through in order to be eligible.

MR BRADDOCK: Is it therefore possible that someone with say motor neurone disease or similar, where they have long-term degenerative conditions where it would be expected to cause death but not for a number of years, who might potentially meet this criteria?

Dr Swan: I think you have to put it in the context of all the eligibility criteria that a person has to meet. But motor neurone disease, and quite a few neurodegenerative diseases, are complex because the trajectory is not clear. So you can have people that may look like they are going to survive for another two to three years, but there is a sudden complication and a turn of events, and suddenly their life expectancy is much reduced.

That is some of the complexity that we have seen play out in other states around Australia, where, with the best of intentions, someone presents to their healthcare professional, and they look well. They look like they are stable on their oncology medications, or they look like they are managing well with their disease, and it looks, on the balance of probability, that they may live six months or more. Then a month later they come back, and something has happened, and they have deteriorated dramatically, and they only have a month to live. Suddenly, they have gone from a world where they were not eligible to actually now either needing to race at the very last stage of life, or tragically, cannot even get through the eligibility checks and balances at all.

So people are missing out and that is not the intent of this law. It is about enabling people to make a choice at the end of life and relieving suffering. What we hear is that most people at the end, the last months of their life, they just want to spend it with their family and their friends and doing the things that they love. They do not want to spend it running around trying to fill out forms and be transported from one person to another and involving all the complexities of going through voluntary assisted dying. So if there is one thing we could do to improve laws in other states, it would be to find a way to enable people to start the process a bit earlier because it is the rush and the anxiety that can actually add to people’s suffering.

MS CASTLEY: Thanks, Chair. I think you have covered this a little: removal of the waiting period. You earlier referred to the first port of call. Others—it might have been Advocacy for Inclusion—were concerned about when someone has had an accident—

THE CHAIR: They were worried about the removal of the time frame and how that might go for vulnerable people or people with disability, because they interpreted it as changing the criteria. Sorry to finish the question for you.

MS CASTLEY: Sure. I just wonder what your thoughts are on that. The comment that struck me was that, if someone has had an accident and is paraplegic, in that moment that would be intolerable suffering for them and there is every chance they could say, “Please, I would like voluntary assisted dying,” and go through that process. They talked about six months down the track, after that person has had rehabilitation and has learnt how to live with their disability. It might get better and there is a bit of ebb and flow. I am wondering what your thoughts are in that sort of situation. If there is the removal of the waiting period, what are your thoughts about that group?

Dr Swan: You always have to look at the eligibility criteria in totality. In that particular instance, where someone has just had an acute accident and their life has completely changed, they are in a state of shock and they are just coming to terms with what their new life might look like. I think that is very different to the type of people that we are talking about for voluntary assisted dying. People need to demonstrate an enduring intent to end their life. That is why you have to make a number of requests over a period of time and you have to have at least two independent health practitioners determine that you meet all the criteria.

You are talking about caring health professionals. They are going to talk to the individual about their options—the things that are available to them in addition to voluntary assisted dying. They need to talk to them about whether they would like to access palliative care, pain relief options, and the ways that they can be cared for. This is not a quick and simple process where someone just wakes up feeling unhappy one day and accesses voluntary assisted dying.

Firstly, under the proposed eligibility criteria, the person has to have an advanced progressive condition that is expected to cause their death. I am not sure that someone just having a spinal injury would meet that criteria. Secondly, they have to demonstrate they are suffering intolerably, and then they also have to, as I said, go through the process of making a number of requests over a time frame. It is not something that is going to happen without an opportunity to think about it at some length.

THE CHAIR: I have a supplementary to that. An example of concern that was put to the committee—and I want to check your interpretation and your read of the legislation, just to clarify—is that someone who has an illness that may be considered terminal or may be considered incurable and impacts on their wellbeing would not necessarily be able to access voluntary assisted dying in the way the bill is currently written. Is that your read of it and that there is more nuance to eligibility and the criteria than that?

Dr Swan: Yes; that is right.

THE CHAIR: Okay. For my substantive—

MS CASTLEY: Can I have just one more little supplementary?

THE CHAIR: Yes; please do.

MS CASTLEY: A heading says, "Removal of the waiting period," but what you are saying is that you think it is a good idea that they have to make multiple requests.

Dr Swan: Yes. This is not a rushed process. Purposefully, there are a number of requests to demonstrate an enduring intent. That is a good thing. That is a safeguard. People cannot rush into this decision. There need to be at least two independent health practitioners who go through the eligibility criteria and determine that the person is eligible, and they have to meet all the eligibility criteria.

Go Gentle Australia is supportive of what the ACT is putting forward about the removal of time frames. I think it is actually an improvement in the law. What we have seen as the laws have progressed around Australia is that other states and other jurisdictions have looked at the evidence, they have listened to the experience of health practitioners, families and carers, and they have learnt what they could do to improve the law. It is fantastic to see the ACT doing the same thing.

MS CASTLEY: You do not think there is a need for a cooling off period or anything like that?

Dr Swan: I think there is a natural cooling off period in the fact that the process is not quick and, at any time, the person can stop. It is not a case of it starting and then the process rolls on. The evidence would show that about a third of people that actually go all the way through and get approval for voluntary assisted dying do not end up taking the substance at the end of life. Even once you finally have approval, you do not have to follow through. What we hear is that people have an incredible sense of relief and empowerment. For the people that have one of those cruel neurodegenerative diseases, it is the one time they get to have some control and some say in what is happening to their body. People actually say that it gives them their life back. We put some of those case examples in our submission. I want to commend you for having the proper process. You have to listen to a variety of people, and I am sure you will hear directly from patients and families who will tell you their stories.

THE CHAIR: Picking up on that, you note, though, in your submission that there should be a minimum waiting period of at least 48 hours between the first and the last request. Could I clarify: you are not seeking to have a cooling off period or a waiting period. What is the rationale behind the 48 hours?

Dr Swan: In reality, we think that the process is much longer than 48 hours, but it is possible, if you do not have anything in there, that you are going to open up the bill to criticism, because perhaps, theoretically, there is some way someone could be raced through the process in fewer than 24 hours. If you at least have that which says no-one will ever be able to get through in fewer than two days, it is just another safeguard. In practicality, that is not the way the system works; it is very complicated. There are a lot of different steps involved. I cannot even think of a case that we have heard of where someone got through in anywhere near 48 hours. There have been some situations where people have been given special exemptions and tried to move quickly, but I believe that looked more like four or five days rather than two, and that is really fast.

THE CHAIR: Sorry—I have just one more substantive.

MS CASTLEY: Go for it.

THE CHAIR: We have heard a number of witnesses over the last few days saying that there is the ability for health professionals to initiate a conversation on voluntary assisted dying rather than it only being initiated by the individual, and that is a point of concern, particularly where there is a view that people are quite vulnerable and they might want to access voluntary assisted dying for reasons other than being ready to end their life. They may feel that they are a burden. That is what has been put to us. In your experience with the different systems and operations around Australia and with your read of the bill, what safeguards do you see in the bill? And do you think they are adequate for the scenario where people might be feeling vulnerable or exposed, but a health professional can initiate a conversation? Do we have enough safeguards in the bill to allow for vulnerable people not to be exploited? That is essentially the question I am getting to.

Dr Swan: I think that you have a responsibility as a healthcare professional to make sure people are aware of what their treatment choices are. Before they ask, "What are my options at the end of life?" a person should be given a good and clear description of the various options that are available. One of those is voluntary assisted dying and, where it is legal, it should be included in that description. That is the safeguard. This is not about coercing people towards voluntary assisted dying; it is about letting them know the choices that they have available. They should be told all the choices that are available. I think that is reasonable.

THE CHAIR: Along the same lines, we have had a number of witnesses put to us that there should be a higher emphasis on palliative care. It should not be seen as an either/or situation; both should be offered. Noting that you are quite a strong advocate for voluntary assisted dying, how would you see the balance between offering palliative care and voluntary assisted dying—the two interacting with each other—and have we struck the right balance in the bill before the Assembly?

Dr Swan: I am also an advocate for palliative care. About 85 per cent of people who access voluntary assisted dying go through palliative care. In my view, voluntary assisted dying should be part of palliative care. It is just another choice at the end of life. The palliative care clinical teams are the people who are experts in looking after people at the end of life. This is just a choice that is available to the individual at the end of life. I do not see it as either/or; I just see it as another choice. I would hope high-quality palliative care includes thinking about how you would describe that as a choice to individuals, but it is not about either/or. You can definitely have palliative care and access voluntary assisted dying. Most people do.

I think we should definitely advocate for good funding for high-quality palliative care. It is essential for all of us at the end of life. Not everybody wants palliative care and not everybody wants to travel to where they might be able to get palliative care. Some people just want to die at home under their own terms. What voluntary assisted dying is about is genuine and true person-centred care. It is giving the person choice about what happens at the end of life. They may choose to have palliative care and voluntary assisted dying or they may choose not to. That is an individual's right.

THE CHAIR: Mr Braddock.

MR BRADDOCK: Regarding the obligations of care facilities, in your submission you say:

> … evidence now exists from around Australia to show that a blanket right for institutions to conscientiously object … leads to distress and suffering for some who are eligible for VAD, yet blocked in their efforts to pursue this legal medical care.

What is the evidence? Can you please elaborate on that?

Dr Swan: Our expertise is largely in listening to the stories of patients, families and health professionals. We largely get our evidence base from the people who come to us. But the review boards are another source of evidence. I am sure you will have heard from some of the research experts in the space who have done thorough interviews of people involved in voluntary assisted dying. Unfortunately, there are documented cases of people who have been treated quite badly in institutions that were conscientiously objecting to voluntary assisted dying and took that to the extreme by saying, “We’re not going to allow a person to have anything to do with voluntary assisted dying on our premises”. Those people were forced, at the very end of their life, to either leave the facility and talk to their healthcare professionals in the car park or be transferred to another facility where they did not know the care team and might have been away from family and friends. They were transferred at the end of life when they were in pain and they were suffering. It is just cruel and unreasonable.

It is absolutely right that people should have the right to conscientiously object or to choose not to be involved in voluntary assisted dying, but the compassionate and caring thing to do is to make sure that the individual, if that is what they want, can access that care from someone else who is able to deliver it.

MR BRADDOCK: My other concern is where the market may be dominated by operators who seek to conscientiously object. Is there real choice available to individuals to seek relocation to another place where they could actually access the option?

Dr Swan: Yes. If you are in a rural or remote area where the only real facility is a faith-based facility and they object to voluntary assisted dying and you have to be transferred, it could well mean a flight or a transfer to somewhere a long way from home. That is moving people essentially out of their home, where they have lived. They might have been in the facility for some time. It is not fair and reasonable to do that.

MR BRADDOCK: Thank you.

THE CHAIR: I have a supplementary to that. I think Mr Braddock has canvassed institutional conscientious objection, and we have discussed that, but what I am interested in is a little bit more explanation from you as to the views of an individual’s conscientious objection and the impact that can have on an individual accessing voluntary assisted dying.

Dr Swan: I will start by saying there are a lot of people who are conscientious objectors and still treat people with great respect and care and understand that the person in front of them has their own choices and rights to those choices. But we have heard about cases where a person will raise the topic of voluntary assisted dying and their health professional, who is a conscientious objector, is potentially almost quite rude in their response, saying, “We don’t do that. I don’t do that,” in a manner that makes the person feel quite uncomfortable and dismissed. That is one way you could potentially obstruct. By not providing any information about where a person can go for help, there is such a power imbalance in that conversation and the individual might decide not to raise it again and not go elsewhere. They would not know that, if they went to someone else, they might get a different response.

THE CHAIR: One of the things we have heard through a number of sessions is that conscientious objection, in its most absolute form, for a lack of a better way of putting it, means that the person who is objecting does not want any part in the process and may even refer someone on, and that would be considered participating in the process. One of the things that I have been trying to get my head around, and I would welcome your views on this, is the balance of the two rights. When someone wants to conscientiously object and not participate at all in the process, would that start to impinge on the rights of the person seeking access to voluntary assisted dying? And what are the impacts that could have? Certainly, as I said, I would welcome your views if there were any insight from the cases you have heard about through your advocacy.

Dr Swan: I think there is a difference between conscientious objection and obstruction. We all recognise that everybody has a right to have their own conscience and view of this issue. They should, and that view should be respected. But being obstructive, which is actually about blocking access to someone's legal choice, is not right. If somebody asks you for information about a legal medical procedure, my view is that the least you can do is help them access that information, if you do not feel able to provide it yourself.

THE CHAIR: Some of the feedback that has come in has been around the penalties for people who choose to conscientiously object or who, for other reasons, do not provide access to the information. There have been various views put to us about whether the current provisions in the bill are proportionate or whether they need to be considered further. There are also the time frames, but I think we have canvassed the two-day time frame already.

MS CASTLEY: The fine as well.

THE CHAIR: Yes. It has been put forward that the fine is quite high. I seek your views on that discussion and whether you think the penalties for medical professionals, for not reporting a request for voluntary assisted dying, are proportionate or whether they need reconsideration?

Dr Swan: It would seem fair that you have the same sort of weight on the penalty for coercing someone towards voluntary assisted dying as you have for coercing someone away from voluntary assisted dying. If you can strike a fair balance where both are seen to be wrong—and neither should be encouraged and we should do everything we can to try to prevent them—then you would have the same sorts of penalties in place for both.

