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

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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.

WITNESSES

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Amended 20 May 2013

The committee met at 9.47 am.

CORNWELL, MR GREGORY

THE CHAIR: Good morning and welcome, everyone. I declare open this second public hearing of the Select Committee on End of Life Choices in the ACT. The select committee is inquiring into matters referred to it by the Legislative Assembly on 30 November 2017. The hearing program for today and the committee's terms of reference are available from the table near the door or online. The proceedings are public, are being recorded by Hansard for transcription purposes and are being webstreamed and broadcast live.

Before we begin, I remind you, Mr Cornwell, of the protections and obligations associated with parliamentary privilege. I draw your attention to the pink privilege statement on the table. I welcome you today, Mr Cornwell. Can you confirm for the record that you have read and understand the privilege implications of the statement?

Mr Cornwell: I have read it and understand them.

THE CHAIR: Thank you. Mr Cornwell, before we proceed to questions, would you like to make a brief opening statement?

Mr Cornwell: Not really, except to make two observations. The first one is that I am very pleased that the Assembly is undertaking this inquiry. I believe it is long overdue and it is something that we need to address nationally as well as locally. The second point I would like to make is something else. This is the first time I have ever appeared before an all-woman committee.

THE CHAIR: And it is wonderful to see.

MS CHEYNE: Yes, would you like to make a comment about that?

Mr Cornwell: I make no other comment. I am not criticising; I am just stating.

THE CHAIR: Thank you, Mr Cornwell. Thank you for your submission. I found it quite interesting. It is succinct, which is good when we had almost 500 of them. You mentioned in your remarks that you believe this is long overdue for the ACT to look at. I will ask you first to expand a little on that. But I do not know if you had a chance to hear Dr Helen Watchirs this morning on 666 ABC Radio talking about the human rights implications of not being able to make our own legislation in regard to euthanasia and other matters as well.

Mr Cornwell: Yes, I did.

THE CHAIR: I was wondering whether you could give us your opinions on those comments as well.

Mr Cornwell: I would certainly support the comments, because I think it is very important that we do have the rights. I remember many years ago in the advisory assembly I had to present a private member's bill in order to allow us to make organ donations to the rest of the country. We could take them from the rest of the country but we could not give them. This is an absurdity.

THE CHAIR: I actually remember that.

Mr Cornwell: There we are. I put to you that this is the same situation, that we should have the right to make our own decisions in relation to this matter, though I repeat that I think it should be a national agreement, similar to the same sex issue, if you like. But I am tired of individual states and territories making their own rules. It is like the railway problem we had for many years or different road rules. This is silly. Therefore I repeat that I would like to see it done on a national basis.

THE CHAIR: That is good. Can you expand on why you believe it is long overdue for the ACT to look at this particular matter, end of life choices?

Mr Cornwell: The alternative is rather absurd. As we know, Victoria has passed legislation. I understand that Western Australia is looking at the matter.

THE CHAIR: Yes.

Mr Cornwell: New South Wales, though it did not have a formal inquiry, missed by one vote. They will probably come back for another inquiry. Let us look at the situation. If New South Wales legislates, we are surrounded by New South Wales. What are we doing? Are we going to have people sneaking across the border? It is just absurd.

MRS DUNNE: On the issue of the territory's capacity to legislate in this place, do you have a view about whether or not the legislation passed by the commonwealth was legal and constitutionally based?

Mr Cornwell: The Andrews bill?

MRS DUNNE: I have forgotten its full name, but yes.

Mr Cornwell: Yes, I think it is known as the Andrews bill. Perhaps at the time it was thought to be. I know that the Assembly members did not think so. But it was thought to be at the time. But time moves on. What are we—29, 30 years since self-government? I think we are now in a situation where we are old enough to stand on our own two feet.

MS CHEYNE: Mr Cornwell, you talk about having quite a lot of conversations with your peers and that there has been general support for voluntary assisted dying. Are you able to give us some further insights into the types of conversations you have had and, in particular, why your peers have been in support of that? Also, have any of them raised concerns about whether it might be a slippery slope, for example?

Mr Cornwell: Might be a what?

MS CHEYNE: A slippery slope—you know, how you talk in your submission about appropriate safeguards.

Mr Cornwell: Understood.

MS CHEYNE: Yesterday the major general also said politicians will be under relentless pressure if it came in to expand the scheme.

Mr Cornwell: I do not believe that, but let me go back to the point. Yes, as recently as last Tuesday I had a discussion with a group of elderly men. Let me be kind about that. There were 10 of us. I was extremely interested that there was general support not only for the concept of this question but that a couple of them went further and said, “Of course, it should not just be reduced to elderly people.” They said that it should also be available to other people who need it for various reasons, not least being obviously their health. They said that it should be extended. I was interested in that view.

However, to get back to your slippery slope, no, I do not think that is the case. I think it is possible to pull in as many of the rules and regulations that exist in the world. We are not just talking about what you may find here in Australia. Holland and various other places have rules and regulations. If we pull them all together, it is possible to make foolproof, or as foolproof as it can be, legislation that will not involve the slippery slope. I know the matter of people deciding they want to kill off grandma is brought up on quite a few occasions.

MS CHEYNE: It sure is.

Mr Cornwell: I am not sure whether it would be for the money now. Possibly the house might be more important, but never mind. The fact is that I do not think this would be a danger. In fact one could almost argue that there would be a greater safety feature involved if these rules were in place and therefore tightened. People would not be able to do that sort of thing. As to whether it goes on or not, I suspect it probably does but in a very minor way.

MRS DUNNE: I missed the beginning of that sentence, Mr Cornwell. You said, “Whether it goes”—

Mr Cornwell: On.

MRS DUNNE: On?

Mr Cornwell: Now; it possibly does in a minor way but of course it is a criminal offence. I had this feeling that it might be a lot better if the whole thing was tightened up. We must not forget that this is a choice of an individual. It is not the family deciding that they want it. It is the choice of an individual.

MRS DUNNE: Yes.

Mr Cornwell: I have to say that my party, the Liberal Party, believes in freedom of choice. If you can have government and non-government schools, if you can have public and private health, why can’t you have freedom of choice in this area?

MS CHEYNE: A good point, Mr Cornwell. Given your experience in politics, I go to the major general's claim yesterday that politicians will be under relentless pressure. I look to the committee on this but I think he was also suggesting that politicians will cave in to relentless pressure to expand a scheme. Being someone experienced in the field of making legislation, Mr Cornwell, do you think that that is how laws are made?

Mr Cornwell: I do not. On this particular issue, to put it bluntly, I do not think that the federal politicians—and that is really where it should be made, not locally, and I will explain that in a moment—

MS CHEYNE: Please.

Mr Cornwell: I do not think at the moment the federal politicians have the guts to do it, even though, when you examine the polls, over 80 per cent of people are sympathetic. But in spite of that—well, look at the same sex—

MS CHEYNE: That is higher than the marriage equality vote.

Mr Cornwell: Of course. If, for example, you had a referendum on the matter, even if you accept that you would not get that 80 per cent plus vote in favour at a referendum, the margin over 50 per cent is quite enough to ensure that it would go through, in my opinion. That is the first point. But they do not have the courage. Yet, they may find that they are forced into it, because if each state and territory passes legislation or approves it, our federal colleagues will find themselves surrounded.

MS CHEYNE: Yes.

Mr Cornwell: They will have no choice but to adhere, if you like, to the wishes of their voters in each of the states. That is the way I see it. As I have said earlier, I would nevertheless like the matter to be national. I would like it to be done at that level. I suspect, however, that it is probably better being done at this level at the moment because they do not have the courage.

MS LE COUTEUR: I was contemplating talking about the interstate issues, but you were saying you were talking to a group of 10 gentlemen, your peers, so presumably you all at this stage still have your marbles. One of the questions that interests me is from the point of view not just of voluntary assisted dying but palliative care and what happens to you as you lose your marbles. Do you have any thoughts about how people's wishes when they are still mentally competent should be enacted when they become less mentally competent, given that this tends to happen at end of life, and it is an issue for both palliative care and end of life decisions?

Mr Cornwell: Yes, you are right. You have raised an interesting problem, but I repeat: I think we can do this legally. We talk about two doctors having to give permission et cetera. I think it is possible to tie that in with those two doctors, if I can put it that way, by way of statutory declarations or something of that nature—making sure, however, that it is at that professional level. We do not want families involved at that point.

I think we have to be careful about something else, and I might take the opportunity to make this point now. One thing that again worries me in terms of legislation is that if you make it too close to inevitable death—let me put it this way—if it says three months, therefore, frankly, it is hardly worth it. It has to be something that can be looked at in the longer term, bearing in mind the pain, the suffering and the angst that these individuals are going through. I think involving the doctors at that level or bringing in other professionals is fine. As long as they are there to witness the undertaking while people still have their marbles then I think we can overcome that problem.

MS LE COUTEUR: Do you think it would be possible for people, while they still have their marbles, to say, “If X, Y and Z happens, I would like to be allowed to die”?

Mr Cornwell: Yes.

MS LE COUTEUR: The legislation in Victoria would not let you do that. If you lose your marbles then you lose the—

Mr Cornwell: No, I think that’s a mistake, if that was the situation in Victoria.

MS LE COUTEUR: You have to be mentally competent.

Mr Cornwell: How many people have you spoken to? People say, “Of course, I don’t want to live if I have dementia,” or whatever. A lot of people say these things, and it should be possible to organise it so that those people’s views can be respected. It is possible, of course, that they may not. If you face them with the point, they may say, “No, I was just joking or idly thinking.”

MRS DUNNE: “I have reconsidered my position,” yes.

Mr Cornwell: Yes, that is right. I do not have a problem with that at all because we come back to this question of choice.

MS CHEYNE: It is like dying at home or in the hospital. Some people say they want to die at home, and then they get to the hospital and say, “Actually, this is better for me.”

Mr Cornwell: Yes. People can change their mind, and they are perfectly entitled to do it. After all, the one overriding point about this whole inquiry and the difficult question of death with dignity is that we are not trying to make it compulsory. We have to keep in mind that people do have—

MRS DUNNE: Voluntary.

Mr Cornwell: Yes. We do have to keep in mind that people have the choice. I am altruistic on this, by the way. I have no direct involvement, family or anything in this; it is just that I have seen people in hospitals, nursing homes and suchlike, and I have heard stories, of course, of other people, and I cannot say that I am impressed.

MS CHEYNE: On that point, Mr Cornwell, with some of the people that you have seen, and particularly those who have been dying or have died, have any of them expressed to you that they wished they could have made the choice themselves about when to die?

Mr Cornwell: No, they have not, probably because they have reached the stage where it is too late. This is where we come to the question of having something in advance. Probably the best you will get from them is, "I want to die."

MS CHEYNE: You have heard that from friends, family and colleagues?

Mr Cornwell: Yes, particularly very old people. I am thinking of one in particular who had had it.

MRS KIKKERT: Mr Cornwell, can I take you back to the conversation that you had with your friends, those 10 friends that you mentioned? You spoke briefly about the conversation you had with them about assisted suicide and how they wished it could be extended to other people, especially those in poor health. I am wondering how they would feel about extending that assisted suicide to people with disability, or even youth, as their individual choice to end their life. How would they react to that and how would you react to it?

Mr Cornwell: They did not canvass that in depth. A couple of them said, "This should be extended." It is important, though, that we consider this situation because we see a lot of quite wonderful examples of people. You mentioned disability particularly, so let us talk about the Invictus Games people. Although we see examples, wonderful examples, of these people and how they have overcome their disabilities and their problems, how many others out there have not overcome their problems and may find that life, for them, is not what they want? I do not know the answer to that, but I do know that we are constantly given the best examples that can be provided and we do not necessarily consider that there are an awful lot of other people out there.

The *Canberra Times* reported way back in 2012 about a carer of a husband in the UK who said—admittedly, this was the carer, not the husband—she had not been out after dark for 4½ years, presumably because her husband needed constant care that could only be provided by her at night. That is just another example of another problem, I suppose. I feel that, again, it is a much broader question than simply saying, "Death with dignity."

MS CHEYNE: There was something that we spoke about a little bit yesterday or that emerged as a bit of a theme yesterday. I note that you say that voluntary assisted dying is a taboo topic. Would you agree that death and dying in general is a taboo topic? To give you some context, some of the evidence we heard yesterday was that we used to be a community of villagers and death was really a part of life, but in many ways we have outsourced death now. A lot of death happens in a hospital, and we have funeral homes and so on. For that reason people are uncomfortable with that generally. Do you have any views on that? If so, do you think that we should be providing better education about what death actually looks like and exposing people to it a little bit more?

Mr Cornwell: I do not have a great deal of faith, to be honest, in the solution being education. I often feel—let me be blunt—that it is a wonderful cop-out: “We need education to overcome this, that or whatever.” In spite of that claim, we are still having wars and we are still having all the nasty things that happen around the world. However, obviously, I would not object because there is too much of a myth associated with death.

MS CHEYNE: What do you mean by “myth”?

Mr Cornwell: Some people are obviously very frightened of it; others feel, “If it’s going to happen, it’s going to happen.” Again we have this “choice” question, and different attitudes. May I say this: I do not want to be critical of the palliative care people, but there was a COTA study done in 2013, and palliative care was not seen as a good death by 27.6 per cent of the people interviewed. I do not know what a “good death” was; again, it comes back to this myth associated with the whole thing. May I also say that if other people have no right to decide whether I die or not, why should they have a right to decide that I live?

