



**LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL TERRITORY**

**SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT**

(Reference: [Inquiry into end of life choices in the ACT](#))

**Members:**

**MS B CODY (Chair)**  
**MRS V DUNNE (Deputy Chair)**  
**MS T CHEYNE**  
**MRS E KIKKERT**  
**MS C LE COUTEUR**

**TRANSCRIPT OF EVIDENCE**

**CANBERRA**

**FRIDAY, 25 MAY 2018**

**Secretary to the committee:**  
**Mr A Snedden (Ph: 620 50199)**

**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.

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## **Privilege statement**

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

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*Amended 20 May 2013*

**The committee met at 9.07 am.**

**MAY, MS FIONA**, Chief Executive Officer, ACT Disability Aged and Carer Advocacy Service

**CONNOLLY, MS HELEN**, Projects Coordinator, ACT Disability Aged and Carer Advocacy Service

**THE CHAIR:** Good morning, everyone, and welcome. I declare open this fourth public hearing of the Select Committee on End of Life Choices in the ACT inquiry into the matters referred to the select committee by the Legislative Assembly on 30 November 2017. The proceedings are public. They are being recorded by Hansard for transcription purposes and are being webstreamed and broadcast live.

I remind witnesses of the protections and obligations entailed by parliamentary privilege and draw your attention to the pink privilege statement on the table. This is very important. I welcome today's first witnesses from ADACAS. Could you confirm that you have read and understand the privilege implications of the statement.

**Ms May:** Yes, I have, thank you.

**Ms Connolly:** And I have also.

**THE CHAIR:** Before we proceed to questions from the committee, would you like to make a brief opening statement?

**Ms May:** I would, thank you. Thank you for the opportunity to come before you today. ADACAS is Canberra's largest individual advocacy service and works with people with disability and frail older people to ensure that their voice is heard in matters that affect them. We work with some 500 clients each year and have been operating for over 27 years now.

I begin by saying that ADACAS supports the Human Rights Commission submission that the Andrews bill is contrary to the ACT Human Rights Act, and I urge all members of the Legislative Assembly to bring their influence to bear on their federal counterparts to see the Andrews bill repealed.

While we have not had the opportunity to review all submissions received by the inquiry, I am aware that other individuals and organisations representing the interests of people with disability have participated. I anticipate that these submissions have not been homogenous in their views about end of life choices and acknowledge that, like other members of our community, people with disability will have diverse views about this issue.

The concept of state-sanctioned euthanasia is scary for some people. It is particularly scary for those in our community who have lived experience of their lives not being valued by others, of not receiving supports, services and treatments because others do not see them as worthy, of being accused of being a burden on society. If you have lived with that reality, it is not a stretch to fear that euthanasia could be inappropriately used to relieve society of the burden of people with disability.

We acknowledge and honour the very genuine concerns raised by people with disability that any legislation may become a risk to the lives of people with disability. However, this inquiry is important because having the right to choose to both live and die with dignity and at a place and time of one's own choosing goes to the heart of what it is to be human and is a crucial expression of human rights. It is the experience of the clients of ADACAS that they are often not enabled to exercise the right to choose when they are alive, and particularly not in regard to big and important decisions.

From a human rights perspective ADACAS supports the development of any legislation that empowers individuals to have the right to choose in matters that affect their own lives. The key, then, will be to develop legislation that includes sufficient safeguards so that it cannot be used to end the lives of people other than by their own free will. We have some ideas that could assist with that.

Firstly, and most importantly, we believe that a safeguard would be for the legislation to include a mechanism of advance consent so that a person can choose at a time when they are not unwell to record their preferences with regard to end of life choices, similar to an advance care directive, which can currently be used to record treatment preferences in the event that at a future time you are no longer able to communicate your healthcare wishes.

It may be, for instance, that the legislation requires people to preregister their interest in being offered end of life choice should circumstances make that an appropriate option. Such preregistration would have to be safeguarded so that people must do it of their own free will. They must be offered and be able to access support to understand the implications of registering, and they must be able to access advocacy if they need it. They must also be able to revisit their decision at a future time if they change their mind.

Additional safeguards which enable people with disability to participate in the process free of undue influence would also be necessary. One such safeguard is the use of supported decision-making, and Helen joins me today to share with the committee her expertise in the role supported decision-making could play and some case examples of supported decision-making for healthcare decisions.

Frail older people are another group in society that could be at risk if the euthanasia legislation was misused. ADACAS has considerable experience with supporting people experiencing elder abuse, including through the misuse of guardianship and powers of attorney, where substitute decision-makers impose decisions that are not consistent with the person's values, their will and preferences, and are contrary to their rights. The legislation would need to ensure that substitute decision-makers are not able to make an end of life decision on behalf of a person where the person has not pre-registered their preference prior to being unable to express their choice.

ADACAS believes the right to make end of life choices should be both sanctioned and safeguarded in the ACT and welcomes the Assembly's consideration of the issue.

**THE CHAIR:** Thank you. Before we start, I would to make a brief statement that we are meeting on the lands of the Ngunnawal people. I pay my respects to their elders,

past, present and emerging, and I pay my respects to the continuing contribution of their culture to this city and this region. You mentioned supported decision-making. Can you expand on what that is?

**Ms Connolly:** I am the projects coordinator at ADACAS and am particularly looking at supported decision-making at the moment in health care. Supported decision-making refers to a process of offering support to people when and where they need it. Support is decision specific and time specific, but it explores people understanding the decision that needs to be made, exploring the options, weighing the consequences and declaring a decision, with the support that they require for that specific decision.

For some people that looks like making sure that the information is provided in an accessible way; that the process of consideration allows the time they require; that they are offered support to consider the effects of how their decision affects people in their network; who offers them decision support; whether they have had practice making decisions on their own—which we know is not the experience of many people with disability around big decisions; and whether they understand that making a decision does not mean that you cannot change your mind, that you can revisit decisions you make, that we sometimes make decisions that we are not comfortable with, and that we might want them to last for a short time. So it is going through the entire process.

We do it by exploring an existing network of support for people in the many ways that that can exist: asking people about the history of their decision-making, the vision they might have about their good life and what sorts of supports they use. Some of those supports for some people, particularly those considered socially isolated in most terms, still are supports to their decision-making network; they just might not look the same as everyone else's. It might be that they make decisions when they talk to the mechanic, that the mechanic gives them some information and that they process that and they weigh that differently.

**THE CHAIR:** Do you work with families as well to help them understand the decisions of the people you are working directly with?

**Ms Connolly:** Yes. For any decision-maker we will ask them to identify their network. Often those referrals come from family members, from health professionals or from the advance care planning team within ACT Health. They may be visiting someone and identify that that person might need additional support to go through a decision-making process, including about complex things like healthcare treatment or the options around healthcare engagement. We will talk with whoever that person nominates as being in their support network. We might also offer support to ask: "What would Mum think, what would your siblings think, what would your doctor think, or what would other people in your life think?" if that is some space where that person needs support.

**THE CHAIR:** You mentioned having the opportunity to change your mind. One of the things raised in your submission was that we know that, as life progresses, many of us change our views about what quality of life means to us, and the same is also true for dying. Something we have been looking at is if someone makes a decision

such as: “My decision today is that I do not want anyone to use life-saving techniques,” or “Yes, I would like to take part in voluntary assisted dying when I am at this particular point in my life,” or whatever it may be. Making those decisions now does not mean you cannot change your mind down the track, as you get closer to that point in time, does it?

**Ms May:** That is exactly right. As a personal example, my father-in-law died last year. Some years ago, when he first got adult diabetes, he said, “I would never want to be on dialysis.” However, after having some surgery two years ago, dialysis became essential and he decided at that point he would have dialysis. So, although he had told the whole family for many years that that was not what he wanted, he decided then that he would have it. He then had it for about 12 months, but then maybe a month before he died he said, “Enough’s enough. I’m coming off dialysis,” and he made that decision.

That was a difficult decision for those of us who were close to him, of course. In his last days he actually fell and broke his hip and then we had five days of palliative care. The palliative care was the best palliative care there could be. I could not praise enough the hospital where he was. But it was still five days of watching him slowly die, and I would not wish that on anybody ever again.

He made his choices all the way along, but at the end he did not have a choice and we all just had to keep him as comfortable as we could and wait for it to happen. I think that is incredibly sad for a person who indeed had the power and the right to make his decisions all the way along his whole life journey to not have that choice in that last week.

**THE CHAIR:** And he was not compromised intellectually?

**Ms May:** No. So people have the right to make a different decision as different things happen in their life, and we need to be able to design a system that respects that.

**MRS DUNNE:** Ms May, you spoke in your comments this morning about giving people the option of pre-registering their interest, but you also spoke about the need for safeguards. It seems to me that there is a possibility of substantial compromise of safeguards if people are already pre-registered.

How would you envisage a situation, which you have described, where someone could pre-register while they were capable but which allowed somebody else to make the final decision about whether or not they should have access to voluntary assisted dying? What sorts of safeguards could you imagine that would ensure that the original decision was the authentic, final decision of the person and that a substitute decision-maker was always acting in the best interest of the individual concerned?

There was a witness yesterday—and a number of witnesses have spoken about it—who spoke about us as observers of someone dying. You have just spoken about this yourself. They speak about the discomfort and the things that we would not like to see. But how do we authentically know that that is the will of the person who is actually dying? If somebody pre-registers, maybe five years down the track when their decision-making capacity is diminished how do we actually know what they are

thinking at the time?

**Ms May:** I think there are a few different things to that. One of the things, for me, is that this is not a conversation that you have just once. It is not “set and forget” but, in fact, as the journey progresses, ensuring that we continue to check in with the person about how comfortable they continue to be with the decisions that they make.

**MRS DUNNE:** But who would do that checking in?

**Ms May:** I think lots of different people could do that checking. It is very important to make sure that the people who are doing the checking have no vested interest in the outcome of the decision. Where a person stands to benefit in some way or there is a consequence in their life of the decision, they are not necessarily the right person to do that.

If I use my father-in-law as an example, his biggest concern was how difficult it would be for his wife. He had incredible trouble having health conversations with his wife. But he managed to have them with me because I was not as close to him. Then I was able to convey to his wife and then she was able to convey to the healthcare team that he did not want any further intervention.

It is about who is having the conversations, how often the conversations are being had. Palliative Care Australia has some wonderful resources on talking about dying. There are really helpful ways and tools and tips about being able to have those conversations about something that we all know is going to happen. To me, it is really important that we continue to have those conversations in lots of different ways, that healthcare professionals are involved, that family are involved and, where necessary, that decision supporters or advocates who are independent of the decision are also able to be involved. Do you want to add to that, Helen?

**MRS DUNNE:** Just before you do, can we pick up on that. Is there is a risk that the process you have described becomes a bit bureaucratised and then you might have a substitute decision-maker who is making decisions on the basis, as you rightly pointed out at the beginning, of cost effectiveness or that particular lives are not worth living in the same way that other lives are because of disability et cetera?

**Ms May:** I think the legislation would need to be very clear that that is not a basis for making the decision. The basis for—

**MRS DUNNE:** How do you avoid that, though? How do you avoid the spirit of the legislation not being kidnapped by bureaucracy and economy?

**Ms Connolly:** I think one of the things is the opt-in component, not opting to have that part of your decision. The values, wills and preferences by which you have lived are indicators for that. One of the particularly fraught things is an assessment of decision-making capacity. We know that is already fraught and already very difficult.

Very, very rarely, I would suggest, does everyone lose decision-making capacity in every decision in their lives—in fact, only if you are not conscious. Prior to that time, the decisions that you make reflect your values, wills and preferences and therefore



are not about your best interests and not about what someone else assesses as your best interests but are reflective of the values, wills and preferences that you have exhibited and lived your life with.