THE CHAIR: Dr Paterson, I will throw to your substantive.

DR PATERSON: Thank you. We heard from Palliative Care ACT yesterday. They mentioned that there is quite a shortage of health practitioners offering voluntary assisted dying and that there is quite a reluctance to be engaged in the scheme. Mainly proactive doctors are excited about it and interested. I note that in your submission you talk about health practitioner remuneration coming up in one of the conferences. I am wondering how to support and encourage health practitioners to be confident in delivering this service.

Dr Swan: It is a complex issue for health practitioners. Most health practitioners support voluntary assisted dying and most Australians support voluntary assisted dying, but not all health practitioners want to be involved in voluntary assisted dying. It is not easy work. It can be emotionally taxing. The fact that some people are not putting their hand up to be involved does not mean that they do not support it. It is just like not everybody wanting to be a dentist or not everybody wanting to be a gastroenterologist. I do not think it is unusual that you find a world where not everybody says this is what they want to do as part of their practice.

The other piece of it is that there are some complexities around payment. If you are a general practitioner and you have a very busy practice—I think it is quite well documented how difficult it is for general practices to make ends meet as it is—the care of someone through the whole voluntary assisted dying process can take anywhere between eight and 36 hours. It is not a quick process. It takes time to explain, to potentially re-explain, to talk to families, to ensure the person is comfortable and to ensure all the steps in the process are completed. It is not a rushed process. The people doing this work are amongst the kindest and most caring health professionals in the country. They want to do a good job, they want to support the person, and they often spend hours outside of their working hours talking to family or trying to reassure and help people through the process. Unfortunately, under the current MBS payments, there is not a lot of payment for this work, so a lot of this work is being done pro bono.

So you have the double whammy: for some people this is not the easiest work, and it is complex and wrapped with legalese. That is not normal in medicine. You have a law that dictates what you can and cannot do. So it is a bit unusual. And then you are potentially unpaid. It is not straightforward to put your hand up and sign up for voluntary assisted dying. My absolute thanks and admiration go to those caring healthcare professionals that are doing the work.

On a positive note, if you talk to the care navigators, the care coordinators and the consulting people, they say this is amongst the most rewarding work they have ever done. It is so appreciated by the dying person, their family and their carers that they finally get a way to have some empowerment and choice back in their lives. They get to think about death in a more positive way because they can think: "What do we want to do? How are we going to plan this? What would Mum like to have in the last days of her life?" It is a different experience. It is not all terrible, but it is not easy.

What we can do to help them is try to make the training as simple and clear as possible. I would love a world where the training is paid so that, if people take eight hours out of their day, they at least get some coverage for that time. There are some models that are available in New Zealand, for instance, where there are some lump-sum payments at various steps of the voluntary assisted dying process. It would be lovely to have a more comprehensive funding package for the care. The more we could do to educate the community and make them understand that this is just another choice at the end of life—and hopefully it is a legal healthcare option available to all Australians in the future—the more we can send the message out and remove some of the stigma around voluntary assisted dying as well. They are the things that we can do.

Regarding palliative care, if they were willing to be more honest about including voluntary assisted dying in palliative care and not saying it is something separate and different, that would be helpful as well.

THE CHAIR: We are going to have to wrap up there because we have gone a little over our time and I am sure our next witnesses are keen to have their session. I would like to thank you for appearing today. On behalf of the committee, thank you very much. I do not believe you have taken any questions on notice throughout the hearing, but there will be an uncorrected proof *Hansard* sent to you to check for any factual errors. Once again, thank you very much for taking the time to appear today, and thank you for the submission from Go Gentle Australia.

Dr Swan: My pleasure. Thank you.

Short suspension.

SWANTON, DR DAVID, Chapter Leader, Exit International, ACT chapter
CLIFFORD, MS JANET VERONICA, Committee Member, Exit International, ACT chapter
ROBERTS, MS JENNIFER LEE, Executive Committee Member, Exit International ACT chapter

THE CHAIR: I would like to welcome the witnesses from Exit International, ACT chapter. I would like to remind witnesses of the protections and obligations afforded by parliamentary privilege, and draw your attention to the privilege statement, which is the pink card on the desk. 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. Once you have had a chance to read the statement and you are comfortable with it, can I please get you to confirm for the record that you understand the implications of the statement and that you agree to comply with it?

Dr Swanton: Yes, I understand and agree.

Ms Clifford: Yes, me too.

Ms Roberts: Yes.

THE CHAIR: Thank you very much. We are not inviting opening statements, but if you do wish to table one, the committee is more than happy to accept it and we will have a look at it in due course. We will go to questions straightaway. Ms Castley?

MS CASTLEY: I have some questions—thank you for your submission—around kids and your desire to see them involved at this early stage and not wait for the review. Can you talk about that? Many other submissions have quite a concern around the age and lowering it to under 18.

Dr Swanton: It is possibly a legitimate concern, but I think the discrimination against children, against people who are not terminally ill, is as abhorrent and vile as discrimination on the basis of sex or race. Why should we be condemning, in this bill, children to suffer? Children must not suffer. Perhaps you would agree with that. Do you want children to suffer when adults need not do so? I am asking that rhetorically. I presume you would say that, no, you do not want children to suffer. You would say, "How can we make children access voluntary assisted dying? They clearly do not have decision-making capacity." Decision-making capacity includes being voluntary and being well informed. They do not have that.

That premise that they must have decision-making capacity as the only way that they can access services like voluntary assisted dying is false; otherwise children could not have heart operations. They could not have cancer treatment. They could not have organ transplants. We do not limit organ transplants only to adults. Why are we limiting voluntary assisted dying only to adults? If you had a two-year-old child, a toddler, they cannot make a decision. Let us think about the terrible circumstance in which they have three months to live. They are going to suffer over that three months. It could be a tumour on the spine; it cannot be alleviated by palliative care. They can suffer and die; or, in other circumstances, you here, being legislators, can enable a bill which will stop suffering.

We think that is what a humane, civilised society should be doing. It is not hard. You allow parents and guardians to make decisions, acting on the best advice of doctors, in the child's best interests. It must always be in the child's or the adult's best interests.

Children are not the primary concern of Exit ACT. Our members are mainly over 50, but why can't non-terminally-ill people also access voluntary assisted dying? Again, that is discrimination. You would not limit abortion only to women who had been raped. We would not limit marriage only to heterosexuals. Why are we limiting voluntary assisted dying—everybody can suffer, including children—only to terminally ill adults? Children are more precious than adults. We should be looking after their interests just as much as those of adults. I hope that has answered your question.

MS CASTLEY: Yes; you have been very clear on it. My thought, having had children myself, is: if you changed this bill to include children, and a seven-year old says, "Mum and dad, I'm done; I'd like to access voluntary assisted dying," I think that the concern of many—those who have raised this concern regarding lowering the age—is that that would take the family out of the decision. Is that what I am hearing? Would you be happy for that seven-year old to say, "Mum and dad, I would like to access voluntary assisted dying," or at that point are the parents still involved?

Dr Swanton: There is this issue of Gillick competency, when a child has competency to make decisions themselves. A seven-year old would not have Gillick competency. The parent, the guardian, is still responsible.

THE CHAIR: It is 14 years and older, for Gillick competency.

Dr Swanton: I think so, yes. But even if that had not been determined, if there was a disagreement between the parents or guardians acting on the doctor's best advice and the child, perhaps keeping the child alive might be the best option. A seven-year old is not going to be saying, "Sorry, mum; I do need to die." They are not going to have that individual autonomy that is required. What this bill lacks is that, even though it says in the principles that individual autonomy is one of the principles upon which the bill is based, it does not align with that individual autonomy at all.

THE CHAIR: One of the things that has been put to committee is that, by removing the time frame, it has opened up voluntary assisted dying to a range of people who would be considered vulnerable, and who are perhaps not accessing the scheme for the reasons for which the scheme is intended, to make voluntary assisted dying available to them.

From reading your submission, you are quite supportive of the removal of the time frame. Can I please get a bit more of an understanding of your rationale behind supporting that? Also, how do you see the bill as it stands, and the safeguards within the bill, still supporting and protecting people with vulnerabilities from feeling that they should be entering into a voluntary assisted dying decision, perhaps through coercion, or through means other than what would make them eligible?

Dr Swanton: The key issue here is decision-making capacity. That is key, regarding the three eligibility criteria that we believe you need to have. We have surveyed world voluntary assisting dying advocates on this: decision-making capacity, being voluntary, being well-informed. You mentioned "vulnerable". No-one has defined who a vulnerable person is. If they have decision-making capacity, they are not vulnerable. Can you please give me an example of someone who might be vulnerable?

THE CHAIR: Some of the examples that have been put to the committee have been people with disability who might feel that they are a burden on the community. There might be a power imbalance between them and the people who are perhaps doing assessments or providing supports. One example put to us was that that is the case. Other examples included elderly people. Again, the example that was put to us was that they may feel that they are a burden upon their families. Elder abuse, in particular, has been raised as an issue, and this could form another form of elder abuse.

Dr Swanton: You are suggesting, if I am correct, that they could be coerced into voluntary assisted dying without it being voluntary?

THE CHAIR: Yes. That is what has been put to the committee.

Dr Swanton: That would mean they do not have decision-making capacity. If they can be easily coerced, they are not making a voluntary, well-informed decision, acting on the evidence.

THE CHAIR: Dr Swanton, I can see the point that you are making. My next question to you is: how is it assessed? How do we determine that someone has not made the decision of their own volition, that they have been coerced into it, and therefore they do not have decision-making ability?

Dr Swanton: There are standard criteria for determining decision-making capacity. The *British Medical Journal* in various articles describes four or five criteria. You need to know what the implications of the action are. You need to know why you are doing it, and explain that properly to a doctor. We do not think doctors should be involved in this process at all, because that violates our individual autonomy. Where they probably do need to be involved—in one of the two instances—is in determining decision-making capacity. Is that person being coerced? If they are being coerced, they do not have full decision-making capacity; therefore they are vulnerable and they are being ruled out of voluntary assisted dying because they have not been considered to have decision-making capacity. That is very important.

In regard to life expectancy, we are glad it is not there anymore. But you still need to be terminally ill. Someone could have motor neurone disease, locked-in syndrome, where you can communicate only by blinking an eyelid, or some other condition, such as Huntington's disease. You could have five or 40 years left to live with unbearable suffering, and the bill suggests that those people must still suffer. If you have three months left to live, you can access voluntary assisted dying, but if you have to go through this rigorous administrative process, we would rather spend the last three months of our lives with our families.

THE CHAIR: Dr Swanton, it is fair to say that we have had a range of views put to us over the last few days on voluntary assisted dying, from a range of perspectives, and the human rights discussion has come up. You take a very specific view within human rights, or one tenet of human rights, which is individual autonomy. We have also had other people put to us that, if you are not considering the collective, you are not appropriately applying human rights.

My question to you is: with your argument for human rights and the point that you take it to, how, as a community, do we balance these different views on human rights? Flowing from that, do you think that the scheme, as written, while not your preference and not your interpretation of human rights, strikes a balance between these various views that are out there?

Dr Swanton: I still think individual autonomy rules and should be the predominant right. I can say that because if I asked any of you to have a sexual relationship which is not the preferred one that you would like to have, you would say, "No. You can't impose that on me." The religious people who were here yesterday were effectively imposing their religious views on people who are not of their religion. They might consider the sanctity of life; they might consider that their religious views must hold for other people. But they would not want my views to hold for them.

On that conflict between religious and individual rights, we always make a strong argument that individual rights should prevail. We would know that because a woman has a right to have an abortion. That is her right to her body. I have a right to choose whichever sexual partner I choose—male, female or somebody else. Why should I be restricted? I am not. If we allow individual autonomy for sexual relationships, for abortion and for just about everything else, why are we restricting it for voluntary assisted dying, or even contemplating doing that?

THE CHAIR: That answers my first question as to better explaining your philosophies on human rights, and the things behind your position in approaching this. My second question is: acknowledging that there is a range of views out there, with the balance within the bill, while it might not be exactly what you are advocating for, through the application of human rights that you practise, can you see the scheme working if it were implemented as is from day one?

Dr Swanton: For many people, yes. The scheme will be fine for many people. For some people—and I can think of me, in various situations. I do not want to spend the last four weeks of my life looking up at a ceiling in a palliative care facility, so I and many of us will take the legal lethal substances that we have in our homes at the moment to die, as has been happening in Canberra for the past 20 years. Couples have died together in Canberra in the past 20 years because there was no regulation. I am now challenging the ACT government and the Assembly to development legislation that meets the needs of all Canberrans, and we are the group that represents people who will actually use the legislation.

THE CHAIR: Is it fair to say, Dr Swanton, that you see the bill working, if enacted the way it is, from day one; however, you would like it to be accessible to more people?

Dr Swanton: Yes, and otherwise—

THE CHAIR: In the interests of time, we will leave it there. Dr Paterson has a question.

DR PATERSON: On the discussion of rights, we heard from Calvary hospital yesterday. I think that everyone accepts conscientious objection from individuals, and they refer the patient on promptly; all good. Where there has been some debate is around the institutions. Calvary was holding pretty strong yesterday that they should be allowed to hold that their institution does not allow a voluntary assisted dying practitioner onto the grounds. We heard from Go Gentle just before, around how that has led to adverse consequences for patients in other jurisdictions. On your rights-based philosophy, what is your view of an institution, a hospital or an aged-care facility saying no, and conscientiously objecting as a whole to—

Dr Swanton: It is not ideal. Conscientious objectors should need to pass the person, as is required in the bill, to somewhere else. But that might mean them moving outside the hospital. If I were in Clare Holland House now, I would take my legal lethal substance with me as well and be prepared to take it. We have had instances in Canberra where people have gone to Clare Holland House with their legal substance in their bag and it has been taken away from them. So it is not easy.