MS CHEYNE: And keep you alive.

Mr Cornwell: That is right. I find this inconsistent. Of course, let us be honest: there is the hypocrisy of pumping somebody full of drugs until they overdose because they are in such pain et cetera. I find it very difficult to comprehend.

MS CHEYNE: We have heard that evidence but we have also heard evidence of doctors who, when someone is entering palliation, are too scared to give them drugs. What did we hear yesterday? They are scared they might become addicted or scared that they might get sick when they are in their final few days of dying.

Mr Cornwell: They might recover and become addicted; is that right?

MS CHEYNE: It kind of defies belief, but I think that goes to your point, Mr Cornwell, that, regardless, palliative care seems to be very good in very many cases but in many cases it could be done better or it could at least be explained better, particularly when we have survey results like that.

Mr Cornwell: Yes. I think that for many people it is ideal. Again, we come back to the choice question.

THE CHAIR: That brings us to the end of our time today. Thank you very much, Mr Cornwell, for appearing.

Mr Cornwell: You are welcome.

THE CHAIR: When available, a copy of the proof transcript will be forwarded to you to provide an opportunity for you to check the transcript and suggest any corrections that should be required. Again, on behalf of the committee, I would like to thank you for appearing today, Mr Cornwell.

Mr Cornwell: Thank you for the opportunity.

BOERSIG, DR JOHN, Chief Executive Officer, Legal Aid ACT

THE CHAIR: I would like to thank Dr Boersig from Legal Aid ACT for appearing today. Before we proceed to questions from the committee, do you have a brief opening statement that you would like to make?

Dr Boersig: I do. Thank you for the opportunity to meet with you today.

THE CHAIR: I also need to ask whether you have read and understood the privilege statement.

Dr Boersig: I have indeed.

THE CHAIR: Thank you so much. Please continue.

Dr Boersig: Very briefly, just to be clear, as a public institution we have not expressed a view one way or another about this legislation. The aim of our submission was to provide, hopefully, useful information for your deliberations. If this legislation were enacted, these are the kinds of provisions in the act which would provide for appropriate decision-making and for protections of the various parties involved here. That is the direction of our submission. I have, of course, my own personal views but I am not here to share those; I am here to represent the commission on that particular topic.

THE CHAIR: All right, thank you. Mrs Dunne?

MRS DUNNE: Dr Boersig, I was interested, and you have touched on it a little in your opening comments, that the Legal Aid Commission does not have a view as a public institution. What prompted you to make the submission if you do not have a view?

Dr Boersig: We did because, if the legislation is enacted, it is essential—and this is the Victorian experience—to ensure there are protections for all parties. We have particular concerns to ensure that, for example, situations around elder abuse are covered. We have concerns that the hospital staff and the doctors involved are protected as they go about their business.

When we looked at the Victorian act, we saw that there are a lot of provisions and protections that relate similarly to what you might want to do here. We tried to ensure that, in providing this information, it is something that you would consider when making your overall determination about whether this legislation ought to go through.

If I can be so bold as to say that, without these protections, enacting this legislation would be highly problematic. Its interaction with the Crimes Act, for example, and other medical treatment legislation would prove very problematic. There is an aside here because there are issues around, for example, the possibility of private prosecutions by disgruntled people against medical professionals if they were unhappy with it. If they were to arise, it is likely they would arise in relation to public interest groups or family members who were disgruntled with the processes.

MRS DUNNE: I understand all those points but I am wondering what, in the remit of the Legal Aid Commission, would prompt you to make those submissions? How does it relate to your job in Legal Aid?

Dr Boersig: Our job under our act is to provide assistance to the most vulnerable and disadvantaged members of this community.

MRS DUNNE: Legal assistance.

Dr Boersig: Legal assistance. But we also undertake law reform, which is part of our remit as well; it is in our act.

MRS DUNNE: Is it? Okay. I think that is what I was getting at. I saw your remit as providing legal assistance to disadvantaged people; I did not realise that you had a law reform remit in your act. That covers my first question. But I take issue with a statement in relation to withholding treatment where you characterise withholding, withdrawing or refusing treatment—I am adding "refusing treatment" to that—as a level of passive voluntary euthanasia. As a legal term, I would probably need to object or disagree with you. That is clearly not the intention of the medical treatment act in the ACT. Would you comment on that?

Dr Boersig: Nothing further than what I have in our submission, and I—

MRS DUNNE: Do you think that it is a reasonable term to characterise the withdrawal or withholding or refusal of treatment as passive voluntary euthanasia?

Dr Boersig: To pick up from the other speaker, it is implicit in the actions that are taken and can be described as thus. From my point of view, I think strong legal protections and duties are much better and much more explicit around this. In those contexts, yes, I think the word "passive" is arguable.

MRS DUNNE: Okay, thank you.

THE CHAIR: Following on from Mrs Dunne, in your submission you talk about the R v Cox case. You said that that case:

> … expressed that a doctor is not criminally liable for a person's death if the purpose of administering a fatal dose of drugs was not to end a person's life but was given for another purpose, namely relieving pain

Dr Boersig: That is correct.

THE CHAIR: Is that possibly where you are going with the whole passive voluntary euthanasia, as well as other forms that you have mentioned?

Dr Boersig: In a past life I was involved in palliative care. I was on an ethics committee at a hospital. I had quite a bit of purview about the decision-making around what happens in elder care. I have brought that case along. It makes quite interesting reading. I would be quite happy to leave that with you today.

THE CHAIR: Thank you.

Dr Boersig: It is an interesting case. It sets out the complexity of people in this situation and how the court might deal with it. I will hand that to you later today.

THE CHAIR: Thank you. Ms Cheyne?

MS CHEYNE: Could I ask a clarifying question before I ask my substantive?

THE CHAIR: Yes.

MS CHEYNE: Dr Boersig, it is good to see you again. In your submission you say that the Victorian act is for people who have been diagnosed with a condition that will cause death within 12 months. That was changed to six months with amendments, but 12 months for a certain class of people. Does that change your view? Do you maintain that it should still be no more than 12 months in terms of the prognosis that is given, or would you prefer to see a model that requires a prognosis of no more than six?

Dr Boersig: We talked about this and thought there was quite good argument in relation to the 12-month period. I note the changes but, at this stage, we have not changed our submission around that.

MS CHEYNE: Okay.

Dr Boersig: It is not that, again, the six-month period is not arguable. For me, fundamentally, provided that there are the protections around decision-making and the protections to particularly vulnerable people such as the elderly, it is certainly arguable you could change that.

MS CHEYNE: That leads me to my substantive question. Your submission expresses concern—and you have done so today—about elder abuse and particularly the situation where person A encourages person B to enter the scheme because person A is a beneficiary. Are you aware of someone encouraging someone to do something because they are going to be the beneficiary? Is that common behaviour? How can it be detected and prevented more generally?

Dr Boersig: The overall issues around elder abuse are highly troubling. Part of the problem is that we are dealing with people who are in secluded environments where it is very difficult—unless you have other family members coming in and out, health professionals and so forth—to gain an insight into the interpersonal dynamics that are happening. You can see that that issue around elder abuse—and that includes financial abuse—is gaining a lot of traction both nationally and internationally. It has been on the agenda of the Council of Attorneys-General for quite some time.

National Legal Aid has also taken it up as a key issue. One of the difficulties is identifying and obtaining the statistics. A lot of what you hear is information that comes from people who are friends and carers. We indirectly get this, often through our work at ACAT, around guardianship and financial management. We are picking more of those issues up.

One of the benefits of public debate and discussion like this—we saw this most graphically in relation to domestic violence—is that they allow more people to come forward and break their silence. The answer to your question really is that the information, the evidential basis, is developing. At the moment we do not have the best tools to get that information. Clearly, now that there is a focus on this as an issue, we should be able to develop that information.

It is anecdotal. It is coming up indirectly through our other work, which ranges from domestic violence per se through to guardianship and financial management issues for elderly people and people suffering dementia. Having said that, human experience would say that the breakdown and the exploitation of people is sadly evident in a whole range of relationships. We see that throughout legal aid work. If we are seeing only the tip of the iceberg, it would not surprise me at all. We are dealing with very vulnerable people.

We are working with Libraries ACT at the moment. They have a mobile book library, as you know. We are developing materials and pamphlets so that next time they go out to them—they are really focused on people who are housebound—they will have a host of material around seniors' rights, elder abuse, that can go to those people. We are hoping that that might open up an avenue which we can then start. They will say, "Ring this number if you've got a concern." As you expect, housebound people are particularly vulnerable to these circumstances. There will be routes like that. I will put in a plug for Libraries ACT. They have been most amenable to this innovation. We are very thankful that they agreed to cooperate on it.

MRS DUNNE: In the context of your submission and this discussion, if we went down this path, what sort of checklists would those decision-makers need to satisfy themselves that someone was not being coerced?

Dr Boersig: We have set out in our submission a flow chart which we put together. What is important about that flow chart is that it breaks up in quite some detail the process for decision-making and the opportunity for review. That is on page 7 of our submission. When you look at the Victorian legislation, they have essentially two overarching approaches: one is a board of review which looks essentially at compliance generally and reports to their parliament.

MRS DUNNE: But it does not review individual decisions.

Dr Boersig: No, not really. But what is important also is they have an administrative review process that allows people to take that under review, similar to our ACAT. What I liked in that context was the capacity for review and various opportunities. If this decision is to be made, there needs to be the capacity for someone to change their mind or someone to review the decision-making as it goes along the way.

MRS DUNNE: I am aware of that, and I see your flow chart, but I am actually thinking not so much about a formal decision-making process but for someone who is facilitating a decision—a doctor, a psychologist, psychiatrist—do you envisage a capacity to have some sort of checklist or an aide-memoire that says, "Are you satisfied that this person is not being coerced?" et cetera in their decision-making process? I can come along and say, "I don't think my life is worth living any longer.

I’ve had a good life, but I’ve had enough and I meet these criteria,” and I can put up a show. But to what extent is it incumbent upon the decision-making facilitators to ensure that I am not just putting on a good show and that I authentically believe and want to do that but am not being forced by the kids who want to sell my $1 million property?

MS CHEYNE: Just on that, I thought you briefly mentioned in your submission that there might be room for requiring independent witnesses and physicians. Does that go to what Mrs Dunne is asking?

Dr Boersig: It does. We tried to break it up and say at various levels you would want certain obligations imposed on the decision-makers and the advisers. We comment in that context about who would be the independent witness—someone who does not financially benefit, for example, from this decision. Yes, you are quite right that you can develop a very clear checklist about the kinds of things that should be taken into account when this is made. In parallel processes in guardianship work and mental health work you have similar material that is used to assist and to check that the appropriate procedures are taken into account.

In many ways what we address here is what is the right process that should be followed, what is the quality of the decision that needs to be made at each stage and what are the checks and balances that need to be put into place when any of those decisions are made. I am right on song in that context.

When you look at the Cox case, it is quite illustrative initially of the point you are making about the complexity of someone coming to a point where they are making decisions around whether they want to end their life and who might then be accountable for assessing them. It really illustrates that in a most graphic way, which is why I brought it along.

MS CHEYNE: If there was use of independent witnesses and physicians, where in the flow chart do you think would be the best point?

Dr Boersig: Probably early on, but can I take that on notice? I have not thought specifically about the point at which that should occur.

MS CHEYNE: Yes, please.

Dr Boersig: It may well be that you have checks and balances at several points just to ensure that is the decision that is made.

MRS DUNNE: A question about this is the capacity for us to find the independent people. It is not quite like a guardianship decision because the outcomes of being involved in a guardianship decision are probably more nuanced and not as polarising as a decision in relation to voluntary assisted suicide. There would be people who are opposed for a variety of reasons and a group of people who would be actively encouraging; I will not say it any more strongly than that. But there is probably also a group of people who just do not want to know and who do not want to be involved. Do you envisage there would be a risk in not being able to find truly neutral witnesses?

Dr Boersig: No, I do not in practice, once you have professionals involved as well. The complexities around family and friends are evident and you will see that again in that case. The other difference is in the way the guardianship legislation operates as opposed to this kind of legislation. In essence the guardianship legislation is about ensuring the quality of someone's life. In a previous experience I was the presiding member of the guardianship tribunal in New South Wales for about seven or eight years. There was quite some discussion then—this is 15-odd years ago—about where that decision-making should rest—if euthanasia was brought in, who would make those ultimate decisions.

You would have to make sure the legislation was very clear and crisp. We normally do this when we set out regulations attached to legislation that then require certain criteria, and there are a whole range of examples where we set out who might make decisions at a most basic level. Think of a statutory declaration and who could witness a statutory declaration. We set out on the back of that form a whole series of people with their qualifications. I do not envisage that you could not make regulations to make that clear.

At heart much of what you are talking about here is risk and how you manage risk. So putting in controls for risk is partly what we are suggesting here. I guess my answer to you fundamentally would be, yes, I think you can make regulations that would ensure there were appropriate independent persons.

MS LE COUTEUR: Thank you for dealing with some of the issues around mental capacity in your submission because that is one of the things I find most interesting. I will talk about it in two parts. Firstly, with the advance care planning medical directives, my understanding is that you can make an advance care plan some time when you are mentally competent and it will still have effect if you become mentally incompetent. Am I correct on that?