If those conversations have been had, if you have opted into having that choice available to you, then the person to whom you have surrendered the decision when you are well is the person who is going to make it in accordance with value, will and preference—not about best interest. And if there is no-one in your life that you surrender that decision to then the decision still needs to be made based on any evidence of what value, will and preference you have exhibited—not on what anyone thinks is best interest, which would be economic or emotional contact, usually.

**THE CHAIR:** Have you had a chance to review the Victorian legislation at all? Do they pick up on some of these points that Mrs Dunne has made adequately, do you think? Or does there still need to be a bit more work done? If you have not reviewed it, well enough; that is absolutely fine. It was just a question.

**Ms Connolly:** It is one of the things that I think still rest on a decision-making capacity towards people's end of life and does not clearly state what is required to support decision-making or what decision support looks like. If we measured the support required to participate in decisions rather than capacity, we would probably be in a better space.

**MS CHEYNE:** I am still trying to formulate my question based on things we have heard. Bear with me, but I think it draws from what we have talking about in terms of safeguards. We are hearing from Lives Worth Living later today. Have you read their submission?

**Ms May:** Yes.

**MS CHEYNE:** It probably would have been helpful to hear from them and then hear from you, but in their submission they say that the ACT should legislate to strongly reject euthanasia for all disabled people, due to how dangerous it is. I think that is on a basis that their view is that the health system is hostile to people with a disability. I think there are other elements in their submission.

I know that there is a grey area between disability and illness—a history of violence against disabled people and people with a disability rating poorly in terms of mental and physical health. I am picking up some of those fears regarding safeguards. Are you able to refute or, from your own experiences, expand on some of the things that they have raised in their submission?

**Ms May:** I think it is true that people with a disability do not necessarily have a positive experience of health systems. And we certainly have examples of clients whose experiences of health systems have been diminished because people have made assumptions about the value of their life and the value of rehabilitation and those kinds of things. That, unfortunately, is true.

I do not think that denying people end of life choices is a solution to that problem because we have to address the fact, in all facets of life, that the lives of people with

disability have value and that they have a right to equality before the law and equality in our health system, our education system, our employment system and everything else. Those things are true.

But to have this legislation or not will not change that experience. We need to work in other places and other ways to change the way that people with disability are valued and respected in our community.

**MS CHEYNE:** Forgive me if I am putting words in your mouth or please correct me if I am wrong, but on some level, if this was legislated and we had a scheme but specific classes of people were excluded—as I say, people with a disability were excluded—and going to that point about a right to be equal under the law, it would be on one hand excluding them because it is dangerous but on the other hand further denying them equality, is that right?

**Ms May:** That is right, and there were other submissions in your submission list made by people with disability who were supporting the idea of end of life choices legislation. As I said at the beginning, we do not have a single view, across the larger view of people with disability, about whether this is a good thing or not a good thing. We have diverse views.

**MS CHEYNE:** Just like in the general population?

**Ms May:** Just like in the general population. I do not think any of us have had enough time to do all the thinking that needs to be done to craft legislation that will do the best job here. That is the task that is before us if the Assembly decides to go ahead and begin that process. I think there is a lot of work to do, a lot of things to unpack, but the right of people to have a choice and a say in their lives is a human right and we should not deny that.

**Ms Connolly:** And supported decision-making is really a tool. At the moment the project that we are looking at is using that as a tool to advance equitable access to health care. I think the primary concern of people with disability is not just that there is inequitable access to health and inequitable judgement about healthcare services. But you are right: we do not want to say, “Let’s make another service that is inequitable in access” either. We need to make sure that we offer tools that enable inequitable access, and supported decision-making is definitely one of those.

I also think there is a lot of concern generated across the community broadly but particularly for people with disability that, where substitute decision-making happens formally and informally in health care, the people making those decisions are the people from whom they have had a delivered experience of devaluing of the lives of people with disability, not offering service.

Some healthcare professionals might say, “There are prenatal tests for certain disabilities. Those children need not be born.” How can you trust that that person will make a decision that is equitable in terms of offering access to end of life choices as well, if that is an informal substitute? I think that is a very real concern. I think that is the lived experience expressed by a number of clients.

**Ms May:** I think we also need to expand this to frail older people. In fact, frail older people potentially are more at risk of best-interest decision-making, as you described it, Mrs Dunne, than free will decision-making or decision-making based on their lifelong preferences and expressed wish or their human rights. And we really need to think about how we build in safeguards that ensure that the lives of old people are still valued and that their free will in how and when they die is respected.

**MS CHEYNE:** It is early morning. I am struggling to get my head around this, but I am trying to balance the fact that people can and do change their minds about how they feel. But what are the influencing factors in their changing their minds? Is it circumstances or is it someone in their ear trying to do that?

**Ms May:** We certainly see, amongst ADACAS clients, older people who come to us with considerable concern about the way family members are acting with regard to their finances, with regard to their healthcare decisions, with regard to their belongings. And they have incredible influence over the older person because that is a time in your life when the last thing you want is to alienate your family. It is a very fraught space and there is an overlap here around the elder abuse conversations that are going on.

The Australian Law Reform Commission has done a very big investigation into elder abuse. At the pointiest end of elder abuse are people who are dying because of elder abuse. We need to make sure that any legislation does not make that easier for people.

**MS LE COUTEUR:** It was good to hear you talk about elder abuse and that the frail aged are potentially the most vulnerable. I want to talk to you about our other terms of reference, and not just about voluntary assisted dying. There is also reference to palliative care.

You have been talking about disabled people in general not having as much trust in and access to some normal parts of health care. Do you think that is also true for palliative care and, possibly even more interestingly, the bit before that—where you have not reached the palliation stage but clearly you are in the last stages of your life? Do disabled people get equitable access there?

**Ms May:** I do not think I can speak to that question with authority because the authority I bring is with respect to the cases of work that ADACAS has done with people with disability. I am not recalling right now cases where we have had a question around access to palliative care for a person with disability. Have you come across that in your project?

**Ms Connolly:** There have been a couple of people who have said—not just at the beginning of a diagnosis, which talks about palliation at the end as being a likely course of prognosis—that the additional support that people with disability might require to access those services, to understand those services and to consider the options attached to that is not available to people.

Guardians, family members, have certainly contacted us about their concern that palliation was not discussed, was not offered or was offered too quickly. “This person is palliative; you may as well just let them...and not investigate the options.” There

are very emotive reports about how that feels after a lifetime of that sort of experience. There are many false assumptions about the life expectancies of people with disability, about the understanding of health, that conflation of health, illness and disability, that are experiences that we have recorded in our health care and supported decision-making project. Yes, it is an experience that people have.

**MS LE COUTEUR:** I imagine it is also an experience in the stage before palliative care, when they have had a disability for whatever reason but they are now getting closer to end of life, potentially for reasons which are not to do with that disability—unrelated cancer or whatever.

**Ms Connolly:** It delays an investigation. “We don’t need to investigate things that we would do for people without disability because there are all these other things that are likely to contribute. So we’re not going to go down the same path. You’re not going to be offered the option.” That is the basis of inequity.

**Ms May:** An example of such a case was a man with intellectual disability who, in his sixties, needed to have a hip replacement. The hip replacement surgery was done and the allied health professionals in the hospital decided that because he had an intellectual disability he was not a candidate for rehabilitation.

**MS LE COUTEUR:** You’re kidding.

**Ms May:** Sadly, I am not kidding. In fact, their suggestion was that he go home and he have what they called essentially informal rehab. “As you move around your home, you’re going to get some mobility back,” that kind of thing. Our supported decision-making team was, fortunately, already involved with this man with regard to other decisions that were happening in his life at the time.

We were working with him and helping him to learn how to make decisions in his life, which was very fortunate, because it meant we were able to engage with him around the decision to go to rehab or the decision to go home, to help him to understand the consequences of choosing each of those two options and then help him to demonstrate to the allied health professionals that he could have a rehab goal, he could work towards a rehab goal and he could get that rehab before he left hospital.

That is a very real example of assumptions made by health professionals about people whose intellectual ability is questioned, and their ability to participate in other health activities.

**MS LE COUTEUR:** “Appalling” is the word that comes to mind.

**MRS DUNNE:** Yes, it is appalling.

**THE CHAIR:** I note the time. Mrs Kikkert.

**MRS KIKKERT:** In the interests of time, I will put my questions on notice, if that is okay.

**THE CHAIR:** Absolutely; that is fine. I would like to thank you very much for your

evidence this morning. It was very insightful but sad in some places, too; I am sure we would all agree. When available, a copy of the proof transcript will be forwarded to witnesses, to provide an opportunity to check the transcript and suggest any corrections. On behalf of the committee, I would like to again thank you both for appearing today.

*Evidence was then taken in camera but later resumed in public.*

**WALLACE, MR CRAIG**, National Convenor, Lives Worth Living

**THE CHAIR:** Welcome back to the continuation of today's hearing and welcome, Mr Wallace. Can you confirm for the record that you understand the privilege implications of the statement in front of you?

**Mr Wallace:** Yes, I do. That is right.

**THE CHAIR:** Thank you. Before we proceed to questions from the committee, would you like to make a very brief opening statement?

**Mr Wallace:** I would. How long would you like that statement to be?

**THE CHAIR:** About three minutes would be amazing, if possible.

**Mr Wallace:** I thank the committee for the opportunity to address you today and in doing so I acknowledge that we are meeting on the lands of Aboriginal and Torres Strait Islander people and that I respect their elders, past, present and future.

We do not always get a chance to have our voices heard on these issues because they often come from private members' bills; so this process is actually good. I am here representing an informal group called Lives Worth Living, which is a network of prominent Australians speaking about euthanasia, eugenics and related issues. We are not a mass membership organisation. We are not even incorporated. We are just a group of disability leaders with shared concerns in this area.

What is common is that all of us have significant disabilities and we have been senior people in state or national disabled people organisations. We have a core steering group. I will not name all those people but some of the more prominent people are people like John Moxon, Sam Connor and the late Jane Hume, who founded this group with us. We have links to groups like Not Dead Yet in Victoria, WA and the United Kingdom. The symbol on our letterhead that you would have seen is a reverse of the black triangle that was used in Nazi concentration camps to denote prisoners as asocial or work-shy. This was applied to disabled people and also to some gay and lesbian people during the T4 euthanasia program, which killed between 275,000 and 300,000 disabled people.

We do not come from a religious or pro-life position. I am not a Christian. I do not believe that every stone is sacred. I respect that tradition. I respect people who do but that is not the tradition that we come from. We come at this from a disability rights perspective. We listen to people like Stella Young and Liz Carr on these issues. We identify as empowered disabled people and we practise our pride. We campaign against violence, eugenics, philistinism, murder and euthanasia of disabled people as part of a single utilitarian program that we believe is designed to eliminate diversity.

I do not claim to represent all disabled people on this issue or any other, really, and you should be talking to other people in the community. There are people like Kelly Vincent that have quite different views. However, I have to say that my sense is that the balance has actually tipped. It probably tipped around the time that Stella Young started talking about this and said, "We do not want death with dignity. We want lives

with dignity.”

I was also the elected president of the national peak body for People With Disability Australia for two terms. Unless something has changed very recently, PWD also has concerns about euthanasia in a society where people with disability lack the same rights, access and other facilities as other Australians.

Here in the ACT we believe that this debate should be about human rights, not states’ rights. As a proud Canberran since 1995, I personally believe that the federal ban has actually distorted the debate. In 2018 we are a mature jurisdiction. As adults we should be able to legislate but then be grown up enough to ask serious questions about whether euthanasia is consistent with human rights values in a community that welcomes disabled people.

These are not simple issues. You have seen that from many submissions. I read some of those last night. They are really compelling stories. I have had a parent die in difficult circumstances over the last two years. I can understand people who say, “My body is my estate and I have the right to do with it whatever I want.” The problem that we have goes to definitions. Nobody is able to land a clear dividing line between disability, illness and a medical condition unless you were actually to name all of the illnesses involved and exclude disability entirely. In the absence of this, we rely on words that are open to interpretation like “voluntary”, “unacceptable suffering” and “terminal” that are interpreted by medical professionals.