They should be allowed to conscientiously object, but people can change their minds. They might think, “Yes, that hospital is fine for me,” or that palliative care facility, and they might change their mind. The patient’s best interests must be at the forefront of any consideration. If you are a doctor and you are looking after patients, their interests—not yours—should be primary.

MR COCKS: My apologies; I could not be here earlier, so you may have already touched on this. I am interested in trying to find where the appropriate line is for vulnerable people, including people with limited or without decision-making capability, as well as young people or people who are otherwise in vulnerable situations. I would like to understand how you would define a line that protects people from coercion or from making a decision that their future self would regard as a mistake.

Dr Swanton: They need to have decision-making capacity. We need to define what a vulnerable person is. My understanding, from reading the medical literature, is that if you have decision-making capacity, you are not vulnerable. But decision-making capacity needs to be assessed properly. As members join Exit, our group, we can make some rough assessment. That would not be sufficient, I do not think, under a regulatory system. We would need a proper, formal assessment as to whether someone has decision-making capacity, is getting the drug because they have been coerced, providing it to someone else or whatever. That would probably need medical advice as to whether they have decision-making capacity.

MR COCKS: Decision-making capacity is quite a subjective assessment in a lot of ways. I am assuming you are familiar with Gillick competency assessments. An individual’s decision-making capacity around one type of issue may not mean that they are fully able to understand something of extreme significance.

Dr Swanton: Something else, yes.

MR COCKS: Is there an age at which you think decision-making capacity is absolutely possible or not possible?

Dr Swanton: No; no age limit. There might be 25-year-olds who cannot make a decision. There might be eight-year-olds who cannot make a decision. We have to use their guardians or parents, acting on the best advice of doctors, but we must always act in a patient's or person's best interests. Why would we discriminate and condemn people to suffering when they need not do so?

MR COCKS: Who determines those best interests?

Dr Swanton: If the person is unable to make that themselves, the parent or guardian will decide whether the child is suitable for an organ transplant, a heart operation or voluntary assisted dying. An example I gave earlier was a three-year-old who had four months left to live, and they were going to suffer unbearably for those four months and then die; or the bill could be changed so that they did not suffer. What would a humane, civilised society do? It is up to you, but I think the answer is obvious.

MR COCKS: One of our important jobs here is to test the edge cases—the things that are extremely unlikely to happen, often if at all, but we have to make sure that this bill can cover everything. Is there no instance where you can see a parent not having the best interests of their child—who had become, in their opinion, a burden on them—at heart?

Dr Swanton: In that case we would not allow parents to give their kids heart transplants. The parents could say, "They're a bit of a burden, I don't want that. It's going to cost too much for the heart transplant. I wouldn't bother." Why are we applying special rules to voluntary assisted dying when we would not apply them to other issues involving children or adults who are not terminally ill? We should have advance care directives. Most Exit members are concerned about dementia as an issue. We can say, "Take us off life support," but we cannot say, "When I can't recognise my family, and I can't add two plus two, I would like to have the drug, please."

MR COCKS: It seems that you see no difference between the decision around providing a heart transplant and the decision to end a child's life.

Dr Swanton: On the ethical and logical issues, does a child make the decision themselves on a heart transplant or voluntary assisted dying? No, but the parent or guardian acts in the child's or person's best interests in both situations. Ethically, they are the same. The person, the parent or the guardian, makes the decision, acting on the doctor's advice, in that child's best interests, in both instances. If you are worried about a parent making a bad decision about voluntary assisted dying, they should be equally worried about a parent making a bad decision about a heart transplant, and you should ban that as well. It is illogical to do one and not the other.

THE CHAIR: Dr Swanton, do you have anything to finish off on, in one minute or less?

Dr Swanton: I would like to challenge the ACT government to do better. This bill is much better than what has been done in the states, and I congratulate Labor, the Greens and the Liberal Party on supporting the bill so far. Hopefully, it will pass in an amended form, because we from Exit, looking after many elderly people, are all worried about dementia. We are acquiring legal lethal substances at the moment. The AFP in the last year has come into people's places—elderly people's places—after 11 o'clock at night on the basis of a welfare check because these people are alleged to have had legal lethal substances. Hint: they did. They are legal substances. This will still happen if the legislation does not meet the needs of all people. It is about individual choice. No-one can tell me whether I can have an abortion or not, or who I can sleep with, so why can anybody—a doctor—overrule me about, "David, sorry, you're not sick enough"?

The issues you raised about where that line is, Mr Cocks, are very relevant. If you start with the principle of individual autonomy, and everyone is responsible for their own body, as long as they have decision-making capacity, that should be sufficient. With some of the guidelines—yes, I have been through regulatory processes; you do need some background—the process here is such that most Exit members are not going to be bothered going through a regulatory system for over three months. I would rather be spending that with my family.

Thanks very much for hearing from us today. I have tried to challenge you and suggest where you ought to be going. That has not been done too much in this debate. With a lot of the people yesterday, their arguments can be rejected because they are religious, and we are not of that religion. Many other people would be patting the Assembly and the bill on the back, saying, "Yes, congratulations; job well done." But you can do more. If you do not, do not be surprised if Exit members start to suicide using their legal lethal substances. We do not want that to occur. With something as important as voluntary assisted dying, there should be a regulatory system in place. That is important.

THE CHAIR: We will have to finish there. On behalf of the committee, I would like to thank you for your attendance today and for the time you have taken in writing your submission. I do not believe there were any questions taken on notice. You will be sent an uncorrected proof copy of the *Hansard.*

We know that this is a very sensitive topic and it can be quite confronting for a number of people. If anyone in the viewing audience or anyone watching online has in any way been affected by anything that has been said, please reach out to the committee and we can provide support.

MUIR, MR DAVID AM, Chair, Clem Jones Group

THE CHAIR: I would like to welcome our next witness, from the Clem Jones Group. I would like to take a moment to remind you of the protections and obligations afforded by parliamentary privilege and draw your attention to the privilege statement which was sent to you by the committee secretariat. 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 privilege statement and that you agree to comply with them.

Mr Muir: Yes, I do.

THE CHAIR: Thank you very much. We are not inviting opening statements; however, if you do have one, you are welcome to provide it to the secretariat, and the committee can read it in due course. We will jump straight into questions.

MR BRADDOCK: I have a question about the clause "the individual is in the last stages of life", which is currently in the bill.

Mr Muir: Yes.

MR BRADDOCK: Can you please outline what concerns you have about that clause being in the bill, why you are recommending that it be removed and whether that would make any substantive change to who may be eligible for VAD?

Mr Muir: The concern with that wording is that it is perhaps subject to argument. I come from a legal background, so I have seen many arguments over the years about the meaning of words and definitions. It brings in, in our view, an ambiguity and could be a potential barrier because of that argument about to access to VAD. We believe that the other safeguards that are in that bill are more than adequate to allow the scheme to proceed.

MR BRADDOCK: So if that clause was to be removed, you would not see that there would be any broadening in the number of people eligible?

Mr Muir: I think it is really eliminating an area of subjectivity. When you look at the other words that you have got there, the real focus, we believe, is on unrelievable suffering and in the circumstances where there is an advanced progressive disease that is expected to cause death. We believe that those words are more than adequate to comply with the scheme. Otherwise, we are getting back to those periods of time, the six months and 12 months and so forth, which are problematical, in our observation, because for medical practitioners and patients there is a certain amount of uncertainty with the human body in both things. We applaud not having the six and 12 months to put untoward pressure on medical practitioners. It also may cause difficulty in access. By having the words "last stages of their life", in some ways you are pulling back the advantage of not having those time periods.

MR BRADDOCK: Thank you.

THE CHAIR: Just following on from that, Mr Muir, one of the things that have been put to us is that removing that time limit does mean that there could be greater coercion of vulnerable people and people with disabilities. We have had examples of elder abuse raised with us, as, without that time requirement, this could be an area where we see more elder abuse leading to people accessing the scheme. In your view and with your legal background, do you believe that the bill has adequate safeguards to protect against coercive behaviour in those sorts of examples where we know that people are a little bit more vulnerable and perhaps need increased safeguards?

Mr Muir: Yes. Certainly, it is our view that the bill, as drafted with that amendment, would have more than adequate safeguards to protect those people who may be vulnerable to coercion. In fact, we believe that the VAD scheme itself helps to remediate against coercion in the sense that, under present circumstances, as you well know, terminal sedation is practised around the country in hospitals and those decisions are made, in most circumstances, out of the hands of the person who is suffering; it is often medical practitioners or family or whoever who are involved in making those decisions. We see that this safeguard framework actually is a safer environment for somebody who may be vulnerable to coercion.

THE CHAIR: Can you elaborate a little bit on the provisions within the bill that lead you to hold that view?

Mr Muir: I think it is the fact that you have got somebody who is suffering from something that is liable to cause death; you have the safeguards, with more than one doctor involved in the process; you have various time lines there to avoid any circumstance of acting in a spontaneous way; and you have the review board, which will have a role in observing and reporting on the way in which the act operates, once it becomes law. I think that there are multiple safeguards there and none of those exist right now in relation to, say, terminal sedation.

THE CHAIR: Okay; thank you.

DR PATERSON: In your submission you refer to looking at the obligations of facility operators. We have had evidence from Go Gentle today, and also from Calvary Health Care, with opposing views on this. I think everyone accepts the right for an individual health practitioner to conscientiously object, but at the institutional and facility level I am interested in how this has played out in other states and other jurisdictions, regarding facilities that do not allow voluntary assisted dying on their premises versus those that may object as an institution but allow a health practitioner to deliver voluntary assisted dying services on their premises.

Mr Muir: Probably the best examples of that would be in the state of Victoria. In the review of how the program operates in Victoria, there have been found to be unnecessary delays, causing unnecessary suffering in certain institutions. We know that in the debates leading up to the legislation in the other states there was very strong opposition to having voluntary assisted dying performed on their premises. That is something that, from our observation, has been the case in all the debates—that you have an institution that has a particular point of view, in opposition. My understanding is that in Victoria you will find examples where there have been unnecessary delays as a result of the views of those institutions, against the interests of their patients.

DR PATERSON: And how important is it, if this is a legal medical procedure, that everyone in the ACT community has equal access to this?

Mr Muir: That is clearly an important point. Even in some of the larger jurisdictions, like Queensland or Western Australia, you have that remote concept as well, which makes access to practitioners who have been trained and are able to practise the scheme difficult. Access is something which is a matter of human rights and equality. We would be saying that this is very much a human rights issue and a matter of equity and equality.

DR PATERSON: Thank you.

MR COCKS: The discussion has been about conscientious objection. I am interested in understanding what you see the access problems or unequal access would be resulting from institutions conscientiously objecting.

Mr Muir: First of all, transparency is really, really important so that when somebody takes up residence in an institution they are aware of that institution's position. Otherwise they could be effectively ambushed when they get to a stage in their disease or illness where they are looking for access to VAD and they are then surprised by the fact that that institution is going to put up barriers and have an opposition to it.

The beauty of the legislation, we believe, at least in Queensland, is that it puts an obligation on the institution to provide reasonable access. There is a recognition of conscientious objection and they do not have to participate, but there is a duty in the legislation in Queensland which requires that they provide reasonable access. Then you have a circumstance where somebody may not be able to be moved, for medical reasons. The important thing there ought to be the paramount interests of the patient. If moving somebody is going to cause unnecessary suffering and distress, that person ought not to be moved and access ought to be allowed for those medical practitioners to enter the premises to facilitate the scheme.

MR COCKS: Based on what you have said, would making sure that individuals are aware ahead of time of an institutional objection and that assisted dying is not provided in a facility not offset that access concern?

Mr Muir: Not necessarily. As I said, the interests of the resident or the patient are paramount. Bear in mind that sometimes people are transferred in circumstances where there is little choice and there may be no other institutions available to them. That is why it is imperative, we believe, that that institution does not stand in the way of the rights of their patients.

THE CHAIR: Mr Muir, what I take from that is—and correct me if I paraphrase it wrong—you are essentially saying that there needs to be a balance of the rights so that there is the ability for people to conscientiously object but in a way that does not necessarily prohibit the ability of those who wish to access voluntary assisted dying to be able to access it.

Mr Muir: Yes. We believe that the Queensland legislation is a good example of balancing those interests. There is provision in the Queensland legislation for those institutions, or medical practitioners for that matter, who have a conscientious objection. There is no obligation on them to participate, but there is an obligation on them to refer.

MS CASTLEY: I would like to just tease out a little bit the conscientious objection with regard to the two days. Just trying to understand: is it simply the working day? Is it that you would rather it say hours rather than days? Or do you think it should be longer? Can you talk about that for me?

Mr Muir: Yes, certainly. We think that working days could be problematic in the circumstance if somebody were away on holidays or something of that nature. What we focused on here was on the fact that we have an administrative decision being made by an institution, as opposed to say a doctor or a nurse practitioner. Our suggestion is to say 48 hours. Or you could leave the two working days in there but say “whichever is the shorter”, so that you have, once again, a protection for that person at the end of life, so they are not left basically wondering whether they are going to get access or not. If you have 48 hours and/or say two working days that is fine, “whichever is the earliest” I think will facilitate that anxiety.