Dr Boersig: An advance care directive has evidential value which will be taken into account at the time someone is being medically treated. To give an example, if I made an advance care directive now and then in 20 years it might come into operation, the obligations you see on medical practitioners would be to ensure that an appropriate medical decision was made. It is not pristine, as I understand it, but it is not definitive because—

MS LE COUTEUR: You said "pristine".

Dr Boersig: The wrong choice of word. It is not definitive when you make that advance care plan. It does not mean all the obligations on medical practitioners disappear at the time. There are a whole range of cases where those are looked at in other circumstances and where religious views, for example, prohibit people from having drug transfusions. You will see that in those cases the duty often rests on the court to make an independent decision about that. In Victoria, of course, they explicitly pulled this out of their legislation.

MRS DUNNE: Pulled what out?

Dr Boersig: The advance care directive issues, to ensure, I assume, that a decision is made in a contemporary circumstance. What would probably happen in Victoria is that if someone had an advance care directive that would be taken into account when you are discussing with the person whether they wanted to proceed. So much of that legislation is based on someone having the cognition to be able to engage with the providers and say, “Yes, I want this to happen now.”

MS LE COUTEUR: That is one of the more interesting issues. I will give a bit of background from my point of view. My mother was 11 years in a nursing home, so I am well aware of a large number of people in the nursing home who clearly did not have cognition but clearly were in considerable pain. Certainly, in my mother’s case, she was very clear about what she wanted; it was not in any way what she got, of course. You have a situation where close to actual end of life your condition is not what it was. Do you think there is any way that, while safeguarding people, we can also look at the situation where people have made a clear decision in the past and it is clear that what they wanted then is very far from what is happening to them now? Is there any legal way that this could be done with appropriate safeguards? It is always possible, of course, that people may change their minds.

Dr Boersig: The short answer is yes. It is interesting that the Victorians have gone in a different direction. That may have been the process of amendment that went through their various stages of parliament; I am not sure how that was negotiated. If you recall, Premier Andrews’ discussion about this was clearly influenced by his own personal experience and driven by that. People who have been involved in that often have very strong views because of the experience they went though, and quite understandably.

It is interesting that they did not go that further step. Yes, you could have provisions to do that. Again in my view there need to be checks and balances to make sure that a decision that is taken is one that is not abused. That is the underlying theme in our submission—that there are those checks and balances. In that context there is a risk issue that was managed in a certain way in Victoria. It could be managed differently.

MS LE COUTEUR: Have you any ideas about how it could be managed differently?

MRS DUNNE: Do you mean how could it be managed better, because differently could be worse?

MS LE COUTEUR: Sure, differently and better. It could be worse, but not that much worse than what happened to some of those people.

MRS DUNNE: I think this is a very fraught area. People might have quite complex but clear advance care directives but they may have been made removed from the situation. A whole lot of other people are interposed in the decision-making. It would be quite an unusual circumstance where a patient made an advance care directive, had a serious conversation with a treating physician, and a period of time elapses and that same relationship exists so that there is a clear understanding of what the patient’s will is. That is the ideal situation, but it probably rarely, if ever, happens.

Dr Boersig: Yes.

THE CHAIR: I can give you an exact example of that. My father has an advance care plan in place that I worked with him on. He has a heart condition. Just sitting around the dinner table last night, we were talking about the news about the 104-year-old man who took himself overseas to end his own life. He goes, "I think it's ridiculous. You can't end your own life. I want all the interventions. I do not want to die. I want every intervention you can possibly give." And I said, "Hang on a moment. Your advance care plan that I sat with you and developed says no interventions at all under any circumstances." "No, I have changed my mind." That was in a matter of months. So it is very interesting. We also heard evidence yesterday that advance care plans are often not even looked at.

Dr Boersig: Yes. The context of that is advance care plans, as they currently stand, cover situations where people are basically saying, "I don't want to be kept alive." The significant difference here, of course, is that the advance care directive to be developed would be, "and I want my life terminated." That bifurcation is at the heart of this debate and it is why there is some ambiguity around advance care directives and the obligations. The decision that comes before you is more pointed. It is about taking it further to say, "Yes, and if I reach this state, I want my life terminated."

MRS KIKKERT: My question goes back to the flow chart. I noticed that there is no psychiatrist mentioned in the process when somebody ends their life. Considering that depression is a major drive in people ending their lives, do you think it is a good idea to add a psychiatrist in the flow chart?

Dr Boersig: I think the point you raise is important in terms of addressing the quality of the decision-making. One would hope that in the context in which medical practitioners, professionals, are operating, if they felt there was that kind of issue, they would bring someone in. Your position is quite arguable in terms of bringing that to bear in certain circumstances, I would expect.

MRS KIKKERT: The cause of death is noted as the illness or disease. Are we talking here about the death certificate, that this is what will be listed as cause of death?

Dr Boersig: Yes.

MRS KIKKERT: If somebody is dying from cancer and they get injected with a certain drug that kills them, what would be written on the death certificate would be cancer; is that correct?

Dr Boersig: I would assume so, but I have not got a direct answer to that.

MRS KIKKERT: How can I get a direct answer for that?

Dr Boersig: That is probably something where the government solicitor's office could give you a definition here in the ACT about what that would mean. There is probably some Victorian material that would relate to that, given they have already implemented legislation. I am just not aware of it.

MRS KIKKERT: Would you support the idea of having the cause of death noted as the illness or disease on the death certificate instead of the drug itself that caused the death?

Dr Boersig: The most important point to make about this is that everything is open and transparent. As to whether that meant that was recorded on the death certificate, I have not got a view on that. There may be ways in which you could show both that the person had cancer and that certain action was taken.

MRS DUNNE: They had made an election under the act?

Dr Boersig: Yes, under the act. That would be the way you could probably do it. But open and transparent is what fundamentally has to happen.

MRS KIKKERT: That is good. I love doing family history, digging into the cause of death of people who died 50 or 60 years ago, and finding out exactly how they died. It is good and therapeutic for descendants like me. If you die through assisted suicide, yet you are listing the cause of death as something else, it is creating misleading records and also misleading our descendants.

MRS DUNNE: Interesting point.

THE CHAIR: Dr Boersig, I would like to go back to decision-making—in particular, focusing on the advance care directive stuff.

Dr Boersig: Yes.

THE CHAIR: As I am sure you are aware, in Victoria, they have had a major change to their Medical Treatment Planning and Decisions Act.

Dr Boersig: Yes.

THE CHAIR: Although it was a separate debate, it was around the same time as the voluntary assisted dying debate. We were lucky enough to go to Victoria and listen to people tell us about some of those changes: why they were made and how they were made. Having not done as much research on the ACT act, I do note that some of those changes in Victoria have improved. Are those some of the things that could work in the ACT, while still protecting those most vulnerable?

Dr Boersig: The short answer is that there will have to be ancillary amendments to a whole range of legislation. The Victorian act, and I will get back to it, does not amend the Crimes Act, as I read it, but it amends a whole range of other pieces of legislation, around the use of drugs, for example, the Coroners Act and so forth, and their equivalent of our act.

I think what that shows is the complexity of the interaction around how we ensure that there is a fully accountable system and that in relation to, for example, our medical treatment act, we would have ancillary legislation that ensured those protections were in place. Our act is, in my view, clearly quite explicit.

THE CHAIR: Sorry, which act?

Dr Boersig: The medical treatment act. It is the Medical Treatment (Health Directions) Act 2006. It would clearly have to be amended to take that into account, and you would think it would be ancillary to do this.

THE CHAIR: Yesterday we heard evidence that the ACT is an island within the borders of New South Wales and there were discussions about how, particularly from an advance care planning perspective, if you make an advance care plan in the ACT, it may not be recognised anywhere else, just as if you make it somewhere else it may not be recognised in the ACT. In your opinion, from a legal perspective, are there advantages to harmonising some of that, possibly with New South Wales but definitely harmonising. We know for a fact that a lot of Canberrans retire in New South Wales, generally to the South Coast. Are there views as to how we can harmonise that?

Dr Boersig: There are strong reciprocal relationships already amongst regions. Clients move back and forth, from our point of view, between Yass, Queanbeyan, Goulburn and Cooma, and indeed, in relation to family matters, we pool right throughout the south and south-west of New South Wales. National legislation and national consistency are certainly a best practice objective. Yes, I would endorse that, really. Having said that, I think the ACT is in a good position to take advantage of the best of all of the reforms around Australia. It may well be that the Victorian experience should inform what is done here and that New South Wales should take note of what the ACT is doing.

THE CHAIR: Mrs Dunne, I know you wanted to ask something further.

MRS DUNNE: I want to go to something that you touched on, Madam Chair—the current state of legislation in the ACT. Dr Boersig said he thought that the medical treatment legislation was not too bad. We have heard evidence that it is cumbersome. COTA described to us yesterday that the sort of decision-making documentation you have to go through is 19 pages or something like that, which makes it cumbersome. Also, I have heard separately that it is a bit lawyerly in the ACT. That is not a reflection on the lawyers, but perhaps it should be more in the medical sphere, rather than, “No, I’ve got a document which was drawn up by a lawyer,”—it was not drawn up by a doctor or with the assistance of a doctor. Has the Law Society, in its deliberations, considered what sorts of amendments, irrespective of which path we go down, are needed? Are there amendments need to the medical treatment act even if we did not go down the path of voluntary assisted dying?

Dr Boersig: I am not aware of the Law Society having considered this.

MRS DUNNE: Legal Aid, sorry.

Dr Boersig: Legal Aid? No, we have not given direct attention to that. The comment that I would make there is that I am a proponent of plain English, and it is crucial that the person receiving the information advice is fully apprised, in language that they can understand. I am certainly a proponent for legislation to be written in a way that is accessible. I understand, on the other hand, why it is sometimes written the way it is, because they are trying to cut off loopholes and trying to ensure that the intent of the legislation is explicit and there are those protections.

I am not able to comment on COTA's experience, because I have not seen any of that. The legislation as it is set out there seems to me to be quite well written in that sense. The way it pans out in practice, though, may well be, if experience is anything to go by, as COTA says, somewhat cumbersome. We do have, across a number of areas, what would seem to be clear legislation but with cumbersome regulations or cumbersome processes to follow, because everyone is making sure they are complying. I cannot quibble.

MRS DUNNE: The problem may not be in the legislation; it may be in the regulation.

Dr Boersig: It may be in the regulation and the way that is interpreted from the policy point of view.

THE CHAIR: Does anyone have anything further for Dr Boersig?

Dr Boersig: Can I just make one comment around the Crimes Act?

THE CHAIR: Please.

Dr Boersig: I was cogitating upon this last night. We have basically said in relation to murder that it would be preferable to have an exception as opposed to a defence. In my deep cogitation around this last night, I think that that may not be the right way to go. When I reflected on this, I thought that setting up an exception to murder might lead to more complications. From a pristine policy point of view, yes, that would be good: "Murder is done here, but if this is the case, it is not murder."

MRS DUNNE: So it disapplies?

Dr Boersig: "This does not apply." That is attractive because of its simplicity but—

MRS DUNNE: Simple is not always better.

Dr Boersig: Not always better. In relation to that part of our submission, which we just did in the paragraph, I might just ask if I can hold my thoughts on that. That is something you would really want to work through again. The idea behind it is that you do not end up having people prosecuted who then have to defend themselves. You try and get in and say that this should not be prosecuted in the first place. I think you can probably achieve that by the directed dying legislation itself, which would be read cognisant with the murder provisions. So, on the record, I put that qualification to page 5, the paragraph in our last statement.

THE CHAIR: Thank you.

Dr Boersig: Thank you for giving me the opportunity.

THE CHAIR: Thank you for appearing today, Dr Boersig. When available, a copy of the proof transcript will be forwarded to you, to provide an opportunity for you to check the transcript and suggest any corrections should they be required. I note that you did take something on notice today. As a general rule, the committee is requesting that answers to questions taken on notice are provided to the committee within 14 days of receipt of the *Hansard* transcript.

Dr Boersig: I am happy to do that.

THE CHAIR: Thank you for appearing today and for providing your thoughtful insights.

Hearing suspended from 10.56 to 11.12 am.

WATCHIRS, DR HELEN OAM, Human Rights Commissioner and President, ACT Human Rights Commission

MCKINNON, MS GABRIELLE, Human Rights Law and Policy, ACT Human Rights Commission

THE CHAIR: I welcome our next witnesses. Dr Watchirs, I draw to your attention the privilege statement that is on the table. Can you acknowledge that you have read and understand the privilege implications in the statement?

Dr Watchirs: Yes, I have, thank you.

THE CHAIR: And Ms McKinnon as well?

Ms McKinnon: Yes, I have, thank you.

THE CHAIR: Dr Watchirs, before we start with our questions, do you have a brief opening statement you would like to make?

Dr Watchirs: Yes, I do. I would like to begin by acknowledging the traditional custodians of the land on which we meet today. I respect their continuing culture, the oldest in the world at over 65,000 years, and the contribution they make to the life of the city of Canberra and the ACT region.

Our submission has covered three main areas: firstly, the limitation of democratic freedoms of ACT residents by the Andrews bill; secondly, what would be the human rights implication of voluntary assisted dying laws; and, lastly, what safeguards would be necessary if such laws were to be introduced in the ACT. Since the federal Euthanasia Laws Act 1997, the Andrews bill, there has been legislation passed in Victoria, the Voluntary Assisted Dying Act 2017, which comes into force in June 2019.