Doctors routinely underestimate the life expectancies and incapacities of disabled people. I was told I would never work. It is all I seem to do. Friends were told they would be dead within a year of acquiring an injury or would never breathe independently. They have then gone on to be part of our network and they are still, thankfully, with us.

Bills usually talk about a terminal illness, but how do we define this? Most practitioners would say that a high-level spinal injury considerably shortens a lifespan. It is a matter of how much. Sometimes they get the timing wrong. Sometimes the technology, the supports and the adaptations move ahead of the prognosis. Most bills talk about suffering that is unacceptable or intolerable to a person. When is something unacceptable? Is it when you are unable to walk, like me? Is it when you are unable to feed yourself? Is it when you are unable to evacuate your bowels without assistance?

I know people in the disability community who live like this. When I have met them after their accidents, in places like RILU or the Royal North Shore Hospital, they have said to me, “Mate, turn off the plug. I do not want to be here. I want to die.” If you talk to them down the track a couple years later, they will say that with the right supports, the right assistance, the right technology, the right relationships, they are actually having good lives and there is no way they would give them up.

The degree to which disability is tolerable depends on a decent society and on the level of supports and technology we have around us. The NDIS is a step forward but I think we all know, including some people that are on the committee, that it is off to a rocky start and those supports are not fair.

I am also concerned about coercion, as you would have read in the submission. That coercion does not have to be overt. It could be simply a family withdrawing support and a person being faced with life in a nursing home afterwards. Some submissions have claimed that social attitudes towards vulnerable people can be leveraged or mitigated by public education. I actually do not agree. I think this is a toxic climate for disabled people.

We have national newspapers that are describing people with disabilities on their front pages as a \$17 billion burden. We have an immigration system that will not even allow disabled people to enter the country. I do not trust a country that does not want me here to make decisions about whether I should stay here.

In Australia in 2018 when autistic people are murdered by their parents they get sympathetic treatment by the media and the courts. I mention these other things because we have no reason to trust that euthanasia will be some kind of magical exception to these issues. Why should we somehow believe that when the stakes are highest, the safeguards will protect us? I am sorry; I actually don't. I don't trust carers and families to do the right thing. I do trust that a future government might cut benefits and supports to people with disabilities to the extent that people feel that the only way out is to take their own lives. That is what happened in Britain when the disability living allowance was cut.

I want to talk lastly about some of the double standards that I see here. I think there is a huge double standard in the way that we treat suicide and disability. For any other group of people in the community we see our project as being to prevent suicide at all costs. If it is a woman fleeing domestic violence, if it is a farmer who is under stress on a rural property, if it is a same-sex attracted young person, we do everything we can to prevent that. There is a great program called It Gets Better. Basically, it is designed to show young same-sex attracted people that there is a life after bullying and intolerance in a community that does not support you.

I ask: where is our It Gets Better project to show disabled people that with the right supports, the right help and an accepting and decent community, things can change. I would like to see that happen. At the moment when a person with a disability commits suicide, it is seen almost as a welcome relief. I am worried about legalising euthanasia in a climate like that.

The last thing I want to talk about is that for many people with disability we have actually got really poor access to health care and health supports. We are also excluded from the kinds of supports that prevent us from getting sick. Some of the people that I talk to say things like they cannot get on an examination bed because it is too high. They cannot use the bowel testing kits that are sent out by the government because they are actually not friendly to blind people. People on low incomes do not get annual check-ups because they are rushed through bulk-billing clinics.

I think there is a cancer cluster in our community. For a group of people, even if we were to say that euthanasia is just about a particular condition, we would face a double jeopardy because they are already not getting the screening and the treatment that they deserve.



My watch is telling me that I am out of time. I will end, briefly, on human rights and choice. The ACT is a human rights jurisdiction and it is something we take pride in. The UN Convention on the Rights of Persons with Disabilities has been ratified by Australia with bipartisan support. It started with Ruddock; it ended with Rudd. The ACT signed up to the national disability strategy. Article 10 of that convention says that every human being has the inherent right to life and that states should take all necessary measures “to ensure its effective enjoyment by persons with disabilities on an equal basis with others”.

That equal basis is important because right now we do not share it. We are the only group in the community, with the possible exception of Indigenous people, whose suicides are not actively prevented, whose murders are lightly dismissed and whose health is ignored. Until we get life choices to fix that, I do think we can talk end of life choices in a human rights jurisdiction. I know I am over time. Thank you for listening. I welcome questions.

**THE CHAIR:** Thank you so much, Mr Wallace. We might start with questions from Mrs Kikkert.

**MRS KIKKERT:** Thank you, Mr Wallace, for being here this morning. Your opening statement actually touched my heart because I think you eloquently described a lot of what disabled people would want to say in a situation like this. I can honestly say that because my brother has schizophrenia, and he cannot eloquently describe the worth of living and the worth of his life in the way you just did then; so thank you. I would really enjoy hearing more from you, so if you have anything to add to your submission, you are welcome to take that time now. I do not have any questions for you.

**Mr Wallace:** Thank you for that opening; that is good. I worry about people like your brother. I worry about people that are not in this room and are not as articulate as I am. People that are vulnerable and who have things like schizophrenia will not have a voice in this. Those are the kinds of people with dual disadvantage that can be easily leveraged into euthanasia. I am sure that your brother has a supportive family around him, but I know many people with disabilities whose families are frayed and falling away around them because of a combination of low incomes, ageing parents, dual disability—all of the problems with access to and forming social networks. Many of our people live alone. It is because they live alone that sometimes the depression comes from a simple thing, like a relationship break-up—the last thread basically snapping in their lives.

I worry about saying that now we are going to give those people a legal route to take their own lives and to commit suicide. If this was anybody else who had frayed social networks, we would be doing everything we could to repair those social networks, to put supports around them and to say that they can live decent lives.

For people with disabilities, the condition is only one part of it. Many of us have stable disabilities and stable conditions that can be managed through the right rehabilitation and the right supports. We are not all in pain. There are people in pain, but pain can be managed as well.

I am really worried about this and I am worried about where it might go. I note that some of the Low Countries, Belgium and the Netherlands, were talking about mental illness being one of the conditions that is in the frame for euthanasia. So there is that potential for slippage, and I worry about that here as well.

**MRS KIKKERT:** Me too; thank you.

**MS LE COUTEUR:** Obviously, I do not totally understand, given my position, but I hear your concerns about disabled people not having lives with dignity. Obviously, I think that is a very real concern. Nonetheless, end of life comes for all of us. If there are disabled people who really are in a position of pain and suffering and feeling that they want to end their life, why shouldn't this be available to them? Why shouldn't it be potentially available to everyone? It seems a bit like reverse discrimination at the end.

**Mr Wallace:** My point is that the end of life comes to people with disability as a result of inherent discrimination and blockages in the health and other systems that would stop them getting sick. At the moment we have people with disabilities who cannot access annual health checks to find out if they have a cancer that is developing and that could be managed. Our founder, Joan Hume, who passed away about two years ago, went to her doctor and said, "I'm starting to feel a bit of nausea and some stomach pains." They said, "It's a urinary tract infection. It's part of your paraplegia." This went on for months. She had a cancer growing inside her, and she eventually passed away in very poor circumstances.

Her point was, "If I wasn't a disabled person I wouldn't have had this diagnostic overshadowing." That is a term that means that basically they are diagnosing your disability when they should be diagnosing the fact that you have a burst appendix or a serious condition going on underneath.

There is no clear piece of public policy that is perfect. For me, the risks of having people with disabilities fall into euthanasia as a result of having undiagnosed conditions and not having access to proper treatment are so great now that they outweigh the benefits. I believe that the first project of a state government should be to ensure that people with disabilities have equal access to the kinds of screening and prevention that would stop them getting cancers and terminal illnesses in the first place. Once that happens, let us look again.

I also worry about the fact that none of the bills that we have seen name the conditions. The public face of euthanasia tends to be something like bowel cancer. Well, if it is, name it. Say that spinal cord injury is not in there. Say that motor neurone disease is not in there. Say that my condition, muscular dystrophy, is not in there. Then perhaps we would look at it. None of the bills do that, and that is why we get this endless slippage and it is why disability advocates look at this and say, "It's a worry for us."

**MRS DUNNE:** You talked about slippage, and you talked about the slippage in the Low Countries, Mr Wallace, but you also said that if we had a prescriptive list then you would look at it. Isn't there also a risk that, once you have a prescriptive list, you can add or subtract from that and create slippage through that as well?

**Mr Wallace:** Yes, there is, and that is actually what has happened in other countries. In Belgium we have had two deaf and blind men euthanised, and we have had a woman with dementia euthanised in Holland. We have had people with PTSD euthanised in those other countries.

I do think the slippery slope argument is a risky one to be taking because you would never do anything as a result of that. I am actually seeing it in operation here. Wherever euthanasia is introduced, it slips in terms of coverage. In some of the submissions before this committee people are already saying that the Victorian legislation, which I think says six months terminal illness, needs to be widened to include a greater group of people.

As soon as we say that this is a right, rights tend to get extended. It worries me—giving people a right to something that is basically negative, in our view, and potentially leads to a utilitarian effort to eliminate people with disabilities.

**MS CHEYNE:** It is nice to see you again, Mr Wallace. I note that your submission says that the ACT should legislate—this follows the line of questioning just now—to strongly reject euthanasia for all disabled people as being dangerous, inappropriate and incompatible with human rights, and in particular article 10.

ADACAS appeared before us earlier this morning and we put that to them. They said that that potentially creates a further problem because the lives of people with a disability do have value and we want people who have a disability to be treated equally under the law. If we create a scheme that is for some people but not others, that is potentially engendering this inequality under the law. I want to get your views on what they said.

**Mr Wallace:** Don't give us equality under the law until we have equality of outcome in terms of health care, and equality of outcome in terms of the kinds of risk factors that propel us into the orbit of euthanasia. At the moment I think the balance is the wrong way. There are so many blockages and so many barriers to access the kinds of preventive steps that people can take to manage their own health and ensure that they stay well and do not fall within the arc of euthanasia.

This is assuming that we are talking about a condition like cancer and not talking about an actual disability being the reason that a person is euthanised. I think people with disability are getting a double whammy. We are basically being pushed into the group, in greater proportions than we should be, that get terminal, serious, aggressive illnesses. That is one of my concerns.

The other concern is that the arc seems to shift everywhere this is introduced and disability winds up being one of the reasons that you can say your life is intolerable and unbearable, and seek euthanasia. As a disability rights leader, I do not want to see my people knocked off and caught within that. It is a valid position to take.

I can also understand the ADACAS position; that is also a valid position to take. I just think it is about the sequencing. The project for the ACT government should be to eliminate the risk factors that propel people with disabilities to the front of the euthanasia queue.

**MS CHEYNE:** Are those risk factors about the health system and the hostility that people with a disability are experiencing there? What are the things that we need to prioritise addressing?

**Mr Wallace:** Most doctors do not have height adjustable exam beds, so I cannot get out of my wheelchair and get up and have a full examination where they poke around and say, “Are things going on in your abdomen that we need to be concerned about in terms of cancer?” The bowel screening kits that the commonwealth government sends out to over 55s have sharp implements in them and they are not in braille, so blind people cannot use them.

A woman reported not having had a pap smear for 20 years because she could not get access to local gynaecological facilities. It is almost impossible for me to have an X-ray or a colonoscopy in this town because of the way that the hospital is set up and the way that the equipment is set up. Believe it or not, our hospitals, which you would think would need to be one of the most disability friendly parts of our town, actually have fairly old kit in them and are not disability accessible.