MS CASTLEY: Have you heard from any groups about the concern that two days, 48 hours, is not quite long enough? I know we were chatting with the Australian College of Nursing, and they were explaining that 48 hours in a nurse’s life is far different to anyone else’s working time, and there were concerns raised that it is too short. Do you have any thoughts on that?

Mr Muir: Yes. I think one of the things that we have to realise is that most people at end of life have a human inclination to hang onto life as long as possible. So when they make the request, they tend to be in extenuating circumstances and there is a sense of urgency from their point of view. In my understanding, the human condition is that people want to live. That is in all of us. We want to live. Only at the last, will there be an acknowledgement that I need to access voluntary assisted dying. So you have a sense of urgency in those circumstances. I think that that will facilitate in dealing with those extenuating and urgent circumstances, which is not that unusual.

THE CHAIR: The other part that has come up there around this two day question has been that penalties for not reporting within the two days are not proportionate. Given that you do have a legal background, as you said Mr Muir, I would be quite interested to hear your thoughts on the proportionality of the penalties for not reporting or not referring someone.

Mr Muir: Well that is the aim. It is a bit of a balancing act of proportionality because you do not want to make it too easy for an institution to drag their heels on this and have a smaller penalty, which will not be a disincentive for that kind of conduct. So it is a question of balancing that. I think that is all I can really say about that in terms of the proportionality. It is a question of having something there which incentivises lawful conduct rather than otherwise. That is all really I can add to that, I think.

THE CHAIR: We have actually had a number of people come in and raise the issue and the concern for carers or people closely associated with a person seeking voluntary assisted dying, and making sure, not necessarily that they have a say in the process, but that their needs are considered in the process. I would be really interested to know if in the experience that you have had, looking at the various schemes, the best way that supports could be given to those people close to the person accessing voluntary assisted dying?

Mr Muir: I just might—Chair, if you could just—

THE CHAIR: Have I not spoken clearly enough into the microphone?

Mr Muir: I just could not quite catch that.

THE CHAIR: No, that is fine. Sorry, I am looking at you, which means I am not looking at the microphone. So, one of the things that has been raised with us has been the role of carers and those who support, particularly people who are accessing voluntary assisted dying. We know most people who would be accessing the scheme are going to need an additional level of support, such as informal caring arrangements, family, friends, and so forth, and there is quite a big impact to those people who are supporting the person undertaking voluntary assisted dying. What I was interested in, from your perspective and your knowledge of how schemes are working elsewhere, is what considerations could we take into account, and how could we potentially improve the current scheme as proposed to better support those people?

Mr Muir: I think that is a really important point, Chair, because the impact of somebody dying in any kind of circumstance is significant. We believe that there should be some facility for counselling and support for family and carers in those circumstances because it can be a traumatic experience for people who are in that caring role.

It comes into another area, too, which we believe is really important, which is awareness and education. GPs would be the touch-point for most of this. Even in Queensland, we know that there are people still not aware that we have voluntary assisted dying in Queensland, for instance. So that is why we believe that resources need to be invested into awareness, and GPs might be a point of call.

Organisations like Dying With Dignity we think are very valuable and important. There are many palliative care nurses I know involved in Dying With Dignity around Australia, and they, already I know, are offering support. I would be suggesting that they be further resourced to do it more adequately. They do much of it by telephone, in terms of in a supportive way and in an educated way. So we are certainly recommending that there be adequate resources into support and counselling. An organisation like Dying With Dignity, by and large, is probably well placed to do that, in the sense that they have palliative care nurses and others who are very good at providing those services.

THE CHAIR: Picking up on the theme of palliative care—because that is also something that has been quite a large topic with a range of views put to the committee over the last few days. One thing that is coming through, I think it is fair to say, quite clearly, is that people want to make sure it is not an either or: that it is not a one or the other choice; that is not voluntary assisted dying or it is not palliative care. Mr Muir, in the context of the bill, do you think the bill strikes the right balance, or could it be improved to better facilitate both palliative care and voluntary assisted dying, not have one with precedence over the other?

Mr Muir: I think that is also an important feature. I think of all the campaigning we have been involved in to ensure that it is a hand and glove experience between palliative care and voluntary assisting dying. Voluntary assisted dying is merely one of the options available for somebody at end of life.

In Queensland for instance, I myself am in forums where I am standing up and talking about, obviously, voluntary assisted dying legislation, but I had someone from Palliative Care Queensland talking about the palliative care aspects. We make a point of saying it is not an either/or. Palliative care, in fact, will help most people most of the time. It is a smaller percentage of people that will require voluntary assisted dying, and we always say that palliative care should not be jettisoned. We also need to make sure that we cover the field with end of life. Palliative care, we believe, ought to be better resourced, to be frank. Through the Clem Jones Group, we provide funding to some hospices here in Queensland, and hospitals. So we think that it is something where you need to cover the field with both palliative care and VAD. They should be homogenous, really, and collaborative in the way they operate.

MR COCKS: I want to go back to some of the earlier discussion around coercion. When we were speaking with Advocacy for Inclusion in particular, the discussion around the risks was not necessarily intentional coercion, but the potential for the power imbalance between a doctor's opinion and a person who may have just been diagnosed with a severe disability, having the prospect of assisted dying raised with them creating the potential for a decision a disabled person otherwise would not have made.

Mr Muir: I think the important thing is that a doctor or nurse practitioner, like any service providing professional capacity, should be able to provide advice as to all the options available. When you think that the first touch-point in any of this is likely to be somebody's GP, there will be a relationship, a rapport there and an understanding. I think we can rely on our general practitioners in particular to be able to message their communications in an appropriate way.

I know that in Victoria there is a restriction in terms of raising VAD which we think is problematic, because basically, you are asking a general practitioner to give advice with, sort-of, one hand tied behind their backs, as it were. I think the safeguards there are not only the GP who is the original consulting person, but also the further follow-up doctor, who will be required to assess that person in terms of their capacity and to ensure that there is no coercion. So I think that is a safeguard. Having that second doctor involved is a safeguard to any person who may have vulnerable thoughts in relation to that.

MR COCKS: So you do not think that there are risks that are valuable in offsetting further?

Mr Muir: Well, I am not aware of any that would be appropriate.

MR COCKS: Maybe I can put it in context. This week we have had an instance in the media of a general practitioner who, it seems, has not done the right thing in a number of situations, which raises the concern that just relying on our good general practitioners may not be enough.

Mr Muir: But there is a second doctor involved in the process.

THE CHAIR: Mr Muir, looking at the question of whether a doctor can initiate the conversation, picking up a little bit on what Mr Cocks was saying, it has been put to us as a committee that medical professionals should not be able to raise the conversation. You made the comment that you are not supportive of that. I wanted to get a better understanding of why you are not supportive of that as a proposition.

Mr Muir: Because I think you are putting a medical practitioner in a circumstance where they are aware of other options for their patients, but they are not allowed to talk about them or discuss them. I think that is an unnecessary restriction on the professional duty of a medical practitioner. The way around that, as provided in Western Australia and the laws there, and in Queensland, is that when they raise the topic of voluntary assisted dying, they must also, at the same time, raise the topic of all the other options, and set out all the possible treatments so that the patient is fully informed as to what their options are. I think that works well, in my understanding. Victoria is problematic because they do not have the legislative assistance that they do have in Western Australia and Queensland.

THE CHAIR: Mr Muir, is there anything else that you would like to add before we wrap up, noting we have two minutes left?

Mr Muir: No. I would just like to commend you and what you are doing in the ACT, and Northern Territory is following behind you. I think one of the critical things from the point of the ACT and the NT is that citizens of the ACT and the NT have the same rights as citizens in the other parts of our nation. So I commend you for what you are doing and wish you well.

THE CHAIR: Thank you very much. On behalf of the committee, we would like to thank you for your attendance today and the time you have taken in preparing the submission. I do not believe you had any questions taken on notice, so there will not be any follow-up for those, but you will still be sent an uncorrected proof *Hansard*, and you are welcome to provide any factual corrections that are required. Thank you again.

Mr Muir: Thank you, Chair and thank you, committee.

Short suspension.

BRAUN, DR KERSTIN
WHITE, PROFESSOR BEN
WILLMOTT, PROFESSOR LINDY, Researcher, Queensland University of Technology

THE ACTING CHAIR (Ms Castley): We welcome Dr Kerstin Braun, Professor Ben White and Professor Lindy Willmott. Please confirm that you are appearing as individuals today.

Prof White: Yes, I confirm.

Prof Willmott: Can I just say, Deputy Chair, that I am appearing as a QUT researcher. I am also a member of the Queensland Voluntary Assisted Dying Review Board, but I am not appearing in my capacity as a board member, just as a researcher.

Dr Braun: Confirmed.

THE ACTING CHAIR: I remind you of the protections and obligations afforded by parliamentary privilege and draw your attention to the privilege statement, which was sent to you by the secretariat. 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.

Prof White: Yes, I confirm that.

Prof Willmott: I confirm that.

Dr Braun: I confirm that.

THE ACTING CHAIR: Thank you. We are not inviting opening statements. If you wish to table one, please provide it to the secretariat. We will now proceed with questions.

MR COCKS: I am keen to understand your views on the lack of a cooling off period. Compared with other areas, it seems to be one of the standout features of this bill. Could you speak to why you seem to think this is an important thing?

Prof White: I am happy to begin with that if it would suit. You are correct in saying that other jurisdictions do have a formal waiting period—a cooling off period—between the first and final request, and it is obviously not written in this bill.

One rationales for, I guess, seeing this as not being a concern is the period of time that applying for voluntary assisted dying takes. We have seen with other states it takes an extended period. Looking, for example, at the Western Australian recent annual report—a jurisdiction which does not require a permit, so is likely to be faster—the median time was 13 days. So the process itself—which requires first assessment, second assessment, a number of requests from the patient—itself embeds that requirement for deliberation; for taking some time.

The other point to mention is that in jurisdictions—particularly the jurisdictions which have enacted laws that provide significant flexibility for the shortening of those waiting periods where that is clinically required—I think in those instances, those factors mean that in practice, I do not anticipate this will lead to a practical difference in the ACT, particularly given the ability for those waiting periods to be shortened under other models.

MR COCKS: It sounds like having a period in-between is worthwhile; you just do not see the necessity of a cooling off period compared with the administration time.

Prof White: I would focus on what the goal is. The goal is to make sure it is a considered, careful decision of the person to seek voluntary assisted dying. Waiting periods in and of themselves are not goals; they are a means to achieve that opportunity for reflection. The view I am expressing is that the process—which judging by Australian standards is a rigorous process and requires multiple engagements along the way—in itself achieves that idea of reflection, deliberation and contemplation.

DR PATERSON: We heard from Go Gentle before. One of their recommendations was in terms of the eligibility requirements to actually remove the "expected to cause an individual's death", in that the relevant condition needs to be "advanced and progressive", and it was sort of unnecessary and redundant to say, "expected to cause an individual's death". Do you have views on that?

Prof Willmott: I am happy to make a start. We believe the current phrasing of the eligibility criteria, the way it is currently phrased, is appropriate, being "progressive and advanced and expected to cause death." We do agree with that phrasing. Where we do have concerns about the definitions in the proposed bill is in clause 4 of the bill, both paragraphs (b) and (c), in particular paragraph (c), which refers to the person being "in the last stages of life." We make a reference to that in our submission, about the possible difficulties that that will raise in practice. I am happy to talk further about that if that would be useful.

DR PATERSON: Yes, very. Thank you.

Prof Willmott: We do applaud the removal of the timeframe to death, for the reasons that we outlined in our submission. We do not think it will expand the eligibility criteria. We do not think more people will be able to access with more conditions, but we do think it enables the person to start that process earlier, which means that fewer people who choose VAD miss out because they do not quite make it through the process. So we agree with the principle, which we have also seen set out in the explanatory notes, as to the justification for that.

The problems we have in "the last stages of life" as being needed to be satisfied for the condition to be advanced is that, firstly, it will cause confusion and uncertainty for health professionals assessing eligibility. We anticipate that different health professionals will have different views about when someone is in the last stages of life. It could be that some doctors, or potentially nurse practitioners, think it will be last days or week or month of life. Others might think, "Well, maybe they are meaning six months. They have to be in the final six months." So we think it has potential for confusion, and that is undesirable. Indeed, it might mean that the ACT model becomes even narrower than currently exists in other jurisdictions.

The other concern that we have, that we did not put in the submission—and I am not sure if I have the indulgence of the committee to mention it—is the requirement of the definition of "advanced" in clause (4)(b). Deputy Chair, am I allowed to speak to that?

THE ACTING CHAIR: Yes.

Prof Willmott: Again, it says, "To be an advanced condition, treatments that are available and acceptable to the person must lose any beneficial impact." We think there is a potential for that to have unintended consequences. For example, a patient might be suffering intolerably from their terminal illness but is taking some medication which helps with some of their symptoms. They are still dying. They are still suffering intolerably, but the medication can lessen some of the symptoms. Our concern is with the current drafting a person may be required to stop those medications to be eligible. We do not think that was intended, and I think it is perhaps a paragraph that may need some more consideration.

MR BRADDOCK: If the clause "the individual is in the last stages of life" was to be removed, would that have any practicable change to who might be eligible?