I think this unreasonably restricts the right of ACT citizens to participate in public life by enabling our elected representatives to make laws in relation to what our values are, as reflected in legislation. I think the debate has moved since the Northern Territory Rights of the Terminally Ill Act 1995. The fact that we actually have Victorian legislation means that the Australian public is open to this issue. We need to debate as a community whether we have such laws and what would be the safeguards contained in such legislation.

I think it shows that ACT and Northern Territory residents have lesser rights than those in the states. It clearly is a state issue because there is an offence to aid or abet the suicide or attempted suicide under section 17 of the Crimes Act 1900. I think a practical way of possibly moving towards repeal of that legislation would be to request the federal Attorney-General under the Human Rights (Parliamentary Scrutiny) Act 2011 to refer the Andrews legislation to the Joint Parliamentary Committee on Human Rights to get its opinion on its human rights compatibility and whether we should be moving forward.

I think a constitutional referendum would be impractical. There are certainly various other topics for referendums that it could be included with, but I think the immediate repeal is a much more immediate solution. It is not a grey area. If we did legislate, a High Court challenge would be lost by the ACT. The federal government has clear legislative power.

The other part of our submission is hypothetical. What if we did have legislative powers? What are the human rights engaged? Firstly, we have the right to privacy under the ACT Human Rights Act, section 12. We have power over how and when to end one's own life—that is autonomy—if you have the capacity to make such decisions. There is also recognition of equality before the law under section 8, the right to life under section 9, and liberty and security of the person under section 18.

There is a 2015 Carter v Canada Supreme Court decision which said that having a blanket prohibition on assisted suicide was found to be a disproportionate limitation on the actual right to life and right to liberty and security of the person because it was actually possible to have a regime where you could have access to physician assisted dying with very strong safeguards to make sure that vulnerable people are protected from abuse and error.

There is also the right to protection from inhuman and degrading treatment under section 10. The absence of such laws could be said to make people's end of life choices limited by their suffering, which may not be relieved fully by palliative care, both mental and physical. I think it is important to draw the committee's attention to the COAG national palliative care strategy that is currently being developed in that respect.

There is also the right to freedom of thought, conscience and religion under section 14 of the Human Rights Act. We would strongly urge that doctors, nurses and any other medical practitioners have the right to conscientiously object to voluntary assisted dying in any individual case so that their own freedom of religion is not compromised.

Thirdly, what safeguards would be necessary? I think it is really important to have very strong community debate and consultation. The number of submissions to this committee, nearly 500, is very impressive. In Victoria they went through a process. They similarly have a Charter of Human Rights and Responsibilities Act 2006. It went through a parliamentary Legislative Council legal and social issues committee, a ministerial advisory panel and, of course, the scrutiny of bills committee generally, which looks at human rights issues.

In Victoria, people are included and excluded with race and the right to equality. In Victoria, you must have a diagnosis of disease, illness or medical condition that is incurable, advanced, progressive, and will cause death within less than six months or 12 months if neuro-degenerative.

In other jurisdictions such as Switzerland—and that has been operating for 70 years, I understand—they actually will enable something broader. The Australian, David Goodall, recently flew to Switzerland at the age of 104 and did not have an incurable, advanced or progressive illness. It was simply his decision.

In Victoria, you cannot have solely mental illness or solely disability; they have to have the criterion of that progressive and incurable condition. Children are excluded.

In Belgium it is interesting to note that since 2014 they actually will allow younger people, and a 17-year-old actually made a decision more recently.

Regulating the process is important. Firstly, the person must clearly and unambiguously request voluntary assisted dying; so not a doctor or a person under a power of attorney. There has to be a detailed assessment by two independent medical practitioners. The person needs to be satisfied with and understand the information about end of life choices and act voluntarily without coercion. The voluntary assisted dying board needs to be notified within seven days and there needs to be a written declaration witnessed by two people not involved in the health care of the person or who are beneficiaries of that person's estate. Then there is a final request with a delay of nine days. A permit is then given for the substance. The death must be reported and reviewed by the voluntary assisted dying review.

I think that is a useful model as a starting point for what kind of safeguards would be necessary for human rights protection. The Victorian model is quite conservative. It is very limited, very strictly regulated. If the community is nervous about how this legislation would operate, I think having a conservative one that could be amended at a later stage may be the way to go, if that is what the community wants, and I think we need a debate about that.

MS CHEYNE: Thank you for appearing today and for your comprehensive submission and opening statement. Just following on from where you ended with your statement, Dr Watchirs, I note that the existing prohibition has negative human rights implications, in terms of the limited control we have over our life and the decisions we make in our private life. You also pointed out that a conservative model might balance concerns in the community.

What I am trying to wrap my head around—this is an inarticulate question—is: how do we balance giving people the right to control their private lives, including their decision on the control they have over the end of their life, versus balancing those safeguards? Some of the safeguards we talked about include that it must be within six or 12 months if it is a neuro-degenerative condition, except that that rules out plenty of people, including people with dementia, for example. How do we get that balance right while trying to get the right human rights outcome here? I am sorry if that is inarticulate. I hope that makes sense.

Dr Watchirs: It does make sense. Under section 28 of the Human Rights Act, if you have a limitation it needs to be proportionate. Because of the danger particularly of elder abuse and the lives of people with disabilities not being valued, they may be in the situation that they feel that their life is not of value and that they are a burden on their family and carers. You do not want those people to be queuing up for voluntary assisted dying. Of course there is a gender element to that. With women living longer and probably being more altruistic, they may be turning up in higher numbers. I think that is why it is a good idea to have—

MRS DUNNE: There is a submission to that effect.

Dr Watchirs: Yes—a situation where there is regulation and where there is data kept on the type of people who are coming forward. In other jurisdictions it is 12 months rather than six months as it is in overseas jurisdictions and it is probably more practical, I think, given the difficulty in predicting how long a person would live. On the practical side you may find doctors willing to give such predictions.

I understand from colleagues in the commonwealth that, where people were invalided out, they needed to get medical certificates that they were not going to live for another two years. And they were given out quite liberally. If you have it too tight, in practice it may be overridden by certain doctors being a bit loose with their predictions.

I think it is actually better to have a different way of defining it than six months. I think where you are not expected to live beyond 12 months may be a better way of putting that.

MS CHEYNE: In your statement you said that you think it is very important that medical practitioners or doctors should be able to conscientiously object. We have heard a range of views about that, with quite a lot of people saying that they also agree but that, if someone does object, they should be required to then refer the person on to somebody else who might not be objecting. Do you have a view on that?

Dr Watchirs: I am not sure how it operates in Victoria but a referral, I do not think, would be an onerous obligation to give to someone. But if you had a regulatory board in existence anyway, you could probably refer someone to that regulatory board and they would have physicians, I imagine, that would not have conscientious objection; so they would refer the person. It is such a strongly felt issue that you could not possibly make a physician participate where they had, for instance, a belief in right to life that prevented them from carrying that out. I think it is very reasonable to allow them to conscientiously object.

MRS DUNNE: Could I just clarify: what you are saying is that it would be an unreasonable imposition upon someone who had a conscientious objection to be forced to refer a patient—

MS CHEYNE: No, it would not be unreasonable. Sorry.

Dr Watchirs: I think it would depend on how it was drafted. A soft referral would not be onerous but a hard referral may be. So it would depend on how you drafted it.

MRS DUNNE: Could you differentiate for me what you mean by a soft referral and a hard referral?

Dr Watchirs: They could refer them not to another doctor but, say, to the regulatory body that may be able to have access to another doctor. That may be something that is not quite as onerous.

MRS DUNNE: Rather than an obligation to refer them to someone that they know? I suppose, in a sense, it might not be a problem in a small jurisdiction like the ACT but in a large jurisdiction it might be.

Dr Watchirs: In remote and rural areas it would be problematic.

MRS DUNNE: It might be quite problematic to even know and then to have a responsibility to refer could be onerous. I want to go back to my initial question. I do not know whether I heard you properly. Do you think that any requirement to refer, from someone who refuses to participate, is too onerous or that there is some middle ground referral that under the Human Rights Act may not be considered too onerous?

Ms McKinnon: If I could take that a bit further, the idea is that certainly it would be a limitation on a doctor's rights to freedom of religion, and their ability to conscientiously object, to require them to participate in the carrying out of voluntary assisted dying. It is certainly arguable that requiring them to directly refer to another doctor, knowing that the outcome of that would be that the person would have access to voluntary assisted dying, is likely to be also seen as a limitation.

MRS DUNNE: Because that could be considered as them materially participating in something that they object to?

Ms McKinnon: Yes. I think the same issues have come up in relation to abortion. But I think that there are certainly more proportionate ways of achieving the same outcome in terms of ensuring that the person seeking that assistance has information. That could be provided in a range of ways but not necessarily a direct referral. There could be a website that could have further information, people to be contacted, hospitals, ACT Health could provide information without placing a direct obligation on the doctor themselves to make that referral. I think we would question whether that would be human rights compliant if there were other more proportionate ways to achieve the same outcome.

MS CHEYNE: I think that is a really important distinction to make and probably is something that has not come through in some of the other submissions we received. It has been emotional for people. But we did hear or read some evidence yesterday from someone who said people do not have a lot of time, particularly in Victoria, where it is, for most people, six months, and making the request once when you do not have much time anyway and you have got quite a few other things to think about. Your having to find someone else could be really quite burdensome and potentially limit the person's ability to enact their own wishes. I think that is why one of the submissions we read yesterday really strongly said no doctor should be able to refer straightaway.

But I note Mrs Dunne's point and your point as well that by giving a hard referral you are not conscientiously objecting at all; you are just handing the responsibility to someone else.

Ms McKinnon: That is right, especially if there is another way that it can be done where the patient still ends up getting the information they need and access to a doctor who can provide that assistance, without requiring the involvement of a practitioner who has a very strong conscientious objection to that.

MS CHEYNE: There is probably a balance that could be achieved?

Dr Watchirs: Yes. I imagine there will be counselling services involved that could assist the person in the situation.

MS LE COUTEUR: One of the comments you made was that one of our human rights is not being subjected to inhumane or degrading treatment. They have got that slightly wrong. I am just wondering how you think that works in terms of equalling some people's experience in the years leading up to death. I am particularly thinking here, of course, of nursing homes, which are notoriously understaffed. Certainly, from the many reports I have read, I would say, on a personal level of observation, that human right is not always observed in nursing homes. Would that be somewhere that we should, from a human rights point of view, be going before anything else?

Dr Watchirs: I think that would be a much broader model, like going for death is imminent beyond the 12-month period. I think that could be problematic in terms of human rights, if you wanted a very tight scheme like Victoria, where you did not want it open to abuse and relatives pushing people towards voluntary assisted dying because they wanted to access that person's will at an earlier stage.

Ms McKinnon: I certainly agree that it does raise human rights issues if people are not being treated appropriately or they are being treated in a degrading or inhumane way in nursing homes. And that is something that needs to be addressed. It is probably something that also treads into the federal sphere of regulation and, I would suspect, in aged care. It is something that would need to be addressed from a range of perspectives. But I think it is a much broader issue, is it not, around the conditions of aged care?

MS LE COUTEUR: Yes. It would seem to me to be a much broader human right, given, I suspect, many more people have difficulty at the end of their life than are likely to want to actually go to the levels of assisted dying. This inquiry is not just about voluntary assisted dying. We also have a term of reference about end of life choices and palliative care. I was thinking that in terms of human rights, given that is a human right, it is probably more aggrieved against in the ACT and Australia than for those who would desire assisted dying and cannot do it. I was wondering, given they were both human rights, if you had any view about how that one was protected at the end of life—

Dr Watchirs: Certainly, I noticed in several submissions palliative care experts saying that probably there was not sufficient access to palliative care in the ACT and it should be extended and that would take off the pressure for people wanting voluntary assisted dying, if they had access to palliative care, not just in Clare Holland House but in hospitals and in their home. There is access at the moment but I think it could be broader access. That would mean that people are not suffering if they have access to proper palliative care.

MS LE COUTEUR: Clearly, from what we have heard, there is not sufficient access. We have heard evidence of people not being able to access palliative care.

MRS KIKKERT: Do you think that everybody should consider palliative care first, before anything else, considering the advanced medicine and continual palliative care?

Dr Watchirs: I think it is up to the individual to make that choice. Certainly, in the Victorian model, the whole of the information about access to palliative care is part of what a person is required to be given information about. I think that is very important so that they are making an informed choice and they know that there could be palliative care available that will stop their suffering. Some people could have other forms of suffering—mental suffering—and may still want to proceed with voluntary assisted dying, even though their pain may be medicated.

THE CHAIR: I think the word you used there was “choice”.

Dr Watchirs: Absolutely.

MRS KIKKERT: Picking up on the word “choice” here, I keep going back to assisted suicide. What message are we giving to youth who want to commit suicide?

Dr Watchirs: That is why the scheme in Victoria is very limited in terms of the person having to have an illness that is imminent.

MRS KIKKERT: I understand that, but what message are we sending to 14, 15, 16 and 17-year-olds who are lonely and depressed and want to end their life? If we say that somebody with a terminal illness who is 79 years old chooses to end their life, what message are we sending to a 17-year-old who cannot compare the depth of a terminal illness that a 79-year-old has to their own poor mental health? What message are we sending to those poor teenagers?