People with disabilities are on low incomes, and there is a lack of bulk-billing options for people in the ACT who are on low incomes. If you get into a bulk-billing clinic, they tend to just rush you through; they do not want to give you an annual check-up and spend time with you. There are a whole lot of things whereby the people I talk to are not getting the kind of screening that picks things up early.

They also do not have access to health and fitness. A lot of our gyms and a lot of our dieticians are not disability friendly. There are a whole lot of things that are leading people down the track to a lifestyle that puts them at the front of that queue, even if we assume that it is just about cancer and other diseases that look like that.

**MRS DUNNE:** I would like to reflect on some of the rights issues you have raised. There have been a lot of people who have submitted, and some that we have heard in evidence, who have contended, Mr Wallace, that the right to life also includes a right to death and choice over death. Do you personally, or the organisation Lives Worth Living, have a view about the extension of the right to life to include a right to death?

**Mr Wallace:** All people seem to think about in terms of disabled people is our right to death and that suicide is actually a good thing for people with disabilities. I do not believe that people with disabilities have a right to death. I have not heard about that as one of the rights within the UN convention. What the UN convention talks about is people having a right to life and bodily integrity that is shared on an equal basis with others. It is because we do not have suicide prevention work and we do not have work within the health system to prevent people with disabilities from getting sick that I do not think that we are sharing that right to life on an equal basis with others.

To be straight with you, I also have concerns about things like programs which seek to eliminate all people with Down syndrome as part of genetic testing. We have concerns about things like genetic testing that excludes people from certain jobs and positions based on disabilities that are hidden. We see these as a set of issues that are basically using new technologies and legislation that is running in advance of our

capacity to cope with it and ensure that the human rights of vulnerable people are maintained. I am sorry; it is probably a very long-winded answer to your question.

**MRS DUNNE:** No, but just to follow up on the subject of suicide prevention—and this is a question I have asked a lot of people in this space because it is one of the issues that particularly interest me—you have talked about there being lots of suicide prevention programs and that governments spend a lot of money on suicide prevention. Do you have a feeling that if you have a program of voluntary assisted dying, where you have state-sanctioned suicide in some circumstances, that creates a permission structure, especially for vulnerable people, to take their lives in other circumstances?

**Mr Wallace:** Yes, and I have talked in my submission about it providing an authorising climate for people with disabilities to take their own lives. We have an authorising climate for homicide for people with disabilities at the moment. There was a woman who appeared on *60 Minutes* after trying to murder her autistic son, who was basically feted and people said, “Well, that’s understandable. She was under pressure.” I am sorry; murder is murder, the same as rape is rape and violence is violence. We have been seeing that in the disability community for some time.

Regardless of this debate, there actually needs to be some work done on suicide prevention in my community. I see far too many people that are pushed to the edge. They are pushed to the edge by a whole lot of factors, in regard to some of which disability is only at the periphery. We make this assumption that because a person is disabled, if they take their own life it is because they could not put up with it anymore or the disability was the primary factor, when, in fact, they were perhaps depressed about a whole lot of issues coming together at once.

I want a project that is like *It Gets Better*, where we can show young people with disabilities that with the right supports, with the right freedom from bullying that might happen to them at school, they can actually live decent lives going into the future—having mentors going out and talking to them about the fact that it is possible to get a job, it is possible to be part of the community and it is possible to be welcomed. We are not sending that message to people. The message people are getting is one of rejection and disenfranchisement, one where there is no hope, and that needs to change.

**THE CHAIR:** Thank you so much, Mr Wallace, for coming in and speaking with us today. It has been very insightful. You have provided lots of information for us to consider. When available, a copy of the proof transcript will be forwarded to you to provide an opportunity to check the transcript and suggest any corrections, should they be required. On behalf of the committee, I would like to again thank you, Mr Wallace, for appearing today.

**Hearing suspended from 11.12 to 11.29 am.**

**STEVENS, DR ADELE**, Consumer Representative, Health Care Consumers Association

**SPILLER, DR SARAH**, Policy Officer, Health Care Consumers Association

**KHAMBATA, MR GEV**, Member, Health Care Consumers Association

**THE CHAIR:** I welcome the Health Care Consumers Association. Could you please all confirm for the record that you have read and understand the privilege implications of the statement in front of you?

**Dr Stevens:** Yes.

**Dr Spiller:** I have.

**Mr Khambata:** Yes.

**THE CHAIR:** Before we proceed to questions from the committee, would you like to make a brief opening statement?

**Dr Stevens:** Yes, we will.

**THE CHAIR:** Okay. Certainly.

**Dr Stevens:** I was president of Health Care Consumers. I joined it in 2005 and shortly after that I was elected president. I was president for five years. In my 70s, I moved back from that position and concentrated on more end of life issues.

I will talk a bit about Health Care Consumers. We are a member-based health-promoting charity and the peak health consumer organisation in the ACT region. We advocate for patients, for people in the health system. We are well aware that the health services are much safer when patients, consumers, are partners in health care. One of the standards for accreditation is how much an organisation partners with their consumers. It is such an important standard that it is the second standard. We work a lot with members of the community. I noticed that in the past you have been asking about membership, so I did pull up our membership.

**THE CHAIR:** Thank you.

**Dr Stevens:** We have 165 individual members, we have 20 organisational members, and we have two staff members who go out and make two presentations a month to external organisations. They may go to libraries. One of our aims is to improve health literacy in the community, because people are much more empowered to be partners in their health care when their health literacy is at an okay standard.

I might also say that Health Care Consumers have been involved with advance care planning in that we partnered with ACT Health. They put out a competitive tender about four years ago to do advance care planning in the community, and Health Care Consumers won that tender. In that work, we concentrated for three years on trying to work with vulnerable people, with people with English as a second language. We worked with ADACAS. What came out of that is that this is about a conversation more than writing the documents. As well as that, Respecting Patient Choices, who

run this program, want to have another contract with Health Care Consumers later in this year to do some more work on promoting advance care planning in the community.

Health Care Consumers has representatives on a number of ACT health committees. I have been the consumer representative on the advance care planning committee for about five years and was involved in a lot of advance care planning work such as the Capital Health Network's be my voice campaign. As well as that, two years ago I was selected to be the consumer representative on the ACT palliative care clinical network.

Sarah, is there anything else we need to say about the organisation?

**Dr Spiller:** Not about the organisation, I think. If we have a moment left in the time for our opening statement, I would just say that if we were to summarise the key points we would like to share with the committee today, based on our consultation with consumers around the terms of reference for this inquiry and some palliative care research, research into consumer experiences with palliative care that we conducted last year, there would be three points.

First, HCCA recognises that consumer views on the question of assisted dying are really diverse. However, people who participated in our consultation around this question are really strongly supportive of a change to commonwealth legislation which would allow the ACT to make our own legislation on the question of introducing termination of life on request. That is the preferred terminology of the HCCA, because it puts the emphasis on consumers requesting a service rather than on the assistance we might need to realise our choices.

The second point we would make is that we see a clear need for additional resourcing for palliative care across all locations where palliative care is delivered so that people can receive consistent, early, exceptional quality palliative care across home, hospital, hospice and residential aged care. That is about delivering a suite of choices to us, including in-location care. In practical terms, that means dedicated palliative and end of life care areas in hospitals, more respite options for family carers with a loved one who is receiving palliative care at home, a consistent palliative approach from non-specialist clinicians, and an expansion of hospice options.

The only other thing that we would add as an opening remark is that HCCA is really supportive of the development in the ACT of a charter for the care of adult patients at the end of life: something that looks similar to an example already in place in Queensland, developed by the Queensland Clinical Senate. The value of that is that it makes really clear what all services should be working collaboratively to deliver to us at the end of life.

**THE CHAIR:** Thank you. We might start the questioning with Ms Le Couteur.

**MS LE COUTEUR:** There are a lot of things that we could ask about. One I will do is advance care planning and capacity. I am particularly talking about where you had capacity at some time in the past and you made whatever choices you made. Time changes and you have less capacity, and it may not appear to people around you that you would still make the choices that you made then. How can we deal with capacity

issues as we age?

**Dr Stevens:** I have thought quite a lot about this. It is a difficult question for end of life work. At the moment we try as much as possible, as people move down their journey, to give people control as much as possible. Someone with dementia often will be able, in the mornings, to say some of the things that they want, in early dementia. It is really important. I notice you had Dementia Australia come earlier. That is one of the things that they have been advocating; I do not know if they made it clear to you at the time.

From my perspective, I have a father who had dementia in his 80s, and his father did too, so I am looking at a real possibility. I have done an advance care plan that says, “If I ever am diagnosed with dementia, I do not want to be saved; I do not want antibiotics; I do not want surgery. I want good pain relief but do not use the technology that you have got to save me, to lengthen my life.” That is the only choice we have at the moment. At least you can use an advance care plan to do that. I think that is about where we are at the moment.

I do not anticipate that any kind of end of life legislation is going to change that system. There is nowhere in the world where someone who does not have capacity, who is not recognised to give informed consent, is eligible for end of life. You have to have informed consent. I do not know what is going to happen in the future, but at the moment that is where it is. We know that very small numbers of people actually take advantage of the legislation in other jurisdictions: about four per cent of deaths in the jurisdictions where it is legal are by people who actually make use of it. So it is very restrictive.

**MS LE COUTEUR:** A lot of the legislation is very restrictive around you having to have capacity at the time of death.

**Dr Stevens:** Yes.

**MS LE COUTEUR:** Clearly there are people—you have possibly said yourself—who would not wish to have their life prolonged and there may be a period of time before death when you do not have capacity. That means that under any likely legislation there is no longer an option.

**Dr Stevens:** Yes. At the moment, all around the world, as far as I know, nobody looks at people with dementia in that kind of shadow area. We know people that are able to say some of their wants; even though they might have already been diagnosed, they still have mild cognitive impairment. It is very important that those people are able to say what they want and that we take notice of their wishes. No legislation has recognised that that would be a time when you could have a say through your end of life choices of having termination of life on request.

The chance of getting assisted dying in the ACT is pretty remote at this time, so to move to that area is just Greenland as far as I am concerned. The Health Care Consumers project really worked with ADACAS and others to try and help people to do advance care planning, even though they may have limited capacity. Our aim is really to give people some power in their lives, as much as possible for as long as



possible.

**MS CHEYNE:** Your submission argues that the Victorian assisted dying legislation is too restrictive and you suggest the Canadian model instead. Are you able to talk us through why the Victorian scheme is too restrictive and what is better about the Canadian scheme?

**Dr Stevens:** Yes. I am sure you know that the original plan from the lower house in Victoria was for 12 months and that they reduced it, on negotiation, to six months because they wanted to get it through. I think that has problems for a lot of people. It is already very restrictive and it is going to make it even more restrictive. So the number of people who will take advantage of that legislation will be quite small.

**Mr Khambata:** I am an ordinary member of the Health Care Consumers Association. I got interested in the subject so I participated in the discussions they had, and we had a good discussion. I went through the Victorian legislation and I saw a whole lot of clauses to protect the safeguards against the legislation being misused by whoever—maybe doctors or family members. There are a whole lot of clauses a patient has to comply with. With the 12-month restriction, say you are going to die in 12 months and you want to die, the way I interpret it after going through the legislation is that the whole process would probably take six to eight months, so I thought there was no real sense. If I am going to die in 12 months and if it is going to take eight months to decide whether I can die or not, that four months is just in the air.

I read the Canadian legislation when we had a discussion, but I have forgotten most of the things because, as you know, it is a very legal document. But when I compared the two I found that the Canadian legislation was more realistic, more practical.

**Dr Stevens:** And I do not think it had the time lines that other—

**Mr Khambata:** That is right.

**MS CHEYNE:** What about a model of preapproval where I could say when I am cognisant and of sound capacity that if a doctor's prognosis for me is that I have less than six months to live and I have a terminal illness and it satisfies this, this and this, I want to be preapproved. What do you think of a model like that?