Prof Willmott: We do not think it would change who would be eligible, or what conditions would satisfy the eligibility requirements, because they are drafted fairly narrowly. We think it will just mean that more people will not be able to get through the process because it is likely that they will start the process later. As happens now in other states, people lose capacity or die during the process, because it is quite a rigorous process.

THE CHAIR: Picking up on Mr Cocks' comments on removing the time limit, we have actually had a number of witnesses over the last few days say that this will put vulnerable people in a higher position of vulnerability and might increase coercion into using voluntary assisted dying. The examples given have been people with disabilities, people who might be experiencing elder abuse, and a few other reasons have been thrown up, but those are the main ones I think we have heard consistently.

Hearing the comments you were making, that you do not believe it will make the scheme more accessible to people, and that arguably following on from that, coercion will not be such an issue, I wanted to drill down a little bit more and get your reasonings as to how, in those scenarios that have been put to the committee, that people who are experiencing elder abuse or have a disability would or would not be eligible under the scheme, and the safeguards in place as you see them, to make sure that coercion cannot become a larger factor, given that we do not have that time limit to death included in the bill.

Dr Braun: Perhaps importantly, if we think about it, the time limit—six to 12-months—as such does not really come from any place of particular reason. It was simply adopted in other jurisdictions because it was adopted in Victoria, and they simply adopted it because it had been in Oregon. So there is no specific reason why a person could potentially be abused outside of the 12-months but not inside of the 12-months. So the 12 or six-months—whatever it is in a particular jurisdiction—does not really have any particular purpose as such.

I sort of feel, if one thinks about it, a person is allowed, as per the legislation, to request and access VAD within six months, and then suddenly there is no question about abuse, but in seven or eight months then there would be a question about abuse. So I am wondering how can a timeframe determine whether there is a greater or lesser risk for elder abuse? Because what we would see within that six to 12 months when a person is eligible, is that all the assessments still have to be undertaken. That would be the case here as well—that it would have to be assessed whether a person is acting while being coerced. So, I do not really see a greater risk of a person being forced or coerced into it where there is a six- to 12-month time limit, or where there is not. In fact, I argue that from a human rights perspective, it is questionable whether those timeframes comply with human rights at all because they are so restrictive and arbitrary.

THE CHAIR: Dr Braun, I think it was you who was making some comments around that you do not believe the way the bill is written that it suddenly opens up or expands by removing the time limit. What has been put to the committee was that by not requiring the time limit and not having it, someone, say, with a degenerative disability where it will result in death—it is incurable and will result—would suddenly be eligible for the scheme. I would be interested, given your previous comments and the comments in this discussion, to understand if you have a counterview to that, and the reasoning behind it.

Dr Braun: I suppose in order to be eligible a person would continue to have an advanced, progressive illness that will cause death. So then I am wondering, from that perspective, if that is already the case, why does it matter if the death occurs within six or 12 months, so why do we need a further limitation of this requirement?

THE CHAIR: I think the point that was put to us, and the counter to that that I want to tease out, is that it was put to us that someone in that position might be feeling quite vulnerable and see voluntary assisted dying as a way to be less of a burden, when actually if they were given support—so we are talking very much I think in the context now of disability, and potentially just older age as well—whereas if they were given access to the supports that they needed to have a much more positive take on their life, that they would not necessarily be choosing VAD.

Other committee members might want to jump in and help me out here if they think I am going down the wrong track, but I think it is fair to say that the people who put this to us were very much of the view that they were worried that VAD would become the easier option than providing the supports to people in our community who need a lot of additional supports in order to lead a quality of life that would make them comfortable.

Dr White: I might just briefly comment on that. Maybe a starting point is just to clarify—as the committee, of course, knows—is that the bill specifically says access on the basis of disability is not one of the relevant conditions that is capable of qualifying. Indeed, I think sometimes arguments are conflated. There are eligibility requirements to meet before these discussions even arise, so we are, by definition, talking about a cohort who is expected to die, and that, by definition, would exclude, for example, the scenario that you mentioned of someone who had a disability, but it was not going to cause death.

On that point—and we can send this through to the committee—we did an analysis of five different types of illnesses, which include, for example, disability, but going through to cancer, motor neurone disease: all ones which may be used to seek voluntary assisted dying or may be regarded as controversial. The analysis we did of both models, with a time limit and without, shows it would not fundamentally change who would have access.

Just on the second point, there is a question there about concerns about choosing voluntary assisted dying. We now have four years of experience in Victoria about how voluntary assisted dying is operating, and our approach as researchers would be to follow the evidence. That is a claim about facts—about whether things are happening or not. The experience that we have seen and extracted from the oversight body reports, but also the research that we and our colleagues and others have done, do not bear out those concerns. So while I recognise that those are important things for the committee to deliberate on, I am not aware of evidence to support those claims occurring in practice.

Ms Willmott: Chair, might I just make a final observation on that point? There are a lot of end-of-life medical decisions that are being currently made for that same cohort of people that we are rightly concerned about. These are decisions to stop treatment—whether that is chemotherapy, dialysis, whatever—and similar concerns can legitimately be raised in relation to that. Are we providing sufficient supports? Are those people being coerced into making a decision? So it is an appropriate line of inquiry.

My point would be VAD, if this legislation is passed, would be the most highly regulated medical practice in the ACT, and there are embedded in the bill many safeguards to ensure that the decision is made by someone with capacity, voluntarily and without coercion. From the research that we have undertaken, doctors are clearly very, very aware of the need to ensure this is a voluntary decision because of the gravity of the decision. It forms part of the mandatory training, and the doctors have developed steps to make sure that they interview the person separately with the patient and separately from caregivers. So they do take deliberate steps to ensure that it is a voluntary decision.

One other thing that I wanted to add is that, from the research that we have undertaken, the people who request voluntary assisted dying are passionate, and they are very determined about receiving it. It is a rigorous process, and they are determined to get through it. That, in itself, I think, is a safeguard, and there can be more comfort that they are not being coerced and it is a voluntary decision.

MS CASTLEY: Two things that you mentioned there, Professor Willmott, were safeguards and training. With regard to the safeguards, would you say that the safeguards in the ACT bill, stack up against other jurisdictions, or are better or worse?

Ms Willmott: I think the proposed legislation in the ACT is very, very safe. All of the Australian models are highly regulated by comparison with their international comparatives. I think the evidence is suggesting that there is not a problem with safety, and we can be confident that only eligible individuals are assessed as eligible. So I do not have concerns about the safety of the ACT model. I am sorry; I forgot the second part of the question.

MS CASTLEY: The other element you mentioned was training. Now, somebody we heard from—I think it was yesterday—had some concerns that in this bill it was eight hours of training required online. They would like to see more training. Can you tell me what happens in other jurisdictions and what your thoughts are on what the ACT bill talks about.

Ms Willmott: Certainly, and I must declare a conflict here: I, and our team at QUT, are responsible for the mandatory training. We set it up in Victoria, WA and Queensland. Our view is that this training is important. It is important because voluntary assisted dying is such a highly-regulated practice, so it is very important for doctors or health professionals involved to know the precise ambit of the legislation and what is allowed and what is not allowed. So I do think training is an important safeguard. I did not know that there was a statement in the ACT bill about the amount of time of the training.

THE CHAIR: No, there is not. Just to clarify: one of the witnesses we had yesterday raised the issue of training, saying that, overall, the training that doctors do, particularly in palliative care, is, in their opinion, quite brief. They wanted the committee to take into consideration just what sort of training provisions would be provided around voluntary assisted dying, so I—

MS CASTLEY: There was no timeframe. Someone did talk about a timeframe, so that is my error; I apologise.

THE CHAIR: I guess the broader question there, if I can jump in, is: what should the committee be cognisant of, in your opinion, when looking at the training provisions needed around healthcare professionals administering this scheme?

Ms Willmott: I am happy to have a shot at that. Ben, you might want to follow up if you have anything else. In legislation, I think it would be sensible to be fairly broad, as it is in all of the other states, so that the training would necessarily incorporate relevant legal components and possibly anything else which was prescribed. So if there is, in the ACT, a decision that the training should include something else, then that would be made through regulation, and the training could incorporate that. Ben, did you have anything to add about that?

Dr White: Maybe just to reflect that a lot of these questions and discussions that we are having are about safety and access. Australia is unique internationally in requiring health practitioners participating in voluntary assisted dying to undertake mandatory training. So it has this safeguard which other places in the world do not have, which adds to the safety and means that there is a rigorous assessment process.

Indeed, some of the evidence that is coming out of some of the states is that the assessment is quiet challenging. So that ensures safety. On the access side, we want to make sure there is enough health practitioners to support, and having to spend a day's worth of training can be quite challenging. That is the balance. I think that has been struck across the other six jurisdictions, and I think it seems to be working reasonably well in making sure it is safe, but also making sure health practitioners are willing and able to do it, and so on. I do think that is an important consideration for the committee, and that has been, I guess, the national experience.

THE CHAIR: Mr White, following on from that, under the ACT bill, it is possible for medical practitioners such as doctors and nurses—but also medical practitioners prescribed by regulation—to initiate or participate in conversations as the first port of call. For example, we have had the Pharmacy Guild—and a few others—in to talk about their role or potential role in the scheme. What is your view about what sort of training should be undertaken prior to people initiating those conversations?

Dr White: Well, I think there are maybe two categories of situation that we are talking about. What we have been previously discussing is those practitioners who are actually involved with assessing eligibility or providing voluntary assisted dying. Obviously, you would want a higher level of training so we can have confidence in that very, very critical role. In terms of having conversations, we also want to train a wider health workforce.

These are conversations can come up with a range of health professionals. Again, I disclose a conflict. This is something we did in Queensland. Queensland Health initiated the idea of developing a short 30- to 45-minute training module that was available to all health practitioners. So when voluntary assisted dying became lawful, there was scope for anyone in the health workforce to do this relatively short, focused training module. It was not about providing, but to help them with conversations, and to help them with things like conscientious objection. So it might be that there are two streams of training that are worth considering.

MR BRADDOCK: Witnesses the day before yesterday indicated that the level of regulatory oversight was excessive and also recommended that the number of the requests be dropped from three to two, in terms of making it easier to be accessible. Just given your comments and what you had said earlier in terms of having proposed, let us say, a very safe bill—it is at a world-topping standard in terms of the levels of safeguards—would such amendments be appropriate?

Dr White: I might begin. I am happy, of course, if that might be okay. Again, I think it comes back to that safety/access discussion that we had. There is evidence from research that we have done. We have done, for example, 140 semi-structured interviews across three states with pretty much all the stakeholders involved: patients, families, doctors, nurses, health administrators, government departments. The key finding from a national perspective is that Australia is very safe, but access is a challenge. I think the question then becomes, "How can we improve access without adversely affecting safety?" My view—and this is the first time I have publicly reflected on this—on the difference between two and three requests is that I do not see a reason to reduce that to two. I think that it would not be a significant burden in terms of access to require three, but I do think it is worth thinking about the safeguards generally and whether or not they do improve safety. An example in Victoria is that the prohibitions on raising voluntary assisted dying were meant to be a safeguard, but really they have just been a barrier.

The final point I might make is that I think this is obviously a discussion not only for the committee, but, should this bill reach parliament, what we have seen in other states is that when bills go before parliament there is often a large raft of amendments seeking to add safeguards. That is one situation where I would counsel against. We have an integrated bill which has been designed in a particular way, and if you start adding ad hoc safeguards on here and there, that can really damage access and lead to a sort of unwieldy, unworkable bill.

MR COCKS: I have a quick supplementary question. It sounds as if, essentially, what you are arguing for is, as another submission put it, prioritising access over safeguards in that legislative process. Are there any risks that not having sufficient safeguards, while it may not have had problems in other jurisdictions, may make it possible for problems to occur?

Dr White: I should probably just clarify the position I was advancing. It was not that we should prioritise access over safety; instead, it was reflecting on the experience Australia has had. Understandably, especially in a place like Victoria, where the law began first, there was only really discussion about safeguards—the world's most conservative legislation. Indeed, subsequent states added on their safeguards, and it went from 68 to 100-and-something. So the real focus was safeguards and safety, and access were lost—not focused on.

So my suggestion is not that we disregard or prioritise access over safety—safety remains at the centre or the system—but that we think about both. So your second question was about whether or not we should think about removing safeguards. In our submission we have not proposed to remove any safeguards that we did not think were inconsistent with the policy—hence the point we made before about the idea of last stages of life. This appears inconsistent with the policy intention to remove that length of time. That is one of the suggestions we have made, but we are not suggesting—I am not suggesting—that any particular safeguards be removed.

MR COCKS: Okay.

THE CHAIR: I am going to move to Dr Paterson, with her substantive question.

DR PATERSON: Something that we have not discussed in the hearings is the administration of the drug for voluntary assisted dying. And I note that in your submission, the importance of choice in administration for self-administration or practitioner administration. I was wondering if you can outline for the committee why choice is so important, and what other jurisdictions have done, and where we have landed with our bill here?

Dr Braun: In terms of the Australian context, last year we saw that in New South Wales that the legislation does include a true choice between self-administration and practitioner administration, which had not been the case in the acts that were introduced before that.

In terms of the international comparison, if we look at Canada and if we look at the Netherlands, in both of those jurisdictions it is possible to have a true choice between self and practitioner administration. In my submission I put in some of the statistics I was able to find in this context of how often people choose self-administration in those two jurisdictions. In Canada and the Netherlands, the numbers were actually very high of people wanting the practitioner administration and not the self-administration.