Ms McKinnon: It is clearly a distinguishable situation, isn’t it? Teenagers who are in that situation need a lot of support and help, and it is certainly their right to have all the services and assistance they need. The kinds of schemes we are looking at here are looking at assisted dying for someone who is already in that terminal stage; they are dying, but it is about assisting them to do that in a way that is dignified.

I think they are very different things, but I agree that the messaging would need to be very clear, and it is a reason why a very important safeguard is around not extending this kind of regime to children and young people, even though that might limit their rights, in a way. But we do need to provide extra protections and safeguards for the rights of children and young people. I understand the link that you are making, but I think they are very different things.

MS CHEYNE: Do you think that the terminology that we use is important as well? I think the Legal Aid Commission said—and I also know it was a big theme in the Victorian inquiry—that “voluntary assisted dying” should be the term, not “assisted suicide”, because that really starts to confuse things for people.

Dr Watchirs: And even the term “euthanasia”.

MS CHEYNE: Yes. Is that your position as well?

Dr Watchirs: Absolutely. “Voluntary assisted dying” is the preferred terminology. I think it makes it very clear that there are very limited circumstances. You want an education campaign to make it clear and so that it does not have an impact on youth seeing suicide as an easy option.

MRS KIKKERT: Regardless of what words you use, youth will see it as dying, or suicide. To them it is still the same thing. It does not really matter what terminology or what word you use; it is the idea surrounding helping somebody to die in a dignified way and then a 17-year-old who might want to end their life. It does not have anything to do with words.

Dr Watchirs: There is certainly a case for more supports for teenagers in that situation and better access to mental health care.

MRS DUNNE: Following up on the point that Mrs Kikkert has made, there is some statistical evidence from other jurisdictions that there is an increase in the background level of suicide in jurisdictions where there are these regimes, whatever they are called—euthanasia, voluntary assisted dying. They do have different names in different places. There is some evidence that there is an increase in the background level of suicide.

How do we balance rights when we know these things? You are saying that this is a right for extended choice, I suppose, but in doing so we may actually create a permission structure whereby other vulnerable groups in the community are empowered, in a sense, in a way that we do not think is a very good idea. We spend a lot of money on suicide prevention. Dr Watchirs, you have said that we should be doing more to assist vulnerable youth in this space. Is there not a risk that by extending a right in one place we are diminishing someone's life in another place?

Dr Watchirs: There could be a potential flow-on effect. I think it would be really important to evaluate a scheme and to keep data not just on the people who are going through a regulatory agency such as a voluntary assisted dying board, but on suicides generally and at what ages people are most vulnerable. I think it is something that should be strongly monitored beforehand and, if a scheme is introduced, during the life of that scheme to see what the indicator is.

MRS DUNNE: Could you imagine a situation where, once you have introduced a scheme like this, you might say, 10 years down the track, for instance, the suicide rate has risen unacceptably, and we could perhaps draw a connection between them, and a regime like this would be dismantled?

Dr Watchirs: Certainly, it should be strongly evaluated, and if there was a connection then you would want to consider that.

Ms McKinnon: That would raise issues about the protection of the right to life.

MRS DUNNE: Yes.

Ms McKinnon: If we introduced legislation and the effect was that suicide rates massively increased and there was a very clear correlation, if that evidence was available, that would be something that would need to be taken into account in terms of whether that was a limitation on the right to life in the ACT. It would depend very much on the evidence that we have, and if there are overseas jurisdictions—

MRS DUNNE: Also how we collect that evidence.

Ms McKinnon: Yes, absolutely.

MRS DUNNE: We have to be sure about that before we start.

Ms McKinnon: Yes.

Dr Watchirs: It would need to be rigorous—the evaluation.

Ms McKinnon: It would be important to consider, if there is evidence of that kind in overseas jurisdictions, what the regimes there are, and if they are very limited to end of life, to voluntary assisted dying, does that have the same impact or is it in areas where there is a much broader regime that provide for assisted suicide? I think it is very important to evaluate that evidence very carefully and not assume that all schemes are the same.

Dr Watchirs: Some regimes, such as Switzerland, where you can do it on the basis of age, would be different to the Victorian scheme, where it is clearly limited to terminal illness.

MRS DUNNE: It is interesting that in the federal budget last week or the week before, there was money for mental health for the elderly because of the spike in suicides amongst older men. If you went down the Swiss path, you would end up with a regime that validates that as an authentic choice.

On a related issue, one of the things that the committee discussed when it was in Melbourne—it is published in the evidence—is that there is an arithmetical growth in the number of people who apply for this process in other jurisdictions. You start off with small numbers, and over time the numbers balloon, which some would say is part of the slippery slope model—that it becomes less and less a niche thing and becomes more of an accepted part, involving quite large proportions of people. In one of the jurisdictions—I cannot remember which one—it was in the high single digits: six to eight per cent of people die under the legislation.

Would you see that as an issue that would also have to be evaluated and monitored over time in the context of a legislated right to life—whether there are issues associated with ballooning numbers of people who participate?

Dr Watchirs: Certainly, you would want to evaluate the impact of such a scheme. But it would not necessarily mean that you would repeal the scheme. You may want to tighten the safeguards; that would be another way of doing it. Because we are such a small jurisdiction, it would become more obvious what the impact was fairly soon, compared to Victoria, which has a much larger area and has remote and rural communities.

THE CHAIR: In regard to Victoria, you noted in your submission that it is one of the only other jurisdictions that has a human rights act and has passed legislation to be enacted. Have you been watching closely how those two do interact, between the Human Rights Act and the new assisted dying legislation?

Dr Watchirs: Sure. As I said, three committees looked at it, the third one being the scrutiny of bills committee, and they were all satisfied that the legislation was compliant, because of those stringent safeguards in all areas. It was the community that wanted those safeguards. They wanted a limited model where there was much less chance of it being a pressure on vulnerable people, elderly people or people with severe disabilities that they would be caught up in the scheme when it was not designed to be that way.

Ms McKinnon: I think the Victorian model is very useful because they have been through a very rigorous process of assessing compatibility against human rights. Really, the protections in the Victorian Charter of Human Rights and Responsibilities mirror what we have in the ACT. We can look at that process that has been gone through and all the safeguards that they developed as a model. It is not something that we could just take completely without applying it to the particular situation that we have here in the ACT. You would need to look at the way our health system works, and all the other legislative operations here. It certainly shows that a very detailed and careful process of compatibility can be followed and that that kind of very limited and careful legislation can be the result.

MS CHEYNE: I want to draw out this idea of a correlation between suicide more generally and voluntary assisted dying. Unfortunately, an ethicist, Margaret Somerville, published a pretty silly article, in my opinion, which selectively cited statistics about overall suicide rates, particularly in European countries. What we know is that, while there are some countries that have assisted dying laws and have greater overall rates of suicide, there are some that equally have lower rates of suicide, and that there are a number of countries that have voluntary assisted dying laws where their rates of suicide more generally are trending downward. Switzerland, which does not really have any safeguards, actually is trending downward most significantly in terms of broader suicide.

With what you were talking about in terms of rigorous assessment in determining correlation, how could we ensure that correlation does not equal causation? The Netherlands is a great example. For the last 30 years it was trending downwards; then in 2008 suicide more generally started trending upwards, but a pretty significant global thing happened in 2008. How would we balance that, if we were to do that sort of assessment, which I completely appreciate is necessary, without wanting to confuse things?

Ms McKinnon: I think you have pointed to the key issue, which is assessing whether there is some causal link between bringing in this kind of legislation and it having a direct impact—it might reduce protections or impact on the right to life. If it is just a general correlation, it might be explained by other things going on in a particular society or it might be cultural factors or other things, and it does not provide such clear evidence that there is a limitation. There are ways of excluding different variables when you are looking at evidence. Certainly, from a human rights perspective, we would have to think here that not having the ability for people to get assistance at that end of life stage to end their life is currently a limitation on people's rights.

Introducing a scheme of this type also has the potential to significantly limit rights to life and other rights. For that reason, it needs to be done in a very careful and proportionate way so that you can give people that choice but in such a way that there are a lot of protections and safeguards built in. At the same time, you need to look at whether there might be broader issues and broader impacts of that kind of legislation. Those have to be considered as well.

In terms of the statistical analysis, I am not sure how that would be done, but I am sure that there could be careful analysis which might exclude other variables to actually determine whether introducing this kind of very tailored, narrow legislation can be shown to have a real impact on rates of suicide in the community. It would be a difficult study to do, but I am sure there are ways of looking at it.

Dr Watchirs: The important thing would be to have an independent person doing that kind of work—that they are not on one side or the other but are genuinely open to the issue, and having a scientific basis.

MS CHEYNE: Thanks for underlining that.

MRS DUNNE: Could I go back to the beginning of your submission in relation to the issue of the commonwealth legislation? Is there any doubt in your mind that the commonwealth legislation is legal and constitutional?

Dr Watchirs: No; no doubt whatsoever. It is clearly within power under section 22 of the Constitution, and the federal Euthanasia Laws Act 1997 amended section 23A of the self-government act, so it is clearly within power. There would be no point having a High Court challenge because it is not a grey area.

Ms McKinnon: We did say in our submission that it raises human rights issues in the federal context. So there is an argument that that legislation impacts on people's rights in the ACT and that if there were some human rights scrutiny process done of the euthanasia law that might indicate it is unfairly limiting people's rights in the ACT.

MS CHEYNE: Has there ever been that scrutiny process?

Ms McKinnon: The parliamentary joint committee looks now at every bill that goes through in the commonwealth.

MS CHEYNE: Yes, but has it for this one?

Ms McKinnon: Not for this one because it happened in 1997.

Dr Watchirs: No. It is only since 2011. It is interesting to note that since last year the Northern Territory has parliamentary scrutiny of human rights—so that is very recent. Using the model they directly apply the federal legislation.

MRS DUNNE: This is a constitutional question and I am not sure whether this is in your remit or expertise, Dr Watchirs, but what is the power of the commonwealth in relation to making laws in the territory?

Dr Watchirs: Section 122 of the Constitution says:

> The Parliament may make laws for the government of any territory surrendered by any State to and accepted by the Commonwealth, or of any territory placed by the Queen under the authority of and accepted by the Commonwealth, or otherwise acquired by the Commonwealth, and may allow the representation of such territory in either House of the Parliament to the extent and on the terms which it thinks fit.

So they are plenary powers.

THE CHAIR: In your submission you talk a lot about choice, which is fantastic. One thing that has been raised a lot is that as part of choice, advance care planning and advance care directives are not made often enough because in Australia death is still a taboo subject; we tend not to talk about it. We also heard evidence that sometimes doctors either do not know how to read or do not read advance care directives or advance care plans. With the changes to the Medical Treatment Planning and Decisions Act 2016 in Victoria, part of that was to ensure that—and this morning Legal Aid also commented on this—an advance care directive would specifically state, "I want to end my own life. I want to participate in voluntary assisted dying."

Dr Watchirs: And something explicit like, "Do not resuscitate." It probably happens in effect now on a daily basis. People have that legislative framework to make an advance care directive and doctors should have the education to know they exist and actually consult to check them. It would be important to have an education campaign supporting that so that advance care directives are actually put into action more in the ACT. We have the legislation; putting it into practice may be a problem.

Ms McKinnon: The Victorian model does not allow for an advance directive to allow you to make that decision; you still have to have capacity to make that decision at the time you make the final—and that is an important safeguard. In an advance care directive someone might decide that is the path they want to follow, but it is very important that at the time that final decision is made it is not made by another person and is not made in advance, because people change their minds.

Dr Watchirs: Exactly.

Ms McKinnon: It would be concerning from a human rights perspective if that was not to be followed. To include that in something that might last for a period of time and not have an ability to change your mind towards the end would be concerning. I think the Victorian model hits the right approach in terms of ensuring safeguards, even though it limits people's rights. People might lose capacity to make that decision, but they are the critical safeguards that are needed.

MS LE COUTEUR: Could you speak a little bit louder, please, both of you.

Ms McKinnon: I am sorry, Caroline. I was saying in the context of the Victorian legislation that it does not allow for people to make an advance care directive that then has ongoing force that would allow them to be part of a voluntary assisted dying process; they need to retain capacity to make that decision when that process is actually carried out, and we think that is an important safeguard.

MS LE COUTEUR: Or is it? Yes, it is an important safeguard but it is also presumably a reduction of the human rights of someone who was totally clear about what they would like and now cannot have it.

Ms McKinnon: It is. It is a limitation, and all these safeguards to some extent are limiting the rights of the person, but they are also reasonable limitations because of the potential for abuse of this kind of regime. That is the balance that needs to be considered. Limitations can be imposed on human rights provided they are proportionate and are needed to achieve an important objective. Here, it is a very critical objective to ensure that people are not subject to pressure and abuse and not robbed of the ability to change their mind down the track. We might have a very strong view that we want something now but later on it could be an abusive process that could—

MS LE COUTEUR: I would say, though, that pressure and abuse is a different question from losing mental capacity. People can lose mental capacity without having external pressure on them.

MRS DUNNE: But we do not know whether they have changed their mind.

MS LE COUTEUR: And we do not know whether they have changed their mind, absolutely. But it is possible they have not changed their mind, particularly if they are in pain.

MRS DUNNE: I suppose one of the pivotal issues in the Victorian legislation is that it requires the individual's agency.

Dr Watchirs: Absolutely.