**Dr Stevens:** That would only be valuable if that person in that future time did not then have the capacity. Every time you make the decision, you need capacity at that time. With advance care planning we suggest that you look at it every two years and see whether there is anything you want to update. In advance care planning we recommend people make value statements like, "I do not want to live if I am not able to feed myself," or whatever you choose. But people make different decisions at different times of life.

Canberra Hospital has developed what they call a goal-setting and end of life program. It follows on from the work of the safety and quality council commission on end of life because they say there are problems with end of life in acute hospital and that we are doing it quite poorly. They want to encourage professionals in acute hospitals to have the conversation. They use the "surprise" question with the clinician: "Would

you be surprised if this person died in the next 12 months?" If the clinician says, "No, I wouldn't be surprised," then they are required to use this documentation to talk with the patient and the family about their choices, and you do it at every admission.

That is another way of trying to have the wishes of patients recognised in the hospital. So when someone is deteriorating and you call the medical emergency team and you resuscitate them, a percentage of the time those people are on the normal dying path but no-one has had a conversation.

**MS CHEYNE:** I acknowledge your point that the preapproval model would only work if someone at a later point did not have capacity. But could it be a time-saving mechanism where that person already has the preapproval but when a prognosis is made they can then be asked, "Do you want to access this?" So they have already got that but then they—

**Dr Stevens:** So you are saying a person has this document and then some time further down the track you ask that person, "Do you still want this document?"

**MS CHEYNE:** Yes.

**Dr Stevens:** I think that is a good idea, because you have some kind of documentation that you had a conversation.

**MS CHEYNE:** It is like an advance health directive in a way.

**Dr Stevens:** It is Palliative Care Week this week. Did you know that?

**MS CHEYNE:** Yes.

**Dr Stevens:** That is all about encouraging people to have the conversation, not only in the community but amongst clinicians in the acute care hospital. "Death? We don't want to talk about it."

**Mr Khambata:** I think the condition is that you can go back on this at any time. Even at the last minute you can say, "Sorry, I don't want to go through it," and that is it. You may have done everything, but at the last minute when you are asked the question, "Do you still want to go with it," you can say no and that is it.

**MS CHEYNE:** Or you could still say yes and get it and then not go ahead with it, which is common.

**Mr Khambata:** Yes, that is the beauty of it. This is just like having a choice. In the worst possible scenario people think there is another way out, instead of going through excruciating pain, suffering, torment, whatever. It is just to have a choice. I can take it or leave it. I draw the analogy of human organ donation. There was a big moral issue about it but, again, that was a choice. Some people's beliefs do not allow donation; some do not allow acceptance of donated organs. Ultimately the legislation was passed and there is a choice. If I want to get my liver or kidneys transplanted, I have a choice. If I do not want it, it is okay. Whatever happens, I accept it. So that is my belief system. Ultimately the legislation gave a choice and then it was up to us

whether to accept it or not. We know that in general organ donation has been beneficial.

**MS CHEYNE:** How do we ensure the literacy of people around this idea of choice, particularly on something as complicated as the decisions you are making about the end of your life? How do we improve that for all groups in the community, but particularly multicultural groups?

**Mr Khambata:** When I have talked in general with people and raised this topic as after-dinner talk or something like that, the general consensus is that we should want to know more about it, so there should be a proper public debate. There is nothing right or wrong about it. You can listen to both sides of the argument and then automatically your level of awareness goes up. Probably slowly you concentrate on your side of it. If it affects you, what would you do? Then you can have an informed talk with your GP.

There are a whole lot of processes in the Victorian model. First you speak with your GP, then the GP has to refer to a specialist and then if they concur it goes to a medical committee then there is the prognosis by the two doctors. There is a whole lengthy process. So in that process obviously the patient is involved and informed. These are the things you can consider if you want to. Then the patient can take a decision, again being told that they can reverse it at any time. That is the biggest thing about it—it is not written in concrete that, “Okay, now I have to die.”

**MS CHEYNE:** Yes; you are not signing yourself up to anything.

**THE CHAIR:** It is voluntary.

**Dr Stevens:** That is the very important part; it is voluntary. The Health Care Consumers Association has been working on this issue; it is something we have grappled with. Sarah, do you want to say a bit more about some of the work we are doing in that area?

**Dr Spiller:** How do we ensure that people have information to make informed choices? We continue to invest in making sure that that information is available. Not just HCCA but lots of self-help consumer organisations play a really active role in providing information about healthcare options and choices to our members in the community. That information is essential for our informed consent.

One of the reasons HCCA is supportive of services in the ACT developing a charter of care for patients at the end of life is because a statement of that kind sets out really clearly to us: “Here is what you can expect from services. Here are some of the choices and the kind of care that services commit to offering you.”

Early information is also something that is really important. Many of the people who took part in our qualitative research last year about experiences and expectations of palliative care in different locations of care told us that early information about palliative care and early referral to palliative care services is just so important to a better experience of care at the end of life. This is also about supporting clinicians to have those conversations about end of life. That is a really important part of the

picture.

**THE CHAIR:** Dr Stevens, in her opening address, talked about the fact that you have been heavily involved in highlighting the benefits of advance care planning. Some of the things you were talking about then—education for advance care planning—would also go along the same lines as educating for voluntary assisted dying if it was something that happened.

**Dr Spiller:** Yes, absolutely. Shared decision-making is a really important part of this as well. Healthcare consumers told us in our research last year—and they consistently tell us this—that they want to be actively involved in talking with their clinicians and being partners in decision-making about the goals of their care and their care plan. At end of life that is just so essential to a better experience of care—the feeling that we really have the time to ask questions of our clinicians, talk about what we want, have that heard and have an opportunity to really be clear about what are the aims of treatment, what are the goals of care, what is the treatment plan, what are the options. Supporting clinicians to have the time and skills to have those conversations is really important.

**MRS KIKKERT:** As a follow-up question, Mr Khambata, you mentioned individual choices: that it is the person's choice to live or die, really. Do you believe that individual choices have an impact on other people?

**Mr Khambata:** To a certain extent, yes, they would have an impact.

**MRS KIKKERT:** I believe that is probably why we have laws against drink-driving. Right?

**Mr Khambata:** Yes.

**MRS KIKKERT:** It is to protect other people. People have a choice to drink alcohol. They have a choice to get in the driver's seat and drive their car.

**Mr Khambata:** Yes.

**MRS KIKKERT:** We enforce a law to make sure that people on the road are protected by not having a drink-driver on the road.

**Mr Khambata:** Yes.

**MRS KIKKERT:** We recently heard from somebody with disability and he was very concerned that if we legislate this bill to euthanise people it might have a deep impact on people with disability and also people with mental health problems. What are your thoughts on that?

**Mr Khambata:** Like I said, yes, it would affect you, but, again, slowly you step it down to yourself. You see the general effect and then you think for yourself. You know the general information. "I know that it affects this person." But in a sense it is still a part of the education. I know that these things can happen but ultimately it is me. How will it affect me?

It is the last possible culmination of the whole process. Say a patient is diagnosed with some illness. There is a curative process, curative care. The best possible treatment is given. When the best possible treatment does not work, is exhausted, you put the patient in palliative care to make him more comfortable—and his family and carers et cetera. That palliative care process is a very good process. As I say, it is a very holistic and comprehensive process to give the best possible care to the client, the patient. Then, when that gets exhausted, when that does not really work, you start thinking of the choice of end of life. Again, that end of life, as I said, is a very long process.

But at the same time if I am going through unbearable pain and suffering and torment, of course very often the negative part is that if I have a disability I feel pressured that I am a burden on my carer or my family. And that is one negative part against this thing. As you mentioned, it could have an effect like that—people with disability wanting to do that.

But it is not that easy. As I mentioned, the process is very, very exhaustive and I cannot take a decision without doctors also being involved, a medical committee and more. So there are lots of safeguards. As I said, there are negative points for both sides. Both sides have pros and cons, I agree with you. Just to have it there in the case of the most extreme case this way—and we have legislation for the case this way—I thought it was fair to go to the other side, to respect the opinion of the other side too. But legislation like this gives them an ability to decide in the most trying circumstances, the end.

**Dr Stevens:** Could I add something there? I am also a member of COTA. COTA has been very concerned about elder abuse, and there is that consideration. It is interesting to know that the leader of the equivalent organisation to COTA for elder persons in Oregon was against their legislation in the beginning because of that fear of abuse of frail older people. But, having had the legislation in for a number of years, now she is in favour of it because it is very well controlled. There are no problems and it gives older people choices.

**MRS DUNNE:** Sorry, I was called away and I missed some of this. Correct me if this has already been covered. Dr Spiller, you talked about the need for palliative care and the consultation you had with your membership base on this. Does the Health Care Consumers Association have a feel for the size of the missing funding or the shortfall funding in palliative care? If you do not want to put a dollar figure on it, do you have a feel for how many more palliative care beds we need? I am also very interested in issues related to the provision of palliative care in aged-care settings.

**Dr Spiller:** I do not know that today we could give you a sense of how many more beds we think would fix the problem, but perhaps part of the answer is around the kinds of models of care that we know consumers would like and are not always able to access. We know that, if you ask us, most of us would say we would prefer to die in our own home.

In our research last year there certainly was a cohort of people who would have preferred to be at home at the end of their lives and who were advised that that was

not possible for them because of the scale of their needs for care or because of the ill health or frailty of their carer, their family carer, who knew that their preference would have been home-based care but they knew that they would not be able to provide the care that their loved one needed. It might be that you have other caring responsibilities, you know that you do not have the health to do it or you need to work, those kinds of things. There is a cohort of people who would love to be receiving more care at home and at the moment their needs for care and assistance are deemed to be too high.

I think we would suggest that perhaps there is some room to have a look at what options there might be to provide more intensive care at home, even if it is only for a short period of the time that someone is receiving palliative care. That might mean that there is an option to be back at home for the last days or a week. That is part of it.

I think the other thing that we learned through last year's research project was that there really is a need for people who cannot receive care at home or who are not able to get to a hospice and find that they are in hospital—it is rarely the preferred location to receive end of life care but it is what happens for a proportion of people; they find that hospital is where they are going to end their life—to be treated in hospital.

I think we would also advocate that there really is a need to look at what we can do better in the hospital setting around provision of dedicated areas for palliative care in hospital, areas that will deliver some of the things that we know people value across all settings. They are sometimes things that seem really simple: a view of the outdoors, ideally a window or a door that opens, space for loved ones to stay comfortably, including overnight, quiet, privacy, fewer routine medical interventions and unnecessary interventions. Those are the things.

**MRS DUNNE:** Less of a hospital environment, more of a—

**Dr Spiller:** Less of a hospital environment, more home-like in hospital, yes. Many people would really value being able to get from hospital or home to hospice sooner. There is also a group of people who have needs for palliative care that would last for longer than hospice is generally available for. That is about demand for hospice care. I think we would also say that we would really love to see a conversation about what models of care might suit that cohort of people better. We would absolutely agree about the need for support for residential aged-care facilities to provide more consistent, excellent palliative care.

**Dr Stevens:** Perhaps I can add a bit to that. Being on the Palliative Care Clinical Network, the network knew about the inquiry and were very interested in putting a submission to you but they were told by higher people in ACT Health, “You are ACT Health. You can't put a submission to the government,” which I was surprised about later when I saw there was an ACT government submission.

You have a submission from the chair of that committee, Dr Michael Chapman. At the end of his submission, at 3.6 on page 7, he says that there are several areas of action needed to improve end of life choices. One point is about aged-care facilities. He talks about the INSPIRED trial. It was led by palliative care nurse practitioner Nikki Johnston, who is on our Palliative Care Clinical Network. It recently won the

ACT quality and safety award for being the top project for last year.