So from that point of view, I suppose it is possible to say that if given a true choice, this is what someone will choose. Where a person does not have a true choice, if we talk about the right to self-determination, and the right to self-determination at the end of life, where somebody is not given a true choice, it is simply not possible to really have the right to self-determination in that context. That is my view in this regard.

Prof White: I think we would say we would support choice as well. I think that is the optimal model on that point.

MS CASTLEY: I have a question that I am not sure you addressed. I do not think you have in your submissions. Here in the ACT we are an island in New South Wales, and given that the ACT bill is different to New South Wales and other jurisdictions—have you considered that or do you have any thoughts on the impact that may have, for example, say a doctor living in New South Wales but practising in Canberra or vice versa, and patient-wise as well? Have you any thoughts on that?

Prof White: One beginning observation might be about the importance of knowledge of those different regimes. We see this, for example, with things like advanced care planning and advanced care directives, where border communities exist or where practitioners or individual patients live on different sides of the potential border. When thinking about education for example—part of our other work is educating doctors and nurses and other health practitioners on end of life law—I think that would be an important consideration to be aware of, for example, duties when voluntary assisted dying is raised might be different in the ACT than it is in New South Wales.

Prof Willmott: The only other thing I would add to that, and this might be beyond the scope of the ACT path, is the residency requirement in the ACT. Ben and I have advocated before that when all jurisdictions have voluntary assisted dying, there may not be a need to have that residency requirement as one of the eligibility requirements. From our research interviewing 32 doctors in Victoria shortly after they implemented the system, one of the difficulties that they had was being convinced, or being satisfied, that a person had lived in Victoria, for example, for 12 months prior to thinking of voluntary assisted dying.

If all jurisdictions have laws about voluntary assisted dying, there will be less concern about VAD tourism. No system is going to be inundated if all jurisdictions have VAD. Of course it would be ideal in a nation if all of the laws were the same, but that is something which we might take a very long time to achieve I think.

MS CASTLEY: Yes. The ACT bill allows people who have an association to the

ACT to access voluntary assisted dying. The border to New South Wales is about 15 minutes from where we sit, so that is very easy to make happen.

Prof Willmott: Yes, I think there has been improvement on the Victorian model. Queensland have a similar discretion to allow someone who can show that connection. So I think that is a good initiative of the ACT model.

THE CHAIR: In your submission you talk about institutional objection and you note that there is now emerging evidence that institutional objection can cause harm to patients and their care givers. As this is a topic that has come up in a number of the hearings that we have had, and given that you are researchers and have rigorous evidence, not anecdotal, can we please have a little bit of an elaboration from you as to what you are starting to find and the impacts that may come from institutional objection? And how, in your view, managing the conscious objection of an individual or an institution can be balanced with the right to act with VAD?

Prof Willmott: Sure. I am happy to start, and Ben can dive in. Yes, we have collected evidence. Members of the end of life team at QUT, Ben White, Ruthie Jeanneret, Eliana Close and I, have published in *BMC Medical Ethics* an article specifically in relation to the impact on patients when institutions object to VAD. It detailed the data from 28 interviews with 32 family care givers and one patient about their experience in VAD. In 17 of those interviews this issue of institutional objection came up. So it is an issue and it is a serious issue.

The most common issues that arose were: people in particular institutions not allowing a patient’s eligibility for VAD to be assessed; not allowing a patient to receive their VAD medication, even though they have been assessed as eligible; not allowing a VAD medication to be taken on the site or administered by a health professional; delays, because there has been an institutional objection; patients having to be transferred out to either be assessed or to receive their medication; sometimes patients having to choose, if they cannot get VAD in their institution, they have to choose between receiving palliative care or VAD—we would suggest there should not be a choice; and generally negative emotional experiences when they cannot access that medical treatment.

So we do think it is important to balance and recognise that institutions have certain values, and individual health professionals have certain values, but that has to be balanced against terminally ill patients who are seeking a lawful medical choice. It is reasonable for different people to fall on different sides of where that balance should be. We do support what the ACT has done in its legislation in terms of requiring a conscientious objector to advise and provide information about where a person can seek information about voluntary assisted dying.

We do support the legislation having provisions that set out the institution’s obligation. That is preferable in our view to having it in policy. But we do think, with respect, that the bill could be improved. The current provisions in the ACT bill could be improved, and we set out the reasons for that in our submission.

We believe a preferable model for all facilities in the ACT, whether they are for persons of permanent residence or a patient, should be what is contained in the

Queensland model for permanent residents. This basically does not require the facility to participate in VAD, but cannot hinder it, and they must allow access for relevant people, whether that is a doctor, a nurse professional or witnesses, et cetera. That is where Ben and I think there is an appropriate balance, and we think it is very important that is contained in the legislation. Ben, I do not know if you have anything to add?

Prof White: The only point to make is this is not only coming out of our research. The oversight board reports have also flagged that this is a problem in practice from the evidence and reports and that they are receiving challenges when institutions have not allowed this.

MR COCKS: On that matter, in terms of conscientious objection, there is clearly a spectrum of conscientious objection that ranges from directly participating in the administration of life-ending substances through to conscientious objection to participation in the assisted dying process at all. One of the requirements in this bill seems to be for a conscientious objector to actually refer. Now, my understanding is referring is an active step. Is that not something which an institution or practitioner should be able to conscientiously object to?

Prof Willmott: My personal view on this, as I said, is that it is about balance. Again, you have a health professional on the one hand, and you have a terminally ill person who is approaching the end of life and is vulnerable, as we have discussed before, on the other. I do think you have to accommodate both. In my view, the most appropriate place where that accommodation is, is not to require that practitioner to be involved in the VAD process in any way, except to provide a piece of paper with information about where the person can go. I have heard the arguments about being complicit and I understand those arguments, and it is about what balance is reached. It is a matter of values here, and I guess I am being open in where I would choose that balance.

MR COCKS: I really appreciate that, and it sounds like that providing of information is a bit different to a medical referral.

Prof Willmott: Yes, I do think it is. I think that, at the very minimum, should be what is required of a health professional.

THE CHAIR: Is there anything any of our witnesses would like to add before we finish today?

Prof Willmott: I have just one thing that I would like to mention, only because it is not in our submission. It relates to the definition in the bill about a deciding practitioner in clause 98(1). The deciding practitioner has a role in deciding whether, for example, a person is well enough to be transferred out of an objecting institution. We believe that the deciding practitioner should either be the co-ordinating practitioner or a doctor chosen by that particular person. I am happy to elaborate, but I realise we are close to time.

THE CHAIR: We have a couple of minutes, so please take the time to elaborate.

Prof Willmott: All right. As it is currently drafted, the deciding practitioner can be a co-ordinating practitioner or a treating doctor. So as currently drafted, for example, a GP who has an arrangement with a residential aged care facility to visit residents would fall within the definition of a treating doctor, even though they may not have a close connection with the resident. It is also possible that doctor may have views about VAD that align with the objecting institution. If the bill provides that the treating doctor is that person, then they may come to a decision about whether that person is able to be transferred which is different, for example, to the co-ordinating practitioner or another personal practitioner or GP of the person. So our submission would be to make sure the deciding practitioner is one chosen by the patient.

THE CHAIR: That is still within time, so very well done. With that, I would like to thank you all for appearing today and for the time you have taken for putting in a submission. It is very much appreciated by the committee. You have not taken any questions on notice, but you will still be sent an uncorrected proof *Hansard*, for you to check for any factual errors. Thank you again for your time. We will now take a short break.

Short suspension.

HANSEN, MS LINDA, Chief Executive Officer, Palliative Care ACT

THE CHAIR: Welcome back to the public hearings 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 public hearing who are impacted by issues raised in this hearing.

I would now like to welcome our witness from Palliative Care ACT, Ms Linda Hansen. I would like to remind you of the protections and obligations afforded by parliamentary privilege and draw your attention to the privilege statement, which had been sent to you by the secretariat but is also available on the pink card on the desk there. 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.

Ms Hansen: Yes, I do.

THE CHAIR: We are not inviting opening statements but, if you do have one, you are welcome to provide it to the secretariat and the committee will have a look at it after the hearings. We will jump straight into questions. We will start with Mr Braddock.

MR BRADDOCK: In your submission, you talk about taking out the words "takes reasonable steps to ensure" and replacing them with "ensures". Can you tell me the reason that you want to see that in the outcomes that you would hope to achieve with that change?

Ms Hansen: Yes. I think it is important to make sure that people are aware of all of the information that is available to them. So "taking reasonable steps" is for us a little bit vague. Perhaps just saying "ensures" means that there might have to be some other adjustment to the legislation or some kind of additional requirements that a person is supplied with—pieces of information or a conversation with, or whatever that means—to make sure that "ensures" has some kind of weight. What does "reasonable steps" mean? That could mean something different to everybody, unless there is some kind of regulation that says what "reasonable steps" is; otherwise, we would just like to strengthen that a bit.

MR BRADDOCK: Can I just clarify your policy intent? What do you think a doctor or nurse practitioner should do in order to satisfy this part of the legislation?

Ms Hansen: I think they should certainly have a conversation with them and provide them with any resources or access to resources and make sure that they have read those resources in some way—so maybe asking them for feedback on those resources: “Have you read this? Do you understand this?” and sign something that says they have understood. We are talking about something of a slightly more formal process than “takes reasonable steps”.

MR BRADDOCK: Thank you.

MR COCKS: I might just build on that. It sounds like for you it is about more than just being aware of but that an individual should understand that there is palliative care and what that looks like, rather than just being given three options. Is that—

Ms Hansen: Yes. It seems to me that “reasonable steps” could be simply referring them to a website or referring them to a link somewhere or providing a list of resources. I would prefer to see a more focussed approach to that and to make sure that people understand or make sure that they have the information.

MR COCKS: Could you talk to what that is a safeguard against?

Ms Hansen: For us, it really is about making sure that the people having the conversation are engaged in that conversation and that the person involved in that, the healthcare provider or whoever that might be, is very well aware of all of the information and the options to access information, so that everybody involved in that conversation is very well aware of what they are talking about.

MR COCKS: It sounds like that is about making sure everything is fully voluntary and understood right from the earliest steps of the conversation.

Ms Hansen: Yes.

DR PATERSON: A lot of your submission speaks to public awareness and community education. We heard from the multicultural group that came to the hearings about the lack of awareness or understanding around palliative care and end-of-life options in the multicultural community. So they were also advocating for increased education and awareness. I guess it is also an opportunity to raise awareness of end-of-life choices that people have available to them. Is there anything in particular that you think would be worth the committee recommending in terms of really getting the message out or getting the message out to particular groups?

Ms Hansen: This is probably the most complex part of understanding how to get people informed about all of this. People do not really want to talk about death and dying at all until it comes into your life. So getting an understanding in the community, let alone multicultural communities and other less well-served communities perhaps, is a challenge. Talking about trying get out the nuanced messages around end-of-life care, palliative care, generalist palliative care, specialist palliative care and VAD is incredibly complex, but it is also an opportunity to maybe find out who the real gatekeepers are to this information and educate them better. That will be primary health providers, any healthcare providers, that will come across somebody at some time in their professional lives who needs to talk about end-of-life care options, wherever they are.

In some ways, it is a multilayered approach to education and awareness. It is educating health professionals at a whole bunch of levels and educating the community in various ways. That is obviously a major piece of work around awareness raising and education. There are several layers to that. That in itself is a big piece of work for the ACT. Lessons could probably be learnt from other jurisdictions where the emphasis on getting that right before the bill is introduced maybe did not go as well or was not as much of a focus. I am sure the ACT will do a better job of that.

It is a major piece of work, and I think there are a number of people that can contribute to that work. There are a number of NGOs who can contribute to that—us and Carers and others. I know that there is work going on already to try to get some community input into how we might build a community awareness program. So there is already work going on, and I am really pleased to see that there is some funding made available to get that process underway. But I think it is quite a long process, and I think it is probably a multi-year process to kind of bring the community along with you to get this really complex messaging out and repeated. It is almost generational, this information and awareness raising. This is an opportunity to get people talking about death and dying and what all that means and be less afraid of talking about it.

DR PATERSON: The government ran a YourSay panel and things like and there have been multiple surveys. The Seniors submission talked about national surveys that show that voluntary assisted dying is very well supported and is supported in the ACT from the evidence that we have been seeing. But, as someone who works in that space all the time, is that your read of the community in the ACT, that this is something that people come to you and talk about and it is an issue that is important to them?

Ms Hansen: Very much so. I think there might be a little bit of work around understanding that palliative care is palliative care and VAD works alongside palliative care and other end-of-life care options. I think Canberra is very much more in tune with this issue than a lot of other jurisdictions. It is certainly something that we want to be able to support health professionals in dealing with. There is a lot of education around supporting each other as health professionals in whichever way they want to approach this as well, and I think there are other supports that need to be put in place to support whatever environment you are in as a health professional in terms of how you approach VAD and end of life generally.

It needs to be something we just talk about matter-of-factly. All of these options are options for people. People should have access to good palliative care. They should have access to any end-of-life care that they need. We do not really have that yet. We are certainly lacking in the community sector, in that there needs to be more palliative care community nursing, community supports helping people to stay at home and all of those issues.

DR PATERSON: Thank you.