MRS DUNNE: It is not a process that is administered by an external agent. The person can have an assistant, but it does require agency.

Dr Watchirs: They must initiate, yes.

MRS DUNNE: And therefore—and this is the point you make, Ms McKinnon—if you had an advance care directive that followed the full continuum that, "In certain circumstances I want somebody else to do that," you cannot do that under the Victorian legislation. You have to have your own autonomy; not only your own mental capacity but, in a sense, your own physical capacity as well.

Dr Watchirs: But you would still have the advance care directive of "do not resuscitate", which is not active assisted dying.

MRS DUNNE: That is the withdrawal of extraordinary means.

Dr Watchirs: Very different.

MS CHEYNE: Going back to what you were talking about with the joint committee at federal parliament that scrutinises bills according to their human rights compatibility, within your remit as the ACT Human Rights Commission can you write, or have you ever written, to the federal parliament to say, “Hey, I reckon you’ve done a law that is really limiting ACT residents’ human rights,” and, if not, could you?

Dr Watchirs: No, we have not in 14 years.

MRS DUNNE: But do you have that power? I would not have thought so.

Dr Watchirs: We are not prevented from doing it, but there is no explicit power.

MS LE COUTEUR: You might think it might be futile but I would have thought that you could do it.

Ms McKinnon: Certainly, there have been situations where we have engaged in a process of giving advice to the ACT Attorney-General who was then in the process of negotiation with the COAG process, for example. So where it is federal legislation that might have to be brought in in the ACT in some way we would have that correspondence.

MS CHEYNE: But if there is federal legislation that obviously existed before this committee was established?

Dr Watchirs: We have done it on two occasions, to be honest, but not to the parliamentary committee because it did not exist. We did a submission on federal anti-terrorism legislation in 2005 and also the Northern Territory intervention. That intervention could have been carried out in Jervis Bay in the ACT, so it was a live jurisdictional issue.

MS CHEYNE: When you wrote those submissions who did you send them to?

Dr Watchirs: The anti-terrorism submission was direct to the federal—

MS CHEYNE: So hypothetically, you could write to the federal Attorney-General and say, “Hey, this legislation, not cool.”

THE CHAIR: Thank you both for appearing today; your insight was very worthwhile. 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. I do not believe you took any questions on notice today.

Hearing suspended from 11.59 am to 2.01 pm.

STRANGMAN, MR DENIS, Council Member, ACT Right to Life Association Inc
CAINS, MRS BEVERLEY, President, ACT Right to Life Association Inc
HOMAN, MRS MOYA, Council Member, ACT Right to Life Association Inc

THE CHAIR: I start by welcoming this afternoon's witnesses. Can you confirm for me that you have read and understand the privilege implications of the statement on the card that is in front of you?

Mr Strangman: I have, Madam Chair.

THE CHAIR: Has everyone had a chance to read it?

Mrs Cains: Yes.

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

Mr Strangman: Yes, I would. I am accompanied here this afternoon by Mrs Bev Cains, President of ACT Right to Life Inc, and Mrs Moya Homan, a member of the council of the association and a former registered nurse who worked in home-based palliative care in Canberra for more than 20 years. Mrs Cains and Mrs Homan also made personal submissions to this inquiry, being Nos 447 and 106.

We thank the committee for the opportunity to appear before you today and to answer any questions you may have. We would like to avail ourselves of the opportunity to make a brief opening statement. We thought it might be of interest to the committee to present some statistics we have developed about the submissions you received and which were uploaded to the committee's website. We are prepared to provide the secretariat with our working papers for this exercise so they can check their accuracy. There might be some minor variations here and there.

The vast majority of the individual submissions, we note, from ACT residents were opposed to euthanasia and/or assisted suicide. There were a number of submissions, about 50, that were marked "confidential" or where details of the submitter and their location were withheld among the 487 that have been uploaded.

There were also a number of submitters whose position was unclear. However, overall there were 228 submissions from either individuals or organisations that were clearly anti-euthanasia and 205 that were pro. When you look only at the ACT-origin submissions—that is, from organisations or individuals—you see there were 155 anti-euthanasia and 89 pro. This must surely indicate that there is substantial opposition by residents of the ACT to the introduction of euthanasia and assisted suicide in the territory.

When you look at the organisations that made submissions, you see that 20 were pro-euthanasia and 21 were anti-euthanasia, with 16 being neutral or fifty-fifty. One could conclude that your committee has succeeded in attracting a reasonably balanced spread of evidence on which to base your report. But it depends, of course, on what information you choose to accept. Thank you.

THE CHAIR: Thank you. Ms Le Couteur, would you like to start the questioning?

MS LE COUTEUR: I have in front of me, from your submission, at page 10, your definition and discussion of "hope". One of the things that strikes me is your definition that "true hope has no room for delusion". I would have thought, in the circumstances—certainly as proposed by the Victorian legislation, where you have to be within six months of expected death from a life-terminal illness—if true hope has no room for delusion then the people who might possibly be seeking assisted dying would not be in the position of having hope without delusion. They have a fairly certain fate. Given this, I am not quite sure why you say that assisted dying would never be appropriate?

Mr Strangman: I am not quite sure I understand the question, Ms Le Couteur. We wrote that in the context of the submission. Originally, I was not terribly impressed about the role of hope in someone who had a terminal illness. I was kind of referencing my own experience with my late wife, who died from a primary malignant brain tumour. Later on, when I was involved in this organisation of which I was the foundation chair, the International Brain Tumour Alliance, my colleague from the United Kingdom started talking about hope. She got this quote from Dr Groopman, who is an American. I am not quite sure what you are driving at. You may have to repeat it.

MS LE COUTEUR: What I am saying is that I think you are saying that you see hope as an important thing for dealing with life-limiting illnesses. After that you say that it would be very dispiriting for them to know that a fellow resident in a hospital or nursing home has abjured hope and proposes to make use of state-sanctioned euthanasia.

Given your belief that hope is important and the definition which says "true hope has no room for delusion", given that those for whom voluntary assisted dying would be applicable would be those who have a clear prognosis of death in the reasonably near future, I am asking how are we expecting these people to take on "hope with no delusion" as an alternative to looking at possibly death?

Mr Strangman: It is still not too clear to me, but I will answer it as best I can. Unfortunately, I am familiar with hope in the area of terminal illnesses. A lot of people who develop a malignant primary brain tumour have contacted me over the years. Sometimes they express hope, and it takes various forms. It can be realistic hope or unrealistic hope. They talk about, say, new therapies. I might know something about it and I say to myself, "Well, they're going down a dead end there," but I do not try to destroy the hope that they have put on that particular therapy.

You seem to be making a comparison with "true hope has no room for delusion". This is Dr Groopman that I am quoting, not necessarily myself. What he, I think, was alluding to was that you can fasten onto hope, but it has to be realistic. I do not quite see how that gels with a person involved with euthanasia or assisted suicide.

MS LE COUTEUR: I guess that is my point: it does not really gel that once you have reached this situation there is not much true hope around except possibly to end your pain.

Mr Strangman: If pain is the characteristic of the person at that stage; not necessarily in all the cases.

Mrs Cains: Moya has spoken to us about the hope people have. Sometimes it is long term. She can make a good contribution.

Mrs Homan: I worked in home-based palliative care services for over 20 years. I spoke to my colleagues just recently. When a patient is first diagnosed with cancer, they have a long-term hope that they will recover. As their condition changes, that reduces. Things close in so that they might just have hope that they will make it to Christmas. They might have hope that they will have a good week. Then that will gradually reduce until there is the hope that they have good sleep tonight. Those things change and close down. But they can still have hope that they will have a comfortable, peaceful death.

MRS DUNNE: So what you are saying is that hope is a calibrated thing.

Mrs Homan: It changes.

MRS DUNNE: That changes in the course of an illness.

Mrs Homan: That is right.

MRS DUNNE: One's expectations or hopes at one phase may be quite different but still satisfying or consoling, even in the later stages of illness.

Mrs Homan: Yes, correct. That is right.

MS CHEYNE: Can't someone also hope for a peaceful death by way of voluntary assisted dying?

Mrs Homan: No.

MS CHEYNE: Why not?

Mrs Homan: Because if they have very good palliative care, where their symptoms have been controlled, they do not need euthanasia or assisted suicide.

MS CHEYNE: We heard yesterday from nurses that there are some cases where palliative care simply is not enough. What about for those people? Should they not have an option to exercise their desire to have a compassionate, peaceful, or as comfortable as possible, death? If there is not palliative care that relieves their symptoms then that seems to me like there is a destruction of hope for them to have that death. So would not giving them another choice give them that hope back?

Mrs Homan: In my 20 years of working with these dying patients, I can always say that no-one needed euthanasia because we managed these symptoms. It is not only pain that they have. They might be lonely; it might be emotional or psychological stress. But I honestly say that we were able to help those people. They did not need to resort to euthanasia.

MRS DUNNE: On that topic—I think this is a question for Mrs Homan because you have on-the-ground experience—in your experience, have you encountered patients in the palliative care process who at various stages have said, “Just let me die. Just give me something to make me die,” and then have changed their minds with treatment and appropriate intervention?

Mr Strangman: I think Mrs Homan is trying to go through in her mind the 1,000-odd patients she dealt with over 20 years.

MRS DUNNE: I will put it in another way. You have had a lot of patients. Did people who say, “I just want to die. I just want to end it now,” stick out in your memory as being a significant number of people?

Mrs Homan: Not a significant number, no.

MRS DUNNE: A small number?

Mrs Homan: I would say maybe a small number, yes.

MRS DUNNE: Of those people, is it your experience that they persisted in that view if they were receiving appropriate palliative care?

Mrs Homan: They did not persist. If they were made comfortable and felt safe they would not persist.

MRS DUNNE: Thank you.

THE CHAIR: Mrs Homan, were you a palliative care nurse?

Mrs Homan: Yes. I worked in a home-based palliative care service.

THE CHAIR: In the ACT?

Mrs Homan: Yes.

THE CHAIR: Okay. Thank you.

Mrs Homan: ACT Health, yes. A lot of the time I was in an on-call job. I would be called out at night. I could go anywhere in the ACT and deal with people who were dying or who had problems overnight, as well as during the day.

THE CHAIR: I just wanted to clarify that. Thank you so much.

MRS KIKKERT: Sometimes when people send in their submissions to an inquiry, they feel that they have forgotten to insert something. Is there something that you want to add that was not in the submission?

Mr Strangman: Not for me as the author, but I have talked to Mrs Cains several times and she has one or two things that are of interest to her that she might like to add to the submission.

Mrs Cains: I would like to say that we do not want to give the doctors the call to say who is going to live and who is not going to live. Doctors are trained to treat the symptoms, not life. Life is never a disease. Death is never a cure. Death can be humane and dignified. Euthanasia is killing, whether it is assisted suicide or plain, straight-out euthanasia.

Any state government who is about to change laws concerning the killing of innocent people should consider their responsibilities. The responsibility is not only to the ACT but to all Australians and indeed to the international community. I think that we often compare our society in some ways to that in the UK. The British House of Commons debated this bill in 2015, having debated it 10 years earlier, when it was thrown out. After 10 years—and might I remind you how close England is to the Netherlands and Belgium—the vote in the Commons was 330 to 118, three to one. It was thrown out because people had time to contemplate and realise the problems with euthanasia in the other parts of Europe.

I would like to put on the record that since Mr Strangman's retirement, he has been an untiring voluntary worker in the sector of palliative care and his brain tumour organisation, and indeed, with his submission and work for this committee. I would like to thank him deeply, which I have done, but it is good to have it on the record that all of that work was voluntary.

Mr Strangman: Thanks for that, Bev.

THE CHAIR: I want to go both to your opening remarks, Mr Strangman, and to your submission. In your opening remarks, you stated some interesting numerical facts about submissions we have received, which was fabulous, and concluded that the submissions received were a balanced view. Yet in your submission, you say that basically you believe that this committee is only looking at euthanasia, even though we are saying that we are looking at end of life care choices.

I was just wondering if you can explain to me why you feel that that is the case. We have heard evidence given. We are really interested in hearing about palliative care options. We are really interested to hear about advance care planning options and those sorts of things. I was just wondering why you mention that in your submission.

Mr Strangman: In reply to your question, Madam Chair, we were trying to work out what exactly was the overall coverage of your inquiry, what the areas were that you are looking into. As I said in the written submission on behalf of the association, the use of "end of life choices" in the committee's title disguises the fact that the inquiry is primarily about euthanasia and assisted suicide. This is reinforced by four references to voluntary assisted dying in the committee's terms of reference and its mention of the Victorian legislation as a reference point. I went on to say:

> "Voluntary assisted dying" is not a neutral term, it is the terminology of choice by those who are pushing for the introduction of euthanasia and assisted suicide …

I realise the terminology is a thing that has bedevilled this debate, and of course people will choose their own terminology depending on where they are coming from. What is of interest to me is that just a few weeks ago, the American Medical Association reported on a two-year inquiry into what would be the appropriate language to use to advise their doctors. They rejected requests to replace the phrase "physician assisted suicide" with "aid in dying" in official AMA literature or policy statements. I have a copy of their ethics committee report, which says:

> … in the absence of a perfect option, CEJA believes ethical deliberation and debate is best served by using plainly descriptive language.
>
> In the council's view, despite its negative connotations, the term "physician assisted suicide" describes the practice with the greatest precision. Most importantly, it clearly distinguishes the practice from euthanasia. The terms "aid in dying" or "death with dignity" could be used to describe either euthanasia or palliative/ hospice care at the end of life and this degree of ambiguity is unacceptable for providing ethical guidance.