We recognise that there is much more that needs to be done. That was a trial in six aged-care facilities. They have expanded it to 12 but there is much more work that could be done in that area. There are a number of points there. I may not agree with everything Michael says, because he talks from a doctor's point of view and we are from a consumer's point of view, but I agree with all his recommendations of action needed in those areas. I commend that to you.

I would also like to say that on that network is another palliative care nurse practitioner, Ann Burns. Ann comes to us from Belgium. She worked for five years in Belgium where palliative care included end of life choices. She was interested in speaking at the network. She said that in her five years practising there was only one person whom she worked with who chose to use the legislation there. She was saying that it is very rare to use it. There is the odd person who really wants to use it and it was available. She said it worked fine. I think there are sources that you could use for recognising this.

Another thing I do know is that there was a period where it was really difficult to get people into Clare Holland House and they started using the National Capital Private Hospital for palliative care. That has happened in the last couple of years, using services in the private sector when people are in Canberra Hospital and cannot get into Clare Holland House. I think it is a bit better at the moment, but there was a time a couple of years back when it was really difficult and they started using the private sector. It is good for people with private health insurance but not for others.

**MS LE COUTEUR:** Do you have any idea how many beds are being used for that?

**Dr Stevens:** In Capital Health Network?

**MS LE COUTEUR:** Yes. We are trying to get an idea of unmet demand.

**Dr Stevens:** They have some allocated beds that they use, yes. That is what I have heard. Perhaps you need to talk to them.

**THE CHAIR:** I had so many questions, then I got lost in what you were saying. It is very interesting. From an advance care planning perspective, in talking to consumers, do you have an opportunity to talk to people who have lost family members who had advance care plans in place that perhaps did not get the attention they could have? I am trying to be very—

**Dr Stevens:** Diplomatic.

**THE CHAIR:** Delicate, yes. Do you hear about that from consumers?

**Dr Stevens:** Go on, Sarah; it is your turn.

**Dr Spiller:** Yes, we do. We do, and those experiences are often really grievous for loved ones. Yes, we do. Certainly we hear that with regularity, yes.

**THE CHAIR:** Obviously, education is a great start. But as you have been talking to people, mainly consumers, about their fear about advance care planning, are there ideas that have come forth that could be of interest to us? We are looking at end of life choices; it is not just voluntary assisted dying. It is the whole gamut.

**Dr Spiller:** One of the things that we say when HCCA promotes the value of advance care planning to people in the community is that an advance care plan means that people will know what your wishes are and that you can be guaranteed that your wishes are less likely to be followed at end of life if you do not have those documented. That is the value in documenting, in thinking through your own values and preferences and having them written down so that you have them articulated and the people around you, your family and loved ones, know what they are as well so that they can be a voice for you if you are unable to speak for yourself. That is the value in doing it.

I suppose it is sort of a longer term piece of work that is about education and continuing to promote the value of a conversation, continuing to support health literacy in consumers so that we have the knowledge, skills and confidence to ask our questions of our treating clinicians, to put forward our preferences in those conversations, and so that clinicians have the skills, time and opportunity to continue to have those conversations consistently with people receiving care.

**MS LE COUTEUR:** You talked about not having an advance care plan making it less likely that your wishes would be accepted. But that kind of opens up the possibility that you have an advance care plan and it does not actually make any difference. How much is that the experience of your consumers?

**Dr Stevens:** This has been an issue in the last five years. I think we are getting better at it. At Canberra Hospital in the last couple of years the respecting patient choices program has resulted in a staff member who now goes around, talks to ward clerks and makes sure that anyone who has an advance care plan has it on the front of their medical notes. They report to committees higher up what is happening. I think that has been really helpful in getting clinical staff to be aware.

**MS LE COUTEUR:** We have heard suggestions from other organisations that Australia needs a national advance care plan system.

**Dr Stevens:** I agree.

**MS LE COUTEUR:** That was very quick.

**Dr Stevens:** I was part of the consultation that went forward to the commonwealth about three or four years ago. I was very disappointed. It went to COAG as a vision statement.

**THE CHAIR:** I note the time. We have come to the end of a very interesting session again. I thank you all for appearing today and chatting with the committee. We have found your insights invaluable. When available, a proof transcript will be forwarded to witnesses to provide an opportunity to check it and to suggest any corrections, should they be required. On behalf of the committee, I thank you all again for coming



and talking with us today.

**Dr Stevens:** There is one more thing that I would like to say. I do not know if you know but just recently the Productivity Commission did an inquiry into human services. End of life is one part of it. Stephen Duckett wrote an excellent article in the *Australian Financial Review* titled “Palliative care needs to be better spent”. His argument is not just that we spend more on palliative care; we also need to look at how we spend it and the range of choices that consumers—

**MRS DUNNE:** Do you have a date for that?

**Dr Stevens:** Yes, I have a copy and I am happy to leave it with you.

**THE CHAIR:** Thank you so much.

**Dr Stevens:** Thank you.

**QUINLAN, PROFESSOR MICHAEL**

**LONG, DR BRENDAN**, Senior Research Fellow, Charles Sturt University

**THE CHAIR:** I welcome the last witnesses for today's hearing. Before we proceed could I ask you to confirm for the record that you understand the privilege implications of the pink statement that is in front of you?

**Prof Quinlan:** I do.

**Dr Long:** Yes, I do.

**THE CHAIR:** Before we proceed to questions from the committee, would either of you like to make a very brief opening statement?

**Prof Quinlan:** Yes, certainly. I am Dean of the School of Law at the University of Notre Dame Australia. I am appearing in my personal capacity, but that is my professional capacity. Rather than repeat what is included in my submission, I thought I would make five quick points.

First—and this frames up the whole issue from my perspective in some respects—there is recognising the need for caution in departing from tradition. Second, there is the risk of eroding the central norm of medicine and the risk of non-statutory and non-lawful expansion, no matter what might actually be put in legislation. I am talking here about legislation, and my whole discussion today is about euthanasia and voluntary assisted suicide, voluntary assisted dying. The third thing is in relation to freedom of conscience, and, if there is time, I will talk a little bit about dignity therapy and dignity generally.

There are a couple of recent papers. I am sure there is a lot of material that you have had to read. The first, in relation to this point about tradition, is from a Canadian academic whose name is Barry W Bussey. He has just written a paper called “The right of religious hospitals to refuse physician assisted suicide” which appears in the Supreme Court Law Review 2018 85 SCLR 189. I want to read to you one paragraph from page 222 of that paper. He says:

Our current approach towards FHLI—

firmly held life issues—

requires a humble appreciation for the cultural underpinnings and mores of Western civilization. We are prone, just as our forebears were, to move from one end of the ideological spectrum to the other on FHLI without appropriately considering why we are at odds with our cultural inheritance. Radical positions from our historical norms require thoughtful reflection of their presuppositions. It would serve us well to maintain a humble appreciation of our cultural heritage even when we think we are right in our newfound positions on FHLI.

That is probably why we are having this inquiry and why I am here talking about it. But the opposition within the medical profession and in Western society to euthanasia has a longstanding history. It pre-dates Christendom. We can go back at least to Hippocrates in 5 BC. So we are talking about a very long-held position. The question

we need to ask is: what is different about today from a millennia of human experience in which that principle has been rejected?

The second point I want to make is in relation to the erosion of the central norm of medicine. Again, this is from a recent paper written by Christopher O Tollefsen on 21 May this year, in an article called “Physician-assisted suicide and personal action: responding to the law” which appears in *Public Discourse*. He makes this point:

As more and more persons request assistance in ending their lives, physicians will become more and more disposed to see killing—a form of harm—as part of their professional vocation. That itself is an erosion of their vocation’s most central norms. But it also opens up the profession to new and pervasive opportunities for abuse, opportunities that will be carried out in a much more secretive context than the abuses of the police are.

He talks there about the fact that there has been a lot of concentration on abuses of police power. Here he is talking about the fact that, with physicians, once they cross the Rubicon to be actually engaged in causing death rather than in trying to prevent death or to heal, that starts to affect their whole moral compass. Once you start to do something like that, it becomes less and less of an issue. That is how you see in other jurisdictions a growth in non-legal or extra-legal euthanasia. That is what you see in many other jurisdictions. For example, the 1995 review of euthanasia in the Netherlands found 0.7 per cent of such deaths occurred without explicit consent of the patient.

Pereira noted in the Netherlands in 2005 that one in five people euthanised had not given explicit consent. A Flemish study showed that 32 per cent of euthanasia cases studied occurred in the absence of a request or consent because the patients were comatose or demented or because the physician decided it was clearly in the patient’s best interest.

**MS CHEYNE:** What is the reference for that?

**Prof Quinlan:** It is included in my paper. It is from Nicole Steck et al, “Suicide assisted by right-to-die associations: a population based cohort study”, *International Journal of Epidemiology* 43 (2014) 1 to 9.

**MS CHEYNE:** Thank you.

**Prof Quinlan:** The third thing I wanted to mention was freedom of conscience. I do not know whether the committee is looking at this question.

**MRS DUNNE:** It has come up frequently.

**Prof Quinlan:** In the Victorian legislation, which has been passed but not enforced yet, they have included freedom of conscience for individuals but they have not explicitly, in the legislation itself at least, included freedom of conscience for institutions. When we talk about freedom of religion, which is an issue of significance to me, there are two components to that. There is individual freedom of religion and freedom of conscience but there is also institutional freedom of religion and freedom of conscience.

I have not actually checked how many medical facilities in the ACT come from a faith-based tradition, but at least in the Victorian model the legislation which they passed does not require any individual to act against their conscience. It does not specifically deal with the question of institutions. The paper that I mentioned at the outset is hot off the press on that very question, about the freedom of religion and freedom of conscience of institutions to have an institution where they say, “In our medical facility we don’t participate in that particular activity.”

Just to wrap up my comments, finally, one of the very valuable pieces of therapy which is mentioned in my paper is dignity therapy. This is a form of therapy which has been found to be very effective in dealing with people who are seeking to access euthanasia in other jurisdictions. The reason it is successful is that when you actually analyse the reasons why people seek voluntary assisted dying or euthanasia, about five per cent, according to a Dutch study, do so because they are in pain. The rest do so because of the same sorts of existential concerns that cause suicidal ideation in the rest of the population. That is feeling depressed, feeling alone or feeling like you are a burden on other people—all of those sorts of things.

They found that dignity therapy is quite a simple process. Essentially, they just ask patients if they would like to make a record which can be provided to their relatives or friends about anything that they want to make a record about. Inevitably, people asked to do that have a scribe and someone that helps them to write up their memories or whatever it is they want to pass on. In doing that it has been found through this study that they find meaning where they previously did not realise that there was meaning, and they find that there are things that they want to share with other people that they had not realised they wanted to share with other people.

**THE CHAIR:** Dr Long, would you like to make an opening statement?

**Dr Long:** Thank you very much. I am a Senior Research Fellow at the Australian Centre for Christianity and Culture, which is a research institute of Charles Sturt University, based in Barton, ACT. My capacity here is as an academic of that institution, and I speak with my personal academic views.

The reason I am here and the reason I have made a submission is that I had the opportunity to engage very closely with the Victorian situation and have some insights from that process I would like to share with the committee. The role I had was essentially to act as an adviser to Dr Mulino, who is a member of the Legislative Council. I actually worked in his office during the parliamentary consideration of the bill and also worked before that in advocacy with persons who were not in support of the legislation. That gave me insights into the process.

The other thing that I offered and that was useful to the deliberations was a statistical analysis—I am a statistical expert—of the likely population estimates, using international experience, of the coverage of the Victorian legislation. That was published in Australia and has not been contested. Also I have included an ACT estimate, which I will briefly outline to the committee.

I might start by saying that in the advocacy role—I will not speak for long—I want to

speak quickly about the political process in Victoria. Then I want to speak quickly about some safeguards and give a couple of insights that the committee might find useful when applying the situation to the ACT.