MS CASTLEY: You said that you hold the position that voluntary assisted dying should never be viewed as an alternative to palliative care, which we have discussed, and that voluntary assisted dying should never preclude them from accessing palliative care services. Is that something that you have seen or is that just a concern from—

Ms Hansen: A part of this awareness is that people need to understand and be supported to understand that it is not an alternative, that an individual's wish to access VAD should not preclude them from accessing palliative care. It should not be that, if you want to access VAD, therefore your palliative care ceases or whatever care you are getting. That should not happen. We know there is a perception that that could be the case. People should be supported in whatever decision they make. There are certainly some concerns from other jurisdictions that expressing a wish to access VAD anecdotally has meant that some people may not then therefore continue to receive palliative care services. That should not be the case.

THE CHAIR: That picked up on my question too. It has been put to the committee by a number of witnesses that they would not like to see it be presented as you must choose one or the other and that both should be considered in how to support a person in their end-of-life choices. From your perspective and your read of the bill, how do you think we can best achieve that balance of making sure that it does not become a one or the other proposition and people know that both are available to them?

Ms Hansen: That is a good question. I am not a lawyer, so I am not sure how to approach that.

THE CHAIR: Well, maybe not in the context of the bill then but just maybe in the context of your professional views or experience.

Ms Hansen: I think there perhaps should be some kind of requirement that this is understood, and I am not quite sure how to go about that, to be perfectly honest. I think that will be part of how we educate, support and raise awareness of the health professionals around what their roles will be and what consumers should expect and what they can expect from their healthcare providers.

MR COCKS: The difference between palliative care and assisted dying seems to be really critical to understand. From my perspective, it sounds like palliative care is about ensuring the best possible quality of life until death rather than being about the process of dying. Would that be a fair—

Ms Hansen: Yes; that is exactly right.

MR COCKS: It seems like the fear on some fronts is that not only might you lose access to having good palliative care if you express a wish but also if you do not have access to good palliative care that that makes it more likely for you to find things intolerable. Would that be consistent with—

Ms Hansen: It really comes down to an individual and confidence in the palliative care system and the provision of quality palliative care in wherever you are living. If you feel that you do not have access to that then it may or may not be the case that but you as a person then needs to be supported to understand whether that is or is not the case. Palliative care in the ACT is more contained, whereas it is more a bit of a postcode lottery in New South Wales where it depends on where you live as to what kind of palliative care there is or, indeed, if there is any specialist palliative care. In the ACT we have an opportunity here to increase the number of palliative care specialists that are available. That is not a simple matter, though. Palliative care specialists—doctors, nurses and allied health and volunteers—are kind of a rare beast. So encouraging people into the palliative care world is another piece of work that needs to be done.

We obviously want to ensure that people have a genuine choice. If they are comfortable and confident that they are receiving quality palliative care, that should be the end of it; they should be able to access quality palliative care.

MR COCKS: Thank you very much. That is really helpful.

DR PATERSON: I am very ignorant in this space, but do dementia patients receive palliative care?

Ms Hansen: Yes.

DR PATERSON: And is there a point in their illness that they receive palliative care. That is quite a diagnostic point I guess.

Ms Hansen: Everybody who is approaching the end of their lives, whatever their issue, should be able to access palliative care if they need it. Specialist palliative care is not always needed for people who are approaching the end of their lives. It might be quite standard nursing care or quite standard medical care. Sometimes you do not need a specialist palliative care input.

With dementia, usually you would benefit from specialist palliative care input. It is very complicated, of course. Most people with dementia or complex symptoms of dementia are in a facility. Another issue that we really need to work on is getting palliative care into residential aged-care facilities more easily and more readily. It is not something that always happens as a matter of course, surprisingly. That is part of the aged-care reforms, and that work is about getting RNs into aged cared but also having better access and more consistent access to specialist palliative care.

So any part of the journey that you are on, whatever you are dealing with, you should be able to access palliative care if you need it.

MS CASTLEY: In the dot points of your submission you talked about having a palliative care professional on any kind of advisory board. So that is something you really—

Ms Hansen: Yes; we would support that.

MS CASTLEY: Thank you.

THE CHAIR: I have a quick question on section 152, which is the one that says “takes all reasonable steps to ensure”, and I know in your submission you said to say “ensures” and to remove the “take reasonable steps”. Is that the only change you would see? In the discussions we have had here, we have actually had a lot of other reasons put forward. Should the committee be considering all ways? Would you like a particular focus on all ways to improve the palliative care.

Ms Hansen: I think “all ways”. That is fine, yes.

THE CHAIR: Thank you. I would like to thank you for appearing today and thank you for persevering with us. We had some IT problems; so thank you for making yourself available to come at an alternative time. The committee is appreciative of that and for your submission. You will be sent an uncorrected proof *Hansard* for you to check for any factual errors. Thank you very much once again.

Short suspension.

PAVKOVIC, MS KATARINA

THE CHAIR: We now welcome Katarina Pavkovic, who would like to be known as "Kat". Thank you for your submission and for agreeing to appear today. We understand your submission may have been distressing and we appreciate your efforts.

I would like to take a moment 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. A privilege statement should have been sent to you by the secretariat. Could you please confirm that you have read and understand the implications of that statement and that you agree to comply with it?

Ms Pavkovic: Yes; I read, understood and agree to comply.

THE CHAIR: We are not inviting opening statements; however, if you do wish to table one, please provide it to the secretariat and the committee will look at it in due course. Kat, if you do find the hearing difficult, please let us know and we can take a short break as we work through this. We will go to Mr Cocks to start with questions.

MR COCKS: Thank you, Chair. Thank you, Kat, for sharing your personal experience and that of your father. It comes through that you cared very deeply for him and that his suffering was painful for you. It takes a lot to share something like that, and I would like to acknowledge that it seems like you have done that more than once too. It seems like the palliative care system for your father was inadequate to meet his needs, and I wonder if you could talk a little bit to what that experience looked like.

Ms Pavkovic: I would probably question whether I would say that palliative care was inadequate. In the case that my dad and for the services that were available to him at the time I think that they were perfectly adequate. It just depends on how you see or how you would experience voluntary assisted dying if your thinking fits within palliative care or if you think it would be completely separate. I guess we find this is as part of this inquiry.

For dad, being a part of the palliative care system, it was adequate when we were there. It did as much as it possibly could within the ability that it had. It enabled a bed for us at a time when we needed it. It enabled quality care from doctors and nurses. They were there answering questions and really basically at our beck and call. Whenever we needed another dose of pain medication for dad, when you could tell that he was in more pain, they gave it to him immediately. So I would not necessarily say it was inadequate in that sense. I would just say that his wish was that he wanted to die and he wanted to die perhaps more peacefully than what he experienced.

In case anyone has not had a chance to have a look at my submission to this inquiry or the previous end-of-life choices that we had prior to COVID, dad made a choice to starve himself to death because there was not an alternative. What that meant was that he needed to choose every single day to die and therefore not to take food, rather than what would be within this bill at the moment, I think, three requests for death. My dad needed to do it for five weeks. If you can imagine that sense of hunger that he would feel personally, if you missed lunch or you have not had a break today, imagine the intensity of what one might feel making that choice every single day, to know what it will eventually lead to.

Again, to answer your question, the system or the instruments that we had at the time were adequate. But, being in the ACT, where we are leaders in often many parts of human rights and health and everything, I think we could do better. Giving an option for voluntary assisted dying, which is hopefully what we are on our way to be doing, would be helpful.

There was perhaps one part where there was a barrier for our family. I am a first generation Australian. My parents were both Serbian born and they came here in their 20s. I think it was a challenge for them, coming from a culturally and linguistically diverse background, to seek the support and services that they needed.

A point that I want to make particularly today is that, when we have people coming in from other cultures, when we want to have them as Australians, get them to be permanent residents, get them to be Australian citizens, they need to jump through a lot of hoops, one of which showing that they can be completely independent and not rely on our system to be able to let them stay. Often we do not necessarily have the entire extent of Medicare or social welfare payments. With NDIS, you need to be a citizen or a permanent resident. So, from a very early age for them being an Australian resident here, they are taught basically that they cannot rely on the government in some cases of need. That does make it a barrier later on in the future for them to seek access to care.

When they are going through a traumatic or terminal illness, it is already filled with anxiety, fear and pain because of whatever the illness might be. To add on top of that you are basically showing the government you are not really independent anymore also adds a layer of anxiety and fear that they perhaps do not really want to engage with. That adds another layer of complexity to accessing some of that sort of thing. That was a very long-winded response, I apologise, but there are just a few facts that make answering something like that quite complex.

MR COCKS: Thank you. I appreciate that.

THE CHAIR: Kat, just picking up on the comments you were making about cultural differences and so forth—because we have had this raised a little bit but I do not think necessarily a lot and the stuff that has been raised has been a factor—can you give us a bit of an insight into the personal circumstances from your experience around how you navigated cultural differences, coming to this decision of VAD what impact the cultural difference might have had on that journey?

Ms Pavkovic: I think it changes depending on the stage of when my father was ill. When it came to the point where he made the decision that he wanted to die, he was in hospital and he got transitioned into palliative care. I think that ended up being okay because we had a lot of different service providers around us at all stages in order to be able to answer questions and ask. Sometimes they had to be a little bit more pushier to get the ball rolling when it came to my parents. In our case, a lot of the barriers ended up being with us to begin with in the sense that there was a lot of personal pride in not wanting to seek that help, and a lot of shame, I guess you could say, in even just asking the question for help.

I remember growing up and saying to my mum, "Hey, I have a question about this thing" and she would say, "No, do not ask that; we can handle this ourselves". That sort of stuff is a deeply rooted cultural thing with the families, and it takes a lot of deep behavioural change to try and combat that. Culturally, in seeking support before the palliative care stage, I would say you would benefit if you were more educated and were able to understand the information that was being relayed.

We were one of the first families to be included within the NDIS program when it was rolled out to metro Canberra at the time. We only thought about that because a community nurse talked to us and said, "You should apply for something like this." Then we would have to go through stacks of paperwork to eventually get into something like that. That was quite challenging. We would not have really been connected in that way if it were not for one particular individual. Maybe it was their job but it was not necessarily their job to be able to communicate with us.

It would be really valuable to having a dedicated source or a "care navigator"—which is what I think is said within the bill—that at least somebody can point to to say, "Hey, you can go to them and they will be able to find out the information if they do not have the information." Seeking the information was a challenge to begin with, both with us not necessarily having the confidence to go out and ask individuals and a lack of knowledge in terms of what services were there. I do want to caveat that with a lot of this stuff was happening around the early 2010s. We have come a long way in the decade since that happened. We made leaps in bounds in that sense. But, at least from that perspective, that is how I would answer that.

THE CHAIR: In the interest of time, I will pass to Mr Braddock for a substantive.

MR BRADDOCK: I just wanted to check if there were any changes or improvements you would like to see to the bill?

Ms Pavkovic: From my personal experience, working within federal government as well as outside of federal government as a service designer, I would suggest that the bill is inclusive of all of the right paths. I think where the bill will really shine is in practice, where we all have the services designed effectively and policies created that can supplement and enhance the bill. There is a challenge in being very, very specific in the bill where it sort of precludes us from being able to make some very small changes that can be held within a policy context. I would not want to necessarily provide any recommendations from a bill perspective but, from policy implementation perspective, there is a lot of opportunity not only to implement voluntary assisted dying but also to be able to improve the end journey of what is end-of-life care, I think.

MR BRADDOCK: Thank you.

DR PATERSON: We heard from some faith-based organisations yesterday or the day before. I would be interested to hear you reiterate how important that choice is and if you feel it would have been empowering to your father to make that choice?

Ms Pavkovic: My simply answer is my dad made that choice regardless of whatever services were there, and he made that choice every single day. Like I mentioned earlier, he made the choice to starve himself every single day for five weeks. There are others out there that make the exact same choice in many other ways, some more violent than others, and that honestly is a stain, in my opinion, in terms of us failing to support people in need. They have already made this choice, and we now need the services and the ability to support them in making this choice.

Again, there is the argument of eligibility. I think the bill follows a lot of what other states have in terms of eligibility. I think we go one beyond that when we say you do not have a time frame for death, which I appreciate, particularly from dad having Parkinson's disease and it was not a specific time frame.

It is so important to have the choice. It is so important to enable people to have their self-determination because they are going to make it anyway, and we need them to be able to do so in a safe environment and also to give them the choice to maybe not die alone if that is not what they prefer but to die at a time that they know when it is coming, at a time when they can have their family and friends around them, when it is not so full of fear and anxiety but there is some room there for families, some room for love and there is some room for respect for the choices that they make as well.

MS CASTLEY: You mentioned the time frame. With your dad's case, you said he chose to starve himself for the last five weeks. We have had a few people talk to us with a concern that we do not have time frames and that that might impact vulnerable people et cetera. What are your thoughts about that? I know you said that you like that we do not have a time frame. Would a time frame have impacted your dad's ability to access voluntary assisted dying?

You have got the experience, and I appreciate that. Was your dad asking for voluntary assisted dying or to want to die before the five weeks happened, or was it from five weeks on? Was his mental capacity still there that would have not precluded him?