So I do not at all assert that your committee has no place in discussing palliative care or talking to or questioning witnesses about it. I think it is very relevant to your inquiry.

THE CHAIR: Absolutely. It is extremely relevant. It is about end of life care choices. It is about what is best for people. It is about choice.

Mr Strangman: Yes, but, Madam Chair, you cannot ignore the history of the use of the term "end of life choices". In America, the original euthanasia group was known as the Hemlock Society. They must have thought that that was not a very attractive name and they changed themselves to the End-of-Life Choices organisation. Then later they changed that to Compassion & Choices. But if you look at the American situation, there are still state organisations in America that call themselves End-of-Life Choices. So it has that historical context, a kind of presuming that it is all to do not so much with palliative care and euthanasia but exclusively with euthanasia and assisted suicide.

THE CHAIR: We had evidence this morning from the Human Rights Commissioner, who stated—I am not going to be giving her words justice—that they had decided from a human rights perspective and from a choice perspective, in ensuring that the citizens of Canberra were given rights, that "voluntary assisted dying" was a better term to use. I believe that is the terminology used in the Victorian legislation, from memory, as well.

Mr Strangman: Yes. You are talking about the Human Rights Commissioner for the ACT?

THE CHAIR: Yes.

Mr Strangman: I did not hear her evidence or look at it on the television feed, but I think what is very relevant—I do not know whether she talked about this—is that some people do argue about the interconnection between the right to euthanasia or the right to assisted suicide and the United Nations conventions which Australia is a party to. This is a document which I think is very useful. It is from the joint human rights committee of the federal parliament, scrutiny report 9 of 2017. They say:

> The compatibility of voluntary euthanasia—

that is the term they are talking about, which I do not agree with—

> with international human rights law is not settled. The UN Human Rights Committee has made clear that States are obliged 'to apply the most rigorous scrutiny to determine whether the state party's obligations to ensure the right to life are being complied with', including stringent safeguards.

They also say:

> The European Court of Human Rights has held the right to life cannot be interpreted as conferring a right to die, and has further held that the right to life could 'not create a right to self-determination in the sense of conferring on an individual the entitlement to choose death rather than life'.

I think those findings, that attitude, by the UN Human Rights Committee need to be borne in mind when you are relying on human rights conventions to buttress your position.

MRS DUNNE: Could I ask you, Mr Strangman, if you could provide either that paper or the reference for the use of the committee.

Mr Strangman: Definitely, Mrs Dunne. There is a copy of it there.

MRS DUNNE: I do not want to take your only copy.

Mr Strangman: No.

Mrs Cains: Could I, through the chair, make a comment? Former Prime Minister Keating said:

> The justifications offered by the bill's advocates—that the legal conditions are stringent or that the regime being authorised will be conservative—miss the point entirely. What matters is the core intention of the law. What matters is the ethical threshold being crossed. What matters is that under Victorian law there will be people whose lives we honour and those we believe are better off dead.

They are quotes from Paul Keating, and I think that that is what is being said in a nutshell.

THE CHAIR: I am not sure that that was part of what I asked, but thank you for your insight. That was very worthwhile.

MRS DUNNE: I want to go to something that is not really in your submission, and that is about the modality of implementing legislation like this if it were implemented. We know, for instance—the committee heard it when we travelled to Victoria, and it was touched on yesterday by the palliative care specialist from Calvary, from the Little Company of Mary—that the modality of bringing about death was uncertain and that in fact there is no registered or approved drug therapy yet in Victoria, so the legislators signed up to something without knowing how it would happen, and some of the drug therapies have been particularly problematic.

The palliative care specialist said in evidence yesterday that it was very difficult to kill somebody. I think I know the answer to this, but I was just wondering whether your association had views about whether or not legislators should sign up to something like this without knowing the full ramifications of what they are doing.

Mr Strangman: Thanks for the question, Mrs Dunne. I watched as much of the live feed as I could and heard a lot of the witnesses who have appeared before you already, but even before that it was very clear to me that there is no bill on the table. You are referencing the Victorian legislation and you are talking about other jurisdictions. There is no bill on the table that you are asking us to analyse.

Having mentioned the Victorian legislation as though it is the panacea, it is the answer, I have tried to inform myself of what the Victorian legislation actually means, its history and its origin. That is the act—130 pages. You told us earlier, I think, that you had been to Victoria and spoken with people. It is very interesting as to whether you know exactly what is in this legislation or its ramifications and its history. I do not know.

I went through all the amendments that had been moved to the legislation, both in the Victorian Legislative Assembly and in the Victorian Legislative Council. You may be interested to know that there were 360 amendments defeated in the Legislative Assembly; no amendments were accepted. In the Legislative Council there were 18 amendments that were moved and were defeated and 39 agreed to. That brings a total of 417 amendments that were moved to the bill before it became law, of which 378 amendments were defeated, either in the Legislative Assembly or in the executive, and only 39 agreed to.

I tried to look at the draft bill as it was introduced, the amendments that were made to it, and then the final legislation, in order to identify what might still be the deficiencies in the Victorian legislation now that it has become an act. I have spoken to people that were intimately involved with that discussion down there.

You alluded to some of the deficiencies. My understanding is that in relation to the Victorian legislation there were five principal deficiencies. First, there was a failure to adequately fund palliative care services. They identified that there was a $65 million shortfall in funding for palliative care services in Victoria. The legislation has been passed, but the money has not been forthcoming. The question of safeguards, No 2, was not dealt with adequately.

The proposed review provisions for psychological assessment were clouded. There is the risk that people with depression can activate the regime due to the episodic nature of their condition. Indigenous persons with high disability rates are particularly vulnerable. There is a significant risk of elder abuse. There was the possibility of doctor shopping. There was suicide tourism which might occur—in other words, people coming from interstate, which may apply to the ACT—which we have alluded to in our written submission.

As I think was stated earlier, the Victorian parliament approved the legislation without having chosen the legal drug. That in itself needs to be explored if you are going to introduce that kind of regimen into the ACT. What is it going to be? Dr Nitschke, the founder of Exit International Australia, originally was advocating asphyxiation of patients who wanted to kill themselves by putting plastic bags over their head, but now the drug of choice is Nembutal, which is commonly used by veterinary doctors.

I have had experience with overseas drugs where we were looking at drugs and the proprietors who manufactured them, and whether or not any of those pharmaceutical companies were also involved in distributing and manufacturing the lethal cocktails distributed to penitentiaries in the American situation who wanted to execute people on death row. None of that has been gone into. There have been stories of very much botched executions in the United States, drastic things that have occurred. They have been about on television and in other interviews et cetera.

I think the veterinary people have an interest in the subject, as it were. We know they are interested in it, but they have a proprietorial interest insofar as they want ready access to Nembutal to kill the dogs and cats and other animals that may be in a very diseased state. They want easy access and ready access, but the veterinary community are not prepared, in my opinion, to accept tighter controls over that drug, and therefore it can be stolen and easily got into the community.

MRS DUNNE: Is the association aware of issues that have arisen with the cocktail of drugs being not particularly satisfactory? We did hear some reference to that, both from St Vincent’s in Melbourne, I think, and from the palliative care specialist from Calvary, in the context that it is not easy to kill somebody. Sometimes the cocktail is not particularly efficacious and can make people sick et cetera, sicker than they already are. Is the association aware of literature in that space?

Mr Strangman: Not immediately, Mrs Dunne. I would have to do a bit of a search and convey it to the committee if I find it.

MRS DUNNE: I am not asking you to do that. That is fine.

Mr Strangman: I did hear the palliative care doctor say that palliative care doctors are not very good at killing people.

MRS DUNNE: Killing people, yes. I think that is what he said, yes.

THE CHAIR: I would like to thank you all for appearing today before the committee and providing your insights. It was very much appreciated. When available, a copy of the proof transcript will be forwarded to you to provide an opportunity to check the transcript and, if necessary, suggest any corrections. Mr Strangman, were you going to leave that information for Mrs Dunne and the committee?

MRS DUNNE: We have got it already.

THE CHAIR: Excellent. Thank you so much.

MRS DUNNE: Thank you for your participation and your analysis.

Mrs Cains: Thank you.

Mr Strangman: Thank you very much for having us.

WONG, MS RACHAEL, Managing Director, Women’s Forum Australia

THE CHAIR: I welcome our next witness, Ms Rachael Wong from Women’s Forum Australia, via phone. Can you confirm for the record that you have read and understand the privilege implications of the statement that was emailed to you?

Ms Wong: Yes, I have.

THE CHAIR: Thank you. Before we proceed to questions from the committee, do you have an opening statement you would like to make?

Ms Wong: I do have an opening statement. Good afternoon, everyone, and thank you for inviting me to address you today. The Women’s Forum Australia is an independent think tank striving to create pro-woman cultural change in Australian society through research, education, mentoring and advocacy, with a particular focus on addressing behaviour that is harmful and abusive to women.

When addressing various issues affecting women, we take particular care to examine the root of a problem and try to find solutions for this, rather than simply treating its symptoms. This is especially relevant to the issue of assisted dying. Our concern for the dignity, freedom, rights and wellbeing of women ultimately comes from a deeper concern for the dignity, freedom, rights and wellbeing of all people and the families and communities that they are a part of. We believe that in raising up women, we also raise up men, children, families, communities and society.

With that in mind, I would first like to reiterate the start of our research note, which highlights general concerns around instituting euthanasia and assisted suicide as standard medical practices that will affect both men and women and our society as a whole. These include the normalisation of suicide; the risk of coercion or pressure to end one’s life; the risk of non-voluntary and involuntary euthanasia; the inevitable expansion of conditions for eligibility as seen overseas, depending on how the state views which lives are valuable and which are no longer worth while; the risk of people’s lives being ended based on inaccurate medical diagnoses or prognoses; the concern that those suffering may be inhibited from giving truly informed consent to their lives being ended; a decreased incentive to develop palliative care; and the fundamental shift in the practice of medicine and the nature of the doctor-patient relationship.

These concerns can be summed up as critical concerns about whether decisions to end patients’ lives will be truly autonomous, free and voluntary under a legalised assisted dying regime; whether such a regime will devalue the lives of certain citizens, particularly those who are old, sick, disabled or depressed; and whether it will overlook and prevent us from addressing the real issues that cause individuals to want to end their lives and extending our genuine care and compassion to them when they need it most.

However, what is especially concerning for us is that these concerns, particularly those around autonomy, may disproportionately affect women. As our submission explains, there is evidence to suggest that there are certain gender-specific risks that may thwart women’s autonomy in end of life decisions and may make them particularly vulnerable to assisted dying laws.

We already know that as a result of various biological and cultural factors, women are disproportionately affected by issues like elder abuse, homelessness, other economic disadvantage, domestic violence, sexual exploitation and depression. These issues could contribute towards women wanting to end their lives because of the suffering caused by such circumstances. It is also reasonable to consider that they may form part of a more subtle pressure on women to end their lives.

For example, if a woman is suffering financially and feels like a burden to her loved ones, is her decision to end her life really a free, autonomous choice or is it the result of entrenched economic disadvantage outside her control? If a woman requests to end her life but has been suffering elder abuse, domestic violence or some other form of abuse, which may also have led to depression or other psychological issues, is the most compassionate and reasonable response to respect her decision to die or to provide her with the help and support she needs to deal with these underlying problems?

It may be maintained that we are talking about people with terminal illnesses, but I would like to point out that women with terminal illnesses can still be affected by such issues which could ultimately affect their ability to make a truly autonomous choice when it comes to assisted dying. Furthermore, we have seen in places like the Netherlands that the requirement of having a terminal illness does not endure once the line has been crossed to allow assisted suicide and euthanasia.

We believe that there are enough serious concerns, questions and doubts raised by the literature on this issue and the evidence coming out of jurisdictions where assisted dying is already legal to deter the ACT from introducing similar laws. There is at least cause for pause to further consider the gender risks we have raised and to undertake further research before any legislative change.

THE CHAIR: We will start the questioning with Mrs Kikkert.

MRS KIKKERT: Thank you, Ms Wong, for joining us by phone. My question relates to the statement in your submission that women may be uniquely vulnerable to euthanasia and assisted suicide laws. This is quite new to me. You mentioned that women are more likely to attempt suicide than men as they are more prone to psychological problems such as depression. You are concerned that that may actually increase if euthanasia is put into place. Can you expand on that?

Ms Wong: It is not necessarily that psychological problems or the tendency to commit suicide will increase. Rather, the fact that there is already a tendency to attempt to commit suicide means that allowing assisted dying may compound women’s already existing disposition to want to end their lives. I guess it may make it easier for them to do so.

MRS KIKKERT: Having said that, do you think that that belief may also extend to youth who are in a very desperate time in their life and want to end their life? Would that be safe to say?

Ms Wong: Sorry, could you clarify the question?

MRS KIKKERT: You believe that women may actually feel the need to end their life if euthanasia is in place. Do you also believe that that belief might extend to teenagers who are depressed and lonely and in a very dark time in their life, that they might also want to end their life?