When I was engaging in advocacy against the bill, one of my best interlocutors was a former cabinet minister who voted and spoke on the Andrews bill. His name was Lindsay Tanner. He made it clear to me that his position in relation to the bill had not changed. He believed that the appropriate analogy in relation to voluntary assisted dying is that of capital punishment, where the state has power over the lives of an individual that people of a social democratic background would be reluctant to grant to a state. It was interesting that when pressed on the issue by me, he said, “I have not changed my views on that, and I am happy to be quoted on that.” So I have done that. His quote is in the paper.

The most interesting part of the Victorian process was the parliamentary process. As a political professional, having worked as a senior adviser in federal parliament for six years, I have to say that it was the most extraordinary process I have ever seen. It was an appalling process. I am not speaking about the committee’s consideration; the committee’s thorough consideration of the bill and putting forward of the bill was done in a systematic, consultative way. The way the minister brought the bill forward with the ministerial advisory committee was a constructive process, and I had the opportunity to engage with that process.

When the bill got to the floor of the parliament, I believe that the challenges of the legislation and the controversy of it were so traumatic that the parliamentary process failed. This is why. Because of a desire to push through the bill before the end of a calendar year, the next year being this year, an election year in Victoria, the government, with the support of minor parties, had control of the parliamentary business and the sitting schedule. Even though there were some really great debates on both sides, including a very passionate speech by Premier Andrews and speeches by others whose personal circumstances were deeply moving, when it got to the consideration in detail stage and the moving a reasoned amendment stage, there was clearly a desire not to engage with any constructive amendments put forward by anyone in the lower house. Furthermore, there was a decision not to allow the sitting schedule to resume its normal sitting but to force a debate through the night for some 24 hours straight. Some brilliant speeches were given at 3 am and 4 am in the morning. Not many journalists were watching. I was watching—I think there might have been four of us watching—but there were not many of us watching.

**MS CHEYNE:** I know lots of journalists who were watching. They were live tweeting.

**Dr Long:** That is excellent. However, no amendments were supported at all in the lower house.

When it got to the upper house there was also a very frustrated political process. While there was consideration of amendments made, again, in order to force the debate through, not to enter an election year, another debate was forced through the night. This went on for another 24 hours. It led to one senior figure having a medical episode and needing medical attention, from which he quickly recovered. That simply

indicates the physical stress associated with that sort of debate.

I have to say that, as a political adviser, I do not believe that the parliament was served well by that process. I do not believe that amendments were adequately considered or ventilated in the public debate because of that process.

I will just leave the committee with the insight that if a bill does come to the floor of the Assembly, one of the things that could be learnt is to gain greater buy-in from the community and greater respect from people, wherever you are in this debate. It would be good to learn from the mistakes of the Victorian parliament and seek to have a considered debate rather than forcing through proposals.

I make one other comment quickly on the Victorian process. A lot of political pressure was brought to bear to achieve a political outcome, as the Victorian branch of the Australian Labor Party is very expert at doing. This took place inside the parliament, inside the political ranks, and also outside the parliament in the health community.

Significant pressure was brought to persons in relation to continued access to funding were they to make comments against the bill. This was communicated to me by CEOs of key health professionals in Victoria. There was pressure placed on those opposing the bill not to continue that stance. The funding was threatened. Again, that is a very sad lesson from the Victorian experience which I saw intimately. I may be prepared to answer more if the committee wants.

Let me proceed quickly to the safeguards, because I have taken too much of the committee's time so far, and the estimates. Using international estimates of what has occurred in international jurisdictions where physician-assisted dying has occurred, the statistician in Dr Long calculated an annual compounding growth rate of 17 per cent, the average annual compounding growth rate. That is year on year. If we take the original estimate of 150 to 200 initial applicants—and that was before the bill was extended; the period in which the regime can be accessed was changed in the upper house—after 10 years of implementation of the scheme, that leads to 1,000 Victorians each year accessing the scheme and a cumulative total of almost 6,000 in those 10 years.

In the ACT, using similar growth rates and our population, I have estimated that after a 10-year period of implementation of a similar type scheme in the ACT, 65 persons a year could be found to be accessing that scheme. That is a significant number.

**THE CHAIR:** Accessing and—

**Dr Long:** The physician-assisted dying scheme: accessing it and ending your life.

**THE CHAIR:** Thank you for the clarification.

**Dr Long:** I am happy to defend those estimates. The safeguards have been well debated, but there has been a large degree of concern about certain groups with considerable vulnerability. The one that is of most significance to me is the mental health cohort. As we know—I have evidence I can cite and have cited in my report—

mental illness is notoriously difficult to diagnose. In the case of safeguards, the New South Wales bill, which was recently defeated, realised that the significance of a safeguard over the mental illness problem was so big that the mental illness cohort was carved out of the bill. And it was still not accepted.

In Victoria, the model is that you have two doctors. There have to be three requests, but there are two doctors that have to be independent. They then can make an assessment as to whether a psychological assessment is required if a person has a history of mental illness. The requirements to take that psychological assessment are weak under the act. They follow the Oregon model. The Oregon model has measured that, in the cases of applicants to the scheme, only four per cent of applicants are referred for a psychological assessment. You would have to say that in the normal community there would be probably much more than four per cent who may be experiencing mental health issues or who have in their lives. It touches most of our lives in some way, at some time. It is very surprising that only four per cent in Oregon were recommended for psychological assessment. And this is the model chosen in Victoria.

So I think there is a real concern there about the safeguards in terms of ensuring that people with mental illness are accessing the scheme for its statutory intent, not because of a sense of comorbidity or depression, which often go with the condition of dying. It is not unbearable suffering, as the Victorian test is, but rather, shall we say, an episodic condition of mental illness that leads them to access a scheme which they might subsequently reject. That is an issue where the committee may wish to look at the Victorian experience.

Another obvious issue for vulnerable groups is elder abuse. Again, there was nothing in the act really to address directly the question of the possibility of elder abuse, in the Victorian legislation.

Also, in relation to persons with disability, while there was some carve-out of certain elements from access to the bill for people with degenerative disability, there still is a lot of uncertainty in the disability community as to who is in and who is out of the bill. This was an issue that caused a lot of concern in the South Australian and Tasmanian consideration. It led to those bills being defeated, actually. That remains a somewhat unresolved issue not adequately addressed in the Victorian legislation.

Time is pressing, so I will go to the most significant point. The most significant point is that when the parliamentary consideration took place in Victoria the parliament put forward a bill to approve a voluntary assisted dying substance, “the drug”, without identifying what the drug was and without identifying how it was to be approved—only identifying that a loophole in the Therapeutic Goods Administration would be used. It was explicitly stated in the parliamentary debate that the loophole of using compound pharmacists who have an exemption to mix drugs for an off-label purpose, a purpose which they are not normally using the drugs for, will be used in this case. That loophole is usually only used for very rare medical conditions like rare skin infections. But that loophole, it has been explicitly stated by Minister Jennings in the upper house, would be used to force through approval of this drug, bypassing the normal approval processes of the Therapeutic Goods Administration.

A lesson for the ACT Assembly, were it to consider this, would be to see whether that is an appropriate way in which a drug that will end a person's life should be brought to consideration of the parliament and whether those processes envisioned under the Victorian legislation and by Minister Jennings are adequate. I would put it to you, members of the committee, that they most certainly are not.

I will be open to any questions the committee might ask.

**MRS DUNNE:** So little time; so many questions. I go to a point you made, Professor Quinlan. You described a growing proportion of people in the Low Countries in particular who were undergoing this life-ending procedure without proper consent. The figures that you read out seemed to grow from 0.7 per cent to somewhere north of 20 per cent over a period of time. What does that indicate to you from a jurisprudence point of view?

**Prof Quinlan:** What those statistics are showing is that people are not complying with the legislative framework which is in place in those places. It is easy to understand why that happens. When you think about any regime which is put in place by a state, unless they allow any assisted suicide, it will involve identification of a particular class of people, a particular class of people who will be able to identify the particular scheme.

There is no rational or logical foundation for how you pick whatever particular class you pick, whether you pick people who are terminally ill, who have a prognosis of six months or a prognosis of 12 months, or whether you pick people who are in constant pain. Whatever criteria you pick, there will always be some people who fall just outside those criteria. Those people will say, "It is very unfair that I cannot access the regime you have put in place when these other people can access the regime."

If you are a doctor who begins to participate in this regime by providing pharmaceuticals—if you are actually injecting substances or whatever the regime is—that has an effect on your attitude to your profession. Instead of seeing yourself only in the position of healing people and letting nature take its course, if that is what happens you are actually taking a positive step to cause someone's death.

When someone is asking you to assist them in that kind of context, it is a very different process that you are going through in your mind to the process that you were going through when it was completely illegal, and when you have never participated in that process before. That is a big part of the problem. Another part of the problem is that physicians think that they know better than their patients. A lot of the statistics from those countries show physicians making the decision for their patient because they believe that the patient will be better off dead.

**MRS DUNNE:** We received in evidence two suggestions that I would like to put to you. One is that perhaps what we should have is a pre-approval scheme so that you might sign up for voluntary assisted suicide sometime in the future if your circumstances change, even if you have diminished responsibility at the time and could not give consent at the time. I would not mind your views on that.

The other thing that was put to us in the same context was that there should be a



Medicare item number for this. I would welcome your views in relation to freedom of conscience, about what we might say to members of the Australian public who conscientiously objected but who then had their taxpayers funds conscripted to this measure?

**Prof Quinlan:** Yes.

**MRS DUNNE:** There are two questions.

**Prof Quinlan:** I will respond to the second question first. It would be very regrettable if taxpayers' funds were used for that purpose. But, despite the conscientious objection of many Australians to many other things that their money is used for, including in medical circumstances—I am talking here about termination of pregnancy for example—that is done. Money is used from Medicare to fund some or all of those operations and that is a consequence of living in society. I mean, it is a serious conscientious objection issue but that is part of what happens in society. You do not get to pick and choose what the government uses your taxpayer funds for.

On your first question, I think ultimately that comes back to the difficulties of really safeguarding vulnerable people from whatever process you put in place. I am sure the committee is aware of the Kissane article that was done in the Northern Territory. I think it is very valuable. One of the things that shows is that, whatever safeguards you put in place, particularly around the mental illness issues that Dr Long was talking about, people see them, once they have decided they want to access the service, as hurdles they have to overcome.

They do not see them as measures to protect them. Rather, they see them as hurdles. You see that Kissane refers to the number of people in the Northern Territory who accessed the service who suffered from undisclosed depression. In one circumstance a patient was referred to the psychiatrist or psychologist but did not disclose an accurate personal history. So she left out of the discussion things which were actually causing her depression. That was not picked up.

A lot of the evidence from psychologists and psychiatrists who are involved in these sorts of schemes says that it is not our role to be a gatekeeper. We actually need to build up a relationship with a patient in order to help the patient and assess the patient's particular condition. That is not something you can do in short periods of time.

I suppose that a longer answer to your question is that if there was a procedure where people could sort of opt in but then a lengthy period of time where they actually had to engage with the medical profession so that there might be a continuous record of their condition, that may be helpful.

Another problem you are going to have in the ACT also arises from something that Dr Long mentioned. It is just the numbers. Even if you had 65 people, you would come to the question of who is going to actually be dealing with those people in assessing whether they satisfy whatever criteria you might put.

What tends to happen, unfortunately, is that you have people who are sort of

advocates of euthanasia or of voluntary assisted dying being the people who gravitate towards doing that sort of work and people who are not interested in it gravitating away. Then you build up a class of people whose job it is to be involved in voluntary assisted suicide, which leads to a sort of continuous diminution of their moral compass around human life.