Ms Pavkovic: To give clarity in terms of the five weeks, he went into hospital, into emergency care, for health reasons. He was then in hospital for a couple of days, and then that is when he expressed his wish to die. We spoke to doctors at great length. Doctors referred us on to other psychologists or psychiatrists—I am not 100 per cent certain on their speciality—and social workers. We had a number of different specialties within the health realm come and speak to us around whether my dad had the mental capacity to make that decision, whether he was depressed and whether he was being coaxed into such a decision. All of the health professionals did end on the agreement that he had the mental capacity to make that decision. At that point in time, he could not walk, talk or eat food by mouth—he had a PEG feeding tube.

So the decision was made that he could go through one or two routes: one, not have water and then perish sooner, or not have food and continue water and perish at the time that he would perish. He chose the food option to enable friends and family to come around and visit him at that point in time, because he was not certain that a week without water would be enough time to be able to get everyone together. So that five weeks was more the fact that his body held on for five weeks in a state of starvation.

To answer your question in terms of the time frame, for someone like my dad, who had a neurodegenerative disease, putting a time frame on something like that, particularly when Parkinson's has over 100 different expressions and 100 different ways on how it can progress, it can be really challenging to nail down a specific date, and it will be absolutely dependent on which doctor you go to. Someone will say three months and someone will say 24 months. It is inconclusive. From my dad's perspective, he had zero quality of life that was acceptable to him, and that made it so that he made that decision and then, from five weeks on from making that decision, he ended up passing away.

Having a time frame puts pressure on the health professionals to make a "clock of doom", I guess, and it is not necessarily something that we want to do when it will put pressure on those individuals when they have so many other pressures. People who are in this state know when it is their time, particularly when they are going through endless amounts of suffering. They will fight and they will fight to the very end, I guarantee you, but, when it is time, it is time and they know.

THE CHAIR: I just have one final question and we have sort of covered it a bit but I will put it anyway just in case you want to add anything. Given your personal experience, are you satisfied that this bill sufficiently protects and promotes the right to life as you understand it?

Ms Pavkovic: I think the bill has all of the major constructs that would enable something like that to occur. I think what it will come down to is how we design the policy, how we design the service and how we integrate that into existing services to ensure that we have that right-to-life component in there. I was hearing some earlier components of the inquiry talking about maybe it is palliative care or voluntary assisted dying and I do not necessarily believe that is the case. I think it needs to be seamlessly integrated in the sense that it needs to be known that it is part of a service that we offer and is part of a service that is delivered without stigma and with respect to a person's choices. But it does need to have that element of separation to show people that it is a choice and that, once they are into the end-of-life sort of stage or process of their illness, they know that that is not the tunnel that they are forced into. There does need to be adequate separation, and I think that that can only really happen through fantastic design of the service.

THE CHAIR: Thank you very much. We will have to wrap up there because we are at time. Before we do finish, is there anything else that you want to quickly add?

Ms Pavkovic: I would very quickly add that my father passed away on his birthday and, through all of this, after speaking to you guys so many times and speaking to other politicians and radio channels, I reflected that I did not actually get him a birthday present. It was only until very recently that I realised that his death was actually his final gift. I want to offer the mind frame for you guys that, whilst you are designing something that some people want and some people do not want, in some people's eyes, particularly that of my father, death was absolutely a gift. If we could try to give that gift to other people with respect and with choice that that is something that they are able to access—so they do not go through the same traumatising end that some people do go through—I think that that is a wonderful mind frame to go about this. Thank you so much for your time and letting me be here. I appreciate it.

MS CASTLEY: Thanks Kat.

THE CHAIR: Thank you. I appreciate you are not well; so thank you for making yourself available to us and being flexible with the time. You will get an uncorrected proof of the *Hansard*. It will be sent to you by the committee secretariat for you to have a look over and correct any factual errors. Again, on behalf of the committee, thank you for your testimony.

Ms Pavkovic: Thank you so much for your time. Have a lovely day.

Short suspension.

HARVEY, MR DONALD ROY

THE CHAIR: We now welcome Mr Roy Harvey. Mr Harvey, can you please confirm that you are appearing today in your capacity as an individual?

Mr Harvey: I am 83 years old. I am appearing in a personal capacity with personal experience with this and 30 to 40 years of health research, including on adverse drugs, which was the cause of my wife's death.

THE CHAIR: That is okay. We can get into the substance of that. We will just run with individual right now—

Mr Harvey: The third element is that I am a member of Exit, but I have nothing to do with their submission. Mine is entirely my work. As I said, I have been an academic—well writing policy papers for 50 years, which is why the first one was so long.

THE CHAIR: Thank you, Roy. Thank you for your submission and the subsequent submissions that you have put in and for agreeing to appear today. I would like to remind you of the protections and obligations afforded by parliamentary privilege and draw your attention to the privilege statement. That is the pink card on the table there. 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 I please get you to confirm, for the record, that you understand the implications of the statement and that you agree to comply with it?

Mr Harvey: I do, and I agree.

THE CHAIR: Thank you very much. We are not inviting opening statements. However, if you do have one, you are welcome to table it with the committee secretariat and the committee will read it in due course. I would remind Roy and everyone who is present that, if you are finding the hearing difficult, please let us know and we can take a short break.

Mr Harvey: I have had my quarter of a Valium!

THE CHAIR: Well, if you need any more support—maybe not Valium—please let us know. We will now go to questions. Mr Cocks will start us off.

MR COCKS: Thank you, Mr Harvey, for your submission. One of the areas that I am very interested in is people with mental health issues. Your submission seems to indicate that you think that would be an expansion that should be considered. I would like to understand if there are specific conditions or a line as to what sort of conditions should be considered reasonable? How would you determine eligibility on mental health?

Mr Harvey: I had a conversation with a person, and I think he had said he had been through 14 different therapies over 25 years and he still is continuing this constant battle against committing suicide—to put it bluntly. To some extent, some of the procedures in the Netherlands I think actually help people identify services that might benefit them. If this were permitted, it could actually be a positive feedback for quality and assessing the effectiveness of psychiatric services in the ACT.

Only four per cent of people in the Netherlands who applied for VAD who have psychiatric conditions are actually granted it. So it is not as if we are talking about a floodgate. That is after 20 years of operations. It is a very small number of people who are actually allowed. To some extent, by exposing them to a series of specialist assessments there was no report on whether it actually helped some people not to suicide. A significant number of people actually suicided while waiting for the process. This is the thing about psychiatric illness.

MR COCKS: It sounds like you think that there would need to be some processes around ensuring that someone was not suicidal as opposed to—

Mr Harvey: Of course. That is sort of obvious, if I can say that. There are protocols developed in the Netherlands. The Canadian government has had a parliamentary and expert committee studying for nearly two years, and I think they brought in the report on access to the mental health. Given that they are not Europeans—they have a British form of law—presumably the sorts of evidence and the sorts of things they have considered would be seen as relevant to a British law context.

MR COCKS: The original question was about specific conditions. Are you aware of any specific conditions—

Mr Harvey: No; I am not a clinician. As I said, the things identified in literature are essentially people with long-term, unresponsive psychiatric conditions. As I said, this person who talked to me said, I think, that he had had 14 different sorts of therapy, some of them several times, and he is still essentially suicidal. But I am not a psychiatrist and I would not pretend to be.

MR COCKS: Absolutely. I understand that.

Mr Harvey: But I can read the literature.

MR COCKS: Thank you.

MR BRADDOCK: I have a question on advanced care directives where you say the ethical issues may not be as complex as the Human Rights Compatibility Statement.

Mr Harvey: Yes.

MR BRADDOCK: Can you please elaborate a bit more on that point?

Mr Harvey: If you look at what is currently permitted in advanced care directives, it enables people to direct not to receive care; they have voluntary starvation and end in drinking a palliative sedation. To some extent, this is a clear distinction in certain Catholic institutions in the United States. They are not even allowed to provide support for that. It seems to me that, if we are going to admit voluntary assisted dying, if you say, “Well, you can starve yourself to death”—and the study suggests that it takes seven to 35 days to die and 15 per cent of people either have delirium or pain which requires continuous management—unless you allow those people to access VAD, you are essentially coercing them into starving themselves to death. As I said, the distinction is not clear in some religious groups' minds that even that is permissible in an institution.

I think that, if you are allowed to choose to starve yourself to death, choosing a less painful thing—which is probably less stressful on your family, instead of spending 35 days thinking is he going to have delirium today, is he going to need pain enhancement, is he going to die today—it is actually a rational decision from an individual to say, "I am 86 and I have had all the medical treatment I can take and need" and that is when you should—

MR BRADDOCK: Thank you.

THE CHAIR: Mr Harvey, it has been put to us by some witnesses that one of the key components of a voluntary assisted-dying scheme is that the decision is voluntary and can be made at the time and that you can reverse the decision and that having advanced care directions, particularly if you are in a state of cognitive decline and you might not have those decision-making capabilities at the time that the death is carried out, takes away the voluntary aspect of the scheme. In the context of what you have just been discussing and your knowledge and research, I am interested in how you would view that proposition.

Mr Harvey: As the directives and all the information on the Palliative Care Australia website, government website, says, you should try to make these things earlier, when you start to develop serious conditions. On the idea that you would actually leave it within 35 days before you die, which is the Victorian experience, where you have already got intolerable pain, you are close to death, you have had diminishing quality of life, it seems to me that you are putting people in an extraordinary vulnerable position then.

In my case—and in the case of many other people I know—I know the sorts of things I do not want. I do not know whether you saw my ultimate submission, but I was saying that the advanced care directives should specify the desire for VAD and the specific circumstances in which it would apply. So the clinical issue would be: are the conditions in your advanced care directive met and, if they were, then that would be the end of it. If they are not met, then—

THE CHAIR: The proposition that was put to us is that, because you would not be able to reverse the decision, it would not be a voluntary decision. I am interested in your view on that. Would you consider it still to be voluntary even if it is in the advanced care directive?

Mr Harvey: The advanced care directive can be revoked at any stage.

THE CHAIR: The proposition that was put to us was that if you do not have, say, the cognitive ability at the time that death is administered, you would not be able to reverse it and that therefore that is the part that ceases it to be voluntary. I was just interested, because you had quite a bit to say on this.

Mr Harvey: That is a Catch-22. If you say that, when you have an incapacity, "I do not want to live if I have to be fed; I do not want to live if I am incontinent; and I do not want to live if I have to be carried in and out of my bed", and you actually reach that stage and you have lost mental capacity, then someone who has lost the mental capacity cannot make an informed decision one way or the other anyway, which is what the Dutch courts found. There was only one case in 20 years that went to a Dutch court, and it found that, by following the advanced care directive, the doctor had behaved properly. It is probably an appendix to one of my many bits of paper to you.

The case the court considered was that of a woman who was actually aggressive towards patients and other staff and used to defecate in a lot of people's rooms, wandered around saying, "I want to die. I want to die." She did have an advanced care directive saying, "I want voluntary assisted dying if I get dementia," but the condition when it was invoked was not clear. Again, that is addressed in my last thing—an assisting person. That someone in their advanced care directive should say, "My daughter" or "My son," or someone "will be by assisting person, if for any reason"—they might fall down the stairs—"I lose mental competence and they can ask for a clinical review as to whether the circumstances in the advanced care directive have been met." I think there are ways to addressing it. You may say, "But how can you trust your daughter or your son?" It is a pretty bad state if that is the case.

THE CHAIR: In the time we have left, Mr Harvey, is there anything that you would like to say to us that we might not have covered?

Mr Harvey: Yes. It is raised in various ways in everything I have put into the committee, and that is that the complex protections to protect the vulnerable have to be balanced against the harm it causes to people who are suffering pain and may not get through all the hurdles. Every bit of public policy that you pass will have an intention to do certain things, but there will be somebody who misses out and other people who are harmed by it. If you have made two requests for VAD and you are clearly suffering intolerable pain and close to death and you lose mental capacity, under the current legislation you are out. Does it seem reasonable to you? It does not seem reasonable to me, especially being reinforced by an advanced care directive.

As I have said in all my submissions, I have done extensive reviews trying to find evidence of abuse and I can find none. Quite often anti-VAD groups will look at enduring powers of attorney. People have been sent to jail because they have abused enduring powers of attorney. Denmark has had VAD for 20 years and only one case has ever got to court and there has never been press coverage of any abuse. I did yet another review in Canada, and the only one I could find was someone had chosen VAD and was being coerced by their family not to.

I urge you to try and look at the public balance between having extraordinary strict hurdles that people have to jump over. As I said, falling before the third hurdle in this legislation, seems to me quite inhumane. People may live three months or 10 days in considerable pain but, because they are no longer cognisant—although they may have already indicated twice that they want to—are no longer eligible. It seems to me that a strict application of what they call the "blanket rule" is inhumane. If you balance harm against benefits, the harm to people of not getting access to VAD is documented and quite considerable. The harm to vulnerable people is allegations and assertions, for which I could not find any evidence.

THE CHAIR: On that note, we will have to wrap up. Mr Harvey, I do very much thank you for the time that you have taken in the submissions that you have made and the supplementary submissions that you have made and also for appearing today.

Mr Harvey: Thank you very much. I am pleased to have had the opportunity.

THE CHAIR: The committee is very appreciative for your input. You will be sent an uncorrected proof *Hansard* for you to read over and, if there are any factual errors, you will be able to amend those.

On behalf of the committee, I would like to thank all of our witnesses who assisted us through their experience and knowledge. I would also like to thank Broadcasting and Hansard for their support. If there is anyone who has been affected by the proceedings today, again, please get in contact with our secretariat. We have supports to assist you there.

The committee adjourned at 4.59 pm.