Ms Wong: Absolutely. I think that is also a risk that would apply to struggling youth. As with women who may have a high tendency to try and end their lives, I think that having the option of euthanasia and assisted suicide for struggling young people may be a risk to them as well. Even if they may not be able to access assisted suicide for particular legal reasons at the time, I think it could normalise suicide for them or make it more acceptable.

MS CHEYNE: Your submission sets out a number of characteristics about women and relationships, including the power imbalances that can occur in a clinical setting. I think you have a bit of a theme that these might create a situation where women accessing voluntary assisted dying might not be acting with autonomy. Do you think there are any safeguards, or any level of safeguards, which would effectively guard against that situation happening? How appropriate are the safeguards in the Victorian legislation in guarding against that?

Ms Wong: Sorry, I missed the last part of the question, the Victorian situation?

MS CHEYNE: Victoria has its scheme. I think it has 67 safeguards in it. In your view, do those safeguards go to reducing the likelihood of women accessing the scheme without autonomy?

Ms Wong: Because the various risks to women are so embedded in our society and so wound up in various biological and cultural factors, it is quite difficult to safeguard against them. In terms of what we have seen in other jurisdictions and even in Victoria, I do not think the safeguards that have been put in place are going to be able to safeguard women in relation to their autonomy in terms of all the different risks that are out there for women.

MS CHEYNE: Hypothetically, if legislation were to go ahead or a scheme was to be established—just imagine that was happening—from your perspective, what safeguards would you want to see absolutely contained in that legislation?

Ms Wong: If I knew the legislation was going to be inevitable then I would want to see things like counselling. I would want to see that any other issues that women are suffering from—people in general but obviously we are talking about women here—are being addressed. Whether it is situations of domestic violence or poverty or psychological issues, I would want to see those being addressed before any request for assisted suicide or euthanasia was granted.

I think that in an ideal world we would be looking at all these different factors before introducing any sort of dying legislation. And we could see whether or not addressing these factors actually makes a difference, whether or not people want to take their lives or end their lives.

MRS DUNNE: I want to go to some of the issues that you have raised in your attached research note. I was wondering whether you could elaborate on the issues that you raised about the prevalence of what is called mercy killing but without consent. It says here "often perpetrated by men and often without consent of the female partner". Could you elaborate on that and the research?

Ms Wong: I am not really sure what more you would like me to elaborate on but an interesting thing we noticed in some of the research that we have found was that in relation to mercy killing there were more women who had been the victims than there were men. We addressed the concern of imbalance and the structure in place where this sort of thing is happening. It could, in a way, be quite analogous to a situation of euthanasia or assisted suicide or could at least be affected by some more variables and factors.

It was really just to point out that there has been some research done which notes there is an issue and before going ahead with amending legislation on assisted dying it would be good to explore this further to make sure that certain gender dynamics which are affecting the figures—things like mercy killings—are not also going to affect assisted dying laws as well when it comes to women.

MS LE COUTEUR: I read your submission with great interest, and a lot of the points rang true. It struck me to an extent, though, that what your submission was, in our context, was a request for more funding, more nursing homes, retirement aged care and palliative care. You made the quite reasonable points about women tending to outlive their partners and tending to have fewer economic resources. While this was not part of your submission I wonder if where you possibly felt we should be going is to have more resources for these things.

Ms Wong: Absolutely. I think that goes back to the point that I made before in relation to someone else's question. If we are able to address things like various economic disadvantages, whether it be for women or men, as you do with palliative care, and if we were to address end of life decisions—with those things in mind first and see what kind of difference that makes—I think that is the best thing we can do before implementing laws which allow people to end their lives without necessarily having these things addressed or without having them, I guess, adopted in practice or actually addressing these people's issues.

MS LE COUTEUR: And do you think that, if there was better availability of these things, if some of the economic issues were gone, the potential harm as you see it to women would be ameliorated?

Ms Wong: Sorry, can you repeat that last part?

MS LE COUTEUR: If there was less economic inequality, better provision of palliative care, nursing homes etcetera—if those practical economic issues were addressed for both men and women, but in particular women, given your submission is for women, do you think that there still would be risks for women that do not exist for men in any proposal for voluntary assisted dying?

Ms Wong: I think the risk would be ameliorated. As I said before, I think it is impossible to create safeguards that completely safeguard people in situations where they are actually thinking of dying. I think also in our submission, which I brought up before, we noticed things like women’s high tendency to have psychological issues and other various structural inequalities when it comes to their relationships with men and obviously links of age and that sort of thing. I think that it is more than just the economic issues.

MRS DUNNE: You did mention in passing that there was a—I think it was you; correct me if I am wrong—tendency in other jurisdictions to move from terminal disease to loosening up of the availability of euthanasia, however described. Do you see that as a particular problem or a particular danger from this gendered point of view that you have raised?

Ms Wong: Yes. For example, if we go back to the tendency of women to be more likely to suffer from psychological issues, my understanding is that in places like the Netherlands—I cannot remember the exact details of their laws—not only do they allow dying in cases of terminal illness but if you have some sort of psychological problem then that could be grounds for assisted dying. If women are more likely to suffer psychological problems and there is that risk there to them that they may be more likely to request and be granted assisted dying, the issue that needs to be addressed is to do with the depression or the anxiety or whatever that they are facing.

MS CHEYNE: On notice please, if I may, in the research note, at point 9, and throughout your submission you quote extensively from the George 2007 article. One of your main points that you draw from that is that the majority of high profile euthanasia and assisted suicide cases are female. I very much appreciate that you have given the reference and the page numbers there but I have just been reading that article and I cannot quite find that. If you are able to maybe highlight that for us that would be extremely helpful for me.

MRS DUNNE: I have just found the article but have not started reading it.

MS CHEYNE: Would that be all right?

Ms Wong: I think there is a page reference. Would you like me to send that to you?

MS CHEYNE: There is a page reference but even on that page I cannot find where you have drawn that from. It might just be the time available and my poor reading, but that would be extremely useful.

MRS DUNNE: Also, the online version does not really have reliable page numbers.

Ms Wong. I will find that, and I will give that separately, if that is okay.

MS CHEYNE: Thank you.

MRS DUNNE: Thank you.

THE CHAIR: Thank you so much for your time today. We really appreciate you taking the time to talk to us. When available, a copy of the proof transcript will be forwarded to you to check and provide any corrections if required. I note that you took on notice to provide the committee with the article. That would be wonderful. If you could seek to do that over the next two weeks, we would be extremely grateful for that. I would like to again thank you on behalf of the committee for your time today and for your submission and your insights today.

GILLESPIE, ASSOCIATE PROFESSOR ARNOLD, National Convenor, Doctors for Assisted Dying Choice
LEAF, DR DAVID, State Convenor, Doctors for Assisted Dying Choice
LUGG, ADJUNCT PROFESSOR RICHARD, State Convenor, Doctors for Assisted Dying Choice

THE CHAIR: Thank you for appearing today via telephone link. Because we are doing this over the telephone today, I would like to confirm for the record that you have understood the privilege implications of the statement that was emailed to you.

Dr Leaf: Yes, I have.

Prof Gillespie: Yes.

Prof Lugg: Yes.

THE CHAIR: Thank you. Before we proceed, would any of you like to make a brief opening statement to the committee or are you happy to go to questions?

Prof Gillespie: I have a very brief opening statement, just to outline exactly what Doctors for Assisted Dying Choice is. It will take 1½ minutes.

THE CHAIR: That would be wonderful. Thank you, Professor Gillespie.

Prof Gillespie: Doctors for Assisted Dying Choice is a national organisation of medical practitioners from every state and territory who believe that rational adults who have an illness which is causing intolerable suffering and for which there is no reasonable cure or relief should have the legal right to end their lives at a time of their choice and with those whom they wish to have present. Our activities, statements and writings are always evidence based. We think this is quite important. In this endeavour we are in major contrast to some other medical organisations and opinion-biased groups.

With respect to the way we run it, we have convenor groups in each state who monitor and comment on actions relevant to assisted dying in each of their own states. To coordinate national activities, lead members from each group have an online audiovisual meeting every fortnight. A member of a group from New Zealand with similar views to ours also attends that meeting.

Here today, our group has convenors from three Australian states. You have already met Adjunct Professor Richard Lugg from Western Australia. We have Dr David Leaf from New South Wales, and I am Associate Professor Arnold Gillespie from South Australia. Each of us has been involved in discussions in our state when bills have been presented or inquiries are being conducted. We hope that our experience from these will be of assistance in the deliberations of the committee here today.

THE CHAIR: Thank you so much, Professor Gillespie, for your words. I will ask what is, hopefully, a very quick question. In your submission you have stated “to have control over pain relief and other symptom control”. Yesterday we heard evidence from a palliative care specialist that there was no circumstance where pain cannot be managed during end of life. I was wondering whether one or all of you would have a comment in regard to that, noting that in your submission you do believe that there is sometimes—

Prof Gillespie: David, you can talk on that, please. You are at the coalface of management every day.

THE CHAIR: Dr Leaf, thank you. We would love you to respond, as Professor Gillespie has indicated.

Dr Leaf: I am a senior GP from New South Wales. I have been in practice for 24 years and I am an examiner for the Royal Australian College of GPs in rural and remote medicine. I am the New South Wales state convenor. We are familiar with these claims by some palliative care physicians. However, it is at odds with both their own national Australia and New Zealand palliative care society's evidence and the international evidence. It would actually be the first medical specialty any clinician has ever seen where they had the answer to all complaints all the time.

In fact, when we look at international data, pain is in the top three reasons that people choose assisted dying. In Oregon, for example, it is other reasons people choose, such as existential crisis and dyspnoea, which is shortness of breath. These are symptoms that simply cannot be controlled by palliative care. In my view, as a clinician, it is a non-evidence-based and reckless claim to say that you can control symptoms in all patients. The evidence says that in about one in 20 patients they cannot be fully controlled.

The other point that is very important to make is that many patients who choose assisted dying do not want to enter the palliative methods of care in the first place. They want to elect to end their lives before they need pain injections and those sorts of things. I hope that answers that part of the question.

THE CHAIR: Thank you. Professor Lugg, I note you were also interested in saying something in regard to that.

Prof Lugg: Yes. I am a public health physician in Western Australia. I want to add to what Dr Leaf has said by saying that I have been in touch with the Palliative Care Outcomes Collaboration, PCOC, to obtain information on this. They have provided me with information which I can send to the committee which shows that 5.2 per cent of patients entering the terminal stage of palliative care have severe symptoms which are intolerable to them.

THE CHAIR: That would be very interesting. If you could provide the committee with that information, we would be very grateful.

MRS DUNNE: I am opening this question up to whomever would like to answer it. In your submission you refer to the qualities of a good death. There is a 10 or 12-point list in your submission. In the current regime, as it stands in the current legal situation in places everywhere except Victoria—actually, still practically in Victoria—to what extent are we, as public officials and health officials, failing to provide those characteristics of a good death, and how, short of this legislation, do we go about ameliorating those?

Prof Gillespie: I did not get most of that. Did either Richard or David hear what was being asked there?

MS CHEYNE: Richard or David, did you hear the question?

Prof Lugg: Yes. In our submission we give several advantages where there would be improvement obtained. For example, the availability of voluntary assisted dying would enable more people to die at home, which is the place where most people prefer to die and where so few actually do die. The same is true with having more sense of control. A sense of control of their destiny is a very important component of a good death. The option of voluntary assisted dying does provide that much more effectively than most of the existing options that are available to them. There are in fact a number of ways in which voluntary assisted dying would improve the options and provide a better sense of patient autonomy to the dying patients.

Dr Leaf: I see it as my role, as a front-line clinician, to give patients options. Infrequently, I might add, but with monotonous regularity, patients ask about it—that is, voluntary assisted dying. It seems to be, if I can say, the elephant in the room; it is the thing that a lot of people are thinking about but refuse to bring up or discuss because of all sorts of fears—being arrested and whatever. There is clear evidence from international jurisdictions that the medical facilities that are able to offer voluntary assisted dying as part of a suite of options find it to be an adjunct therapy; that is to say, it assists them in offering patients options rather than being a standalone.

From a patient's point of view, it gives the patient clear options. It also allows them the freedom to discuss it with their clinicians. Some international data has recently been published, and I know it has been submitted to your committee and Western Australia, by Neil Francis. They have looked at jurisdictions around the world where voluntary assisted dying is legal, such as the Netherlands, versus jurisdictions where it is not legal, such as Italy. They have looked at the frequency of medically inappropriate decisions being made by the treating doctors. Those are things like terminal sedation without consultation with the patient, initiation of tests and investigations without consultation with patients or relatives. It is very clear, to a large extent, that in those jurisdictions where voluntary assisted dying is legal, the frequency of medically inappropriate decisions is much less than in those jurisdictions where voluntary assisted dying is illegal, such as Italy. So the existence of these laws not only benefits the patient directly; they also make the clinician perform better. This is measurable across multiple jurisdictions, not just in the Netherlands. I think this is a very important point.

MRS DUNNE: It may be an important point, but it was not an answer to the question I asked. As people did not seem to hear it, Madam Chair, I will put it in writing to be sent out to the participants.

MS CHEYNE: You make the point that a number of quite prominent medical organisations oppose voluntary assisted dying, like the AMA, but that they do not represent the majority of doctors. In your submission you said that 70 per cent of doctors are not members of the AMA. But I am also aware that at the end of your submission you have many names attached to it, and obviously we have three of you on the phone today. Do you have any figures on how many doctors are part of your organisation