So you either have specialists doing it, in which case they could try to identify the correct chemicals and the right dosage for particular people who have probably been on medication for a long period of time, to make sure that there is no unexpected, unpleasant death; or you allow all GPs and all doctors in the territory to be involved, which is what some patients will probably want. They probably would want their GP to be involved. In that case you have to train all of those people, which will cost you a lot of money and you would be doing it in an environment where it is quite unclear what chemicals you might be able to use.

**MS LE COUTEUR:** The question I would be interested in both your views on is prevention of elder abuse. Clearly, you could say that voluntary assisted dying has the option of the most extreme abuse but certainly this is an existing problem without it. It certainly would be one of the things that could cause some people to consider voluntary assisted dying more generally, not just for this. What can we do?

**Prof Quinlan:** Do you want to say something about that?

**Dr Long:** Yes, the Law Reform Commission's report was a very insightful report. This report was not focused on voluntary assisted dying. It was focused on the threat of elder abuse in the community, using World Health Organisation statistics suggesting elder abuse can occur in two to 14 per cent of relevant cases where you are dealing with an aged person in medical care. That is quite a significant amount.

What was also made very clear in the commission's report is that, after the age of 65, many mature Australians become more vulnerable to dementia. Obviously, not everyone gains dementia, but the instance of dementia doubles every five or six years as you age beyond 65. By the time you are 85, the population estimate is about 30 per cent of people then are in the state of dementia.

That makes them particularly vulnerable. But they are not necessarily carved out from the scheme. So it would be open to the committee, as it is part of its considerations, to see what safeguards can be dealt with to guard against particularly the question of dementia in elder abuse so that people can really make an informed choice. If you have dementia, it can be highly questionable whether you can make an informed choice.

The only other quick comment is that there is a view that sometimes there is an inconvenient truth that, as a person takes time to pass away in their last days, family members can become attracted to the prospect of gaining access to the funds that will flow from the conclusion of the will. That is something that is identified and reported. It is something that there is little evidence to prove the incidence of but generally it is held to be a view that it is a real threat.

**MS LE COUTEUR:** We have heard suggestions that, in fact, the opposite can

happen. Because people have diminished capacity, they may be forced to endure medical treatments which people feel fairly confident they would not choose were they given a choice. This is where they generally have obviously considerable pain and suffering and are medically futile.

**Dr Long:** Ms Le Couteur, if your point is that as a result of medical intervention a person is exposed to a medical direction they might not take if other options were made available to them, in both cases what you are identifying is a situation of diminished capacity, namely, those who have access to medical care without other options or those who may have pressure placed on them to end their lives early.

But in this case of diminished capacity, I think the only alternative the legislator has is to take a high standard of the measurement of informed choice, because we are talking about the defence of the right to life, I would put it to the committee that good legislators should, in this area, choose to be clear and explicit that the burden set for an informed choice is high.

**Prof Quinlan:** I would like to make a couple of points in relation to family. The impact on family is a complex issue around these sorts of schemes. On the one hand there is elder abuse, where family members are encouraging, either subtly or directly, their family member to access the scheme, but there can also be a miscommunication, a misunderstanding. Older people or sick people can feel like they are not valued and they feel like they are a burden to their family. So there have been instances of Australian people going overseas to access schemes overseas without their family knowing anything about it.

When they find out about it, of course, that is not the reaction that they would have had, had they known that they were thinking of doing that. They would have said, “We love you; we care for you” and so on. So it is important to have communications with family members. This raises another issue for the committee to consider about how you protect patient confidentiality whilst at the same time recognising that this decision impacts not just on the individual person but also on their family members. It is taking that whole sort of community into account whilst guarding against elder abuse. We are dealing with complicated things there.

On the question of dementia, this raises the whole issue around dignity. We need to be very careful as a nation not to lose our respect for human beings, because they are human beings. Because someone might be suffering from dementia or any other medical, physical or ailment does not mean that their dignity is somehow impaired. It is one of the things which I find really offensive about that organisation calling itself Dying With Dignity. It is as though people who are in those sorts of conditions of extremis are not dignified. We have dignity because we are human beings. It does not depend on our physical capability.

**MS CHEYNE:** I want to go back to your quite startling statistic—I am reading your own paper that you have drawn on for your submission—that a Flemish study revealed that 32 per cent of the euthanasia cases studied occurred in the absence of a request or consent because the patients were comatose, had dementia or because the physician had decided it was in the patient’s best interests. I know you gave the Steck reference but I believe it is actually Pereira. Are you aware, Professor Quinlan, that

that paper by Pereira has been widely discredited?

**Prof Quinlan:** No.

**MS CHEYNE:** I want to draw to your attention a 2012 journal article in *Current Oncology* titled “Pereira’s attack on legalizing euthanasia or assisted suicide: smoke and mirrors”. They analyse the evidence he puts forward in his article and say that he makes a number of factual statements without providing any sources and that he makes a number of factual statements with sources where the sources do not, in fact, provide support for the statements he made. Their conclusion is that his paper should not be given any credence in the public policy debate. Indeed, Pereira then responded by saying that some errors had been identified in his article:

I humbly accept that there are some errors in the references and subtleties that are regrettable.

Could you please, on notice, review the evidence that you have given?

**Prof Quinlan:** I certainly will. I am pleased you have alerted me to that fact. I will definitely look at that. One of the difficulties in many areas of public debate at the moment is the politicisation of the academy, and this happens on both sides. I hope I have not succumbed to it myself. So it becomes very, very difficult. I am sure in the materials you have read you find that some academics review materials and say, “This is the outcome,” and others review materials and say the complete opposite. So in this area and in other areas it becomes very difficult to actually come to an objective truth, which is what you would have thought you could rely on people to do.

**MS CHEYNE:** Absolutely, and hopefully I can speak on behalf of all of us here: we are trying to get to the truth. But I think the debate can be really skewed by selective references.

**Prof Quinlan:** It can.

**MS CHEYNE:** That is why I wanted to check that further and see if there are perhaps some other sources that you could find which back up that statistic. I think we all took a breath in when you said it. I have not checked that one myself, but, given that article has otherwise and by his own admission been discredited, I would appreciate finding some more evidence.

**Prof Quinlan:** Sure.

**MRS KIKKERT:** Could you talk a little bit about dignity therapy? That is a phrase I have never heard before. I can certainly see that that will be a great benefit in palliative care.

**Prof Quinlan:** This is addressed in my submission, at pages 4 and 5. Essentially, I talk about in the general community the causes of suicidal ideation and then I refer to some of the evidence which shows very similar causes for patients who are terminal or otherwise seeking to access euthanasia. But one method of treating those sorts of issues in the terminally ill which has proved very successful is what I mentioned

before—dignity therapy. That was developed by Harvey Max Chochinov, and his book *Dignity Therapy* was published by Oxford University Press in 2012.

Essentially dignity therapy involves, as I mentioned before, providing patients who are considering euthanasia or who are terminally ill the opportunity of speaking with someone who can help them write down their thoughts about whatever they would like to write down. I quoted in the paper from that book, and this is a quote from Chochinov:

... terminally ill inpatients and those receiving home-based palliative-care services were asked to complete pre- and post-intervention measures of sense of dignity, depression, suffering, and hopelessness; sense of purpose, sense of meaning, desire for death, will to live, and suicidality; and a post intervention satisfaction survey.

Ninety-one per cent of participants reported being satisfied with dignity therapy; 76 per cent reported a heightened sense of dignity; 68 per cent reported an increased sense of purpose; 67 per cent reported a heightened sense of meaning; 47 per cent reported an increased will to live; and 81 per cent reported that it had been or would be of help to their family. Post-intervention measures of suffering showed significant improvement and reduced depressive symptoms.

**MRS KIKKERT:** Do you know which jurisdictions use that?

**Prof Quinlan:** I would be surprised if some palliative care facilities are not using it in the ACT, but it is used in New South Wales and other places.

**MRS DUNNE:** It is used in Australia?

**Prof Quinlan:** Yes, that is my understanding.

**MRS DUNNE:** I want to go to the issue of the right to die. I am interested in both your views on this but particularly from Professor Quinlan, from the legal perspective. We have received a variety of evidence on the subject of right to die and that it is inherent in the right to life. Some people say it is. The Human Rights Commission in the ACT was equivocal about whether the right to life extended to a right to die. We have also heard evidence that august organisations like the European Court of Human Rights, in the case of *Pretty v the United Kingdom*, equivocally said that the right to life did not extend to a right to die. I am interested in your views on the subject.

**Prof Quinlan:** That is certainly my view. My view is that the right to life does not extend to the right to die. We removed criminal sanction from suicide, but that was not because we were endorsing suicide; rather it was to encourage people to come forward if they had a family member or person who was attempting suicide, without the risk of being criminally prosecuted.

For the community the idea of a right to die presents many, many challenges. If that extends to a right to have someone else assist you to die, which I think is inherent in the proposition—that is what the Canadian Supreme Court seem to have found in their discussion—that does not just involve the individual, and there was discussion about this earlier. Obviously, it involves the doctors and the medical professionals who are

involved in providing the pharmaceuticals or injecting the materials in order to bring that death about. But it also involves family members and a wide number of people in the community, depending on how interactive that particular person is.

Somehow we have got to a false sense that we are all individuals in a world where we do not interact with people. But any time someone dies it impacts on a lot of people that they probably do not realise it impacts on—the people in the street, the people they see, the service providers they deal with, the people who care for them, their family, their friends. So I would not agree with that proposition.

**MS CHEYNE:** Does a traumatic death not have a greater impact than just a death where they are surrounded by loved ones, friends, at a time of their choosing?

**Prof Quinlan:** You are making some assumptions there. It may be that there is a death that the loved ones are comfortable with and that everybody is on board with that project and that everybody is there when the death occurs and the death is a peaceful drifting off into sleep, but that may not be the case.

As I mentioned before, there have been instances in Australia of people going overseas. We cannot stop them doing that, I do not suppose. But that could happen in Australia unless there is a regime which requires family members to be informed. That in itself raises questions about patient privacy and patient confidentiality. Otherwise family members might only find out about it after the person has died, and they might die alone.

**Dr Long:** There also tends to be a 10 per cent failure rate sometimes with some of the drugs used and they can actually have traumatic deaths still occurring under a voluntary assisted dying regime.

To go back to Mrs Dunne's invitation for a quick comment, I write on social ethics as a philosopher as well. And every right, of course, then places on others an obligation. That is the way that rights are understood in modern democracies. I believe in this debate those who favour the right to death tend to be those who favour an individualistic notion of political ethics. Those who do not give that right to death tend to be those who see the connectedness of our lives and whether it is possible to have an obligation placed on the wider community to assist someone to die. I would argue that the social democratic perspective would tend to go against the right to die view and that the individualistic more right-wing aspect would go in favour of a right to die view.

**THE CHAIR:** Dr Long, in your submission and in your opening statement this morning you discussed the Andrews bill. I am not necessarily talking about introducing voluntary assisted dying, but we have heard from many people that, with our Human Rights Act, whether it is actually a human rights issue, we do not have the right in the ACT to legislate for ourselves. Where do you sit on that one?

**Dr Long:** In terms of the capacity of the Assembly to legislate, there seems to be an overwhelming view in the ACT and in, shall we say, the federal parliamentary Labor Party that the ACT should have the right to legislate in this area to the extent that the states do. The commonwealth government would, in relation to the ACT and the

states, always have some role to play in the approval of a drug under the Therapeutic Goods Act, so not all powers go to the states. But I would be of the view that the ACT should have as much power as the states should have in relation to this matter.

**THE CHAIR:** Thank you both for joining us today. If witnesses undertook to provide further information or took questions on notice in the course of the hearing, whilst the committee has not set a deadline for receipt of responses, answers to these questions would be appreciated within two weeks of receipt of the *Hansard*. When available, a proof transcript will be forwarded to you to provide an opportunity to check the transcript and suggest any corrections, should they be required. I will now close the hearing. The committee's next public hearing will be Thursday, 31 May.

**The committee adjourned at 1.09 pm.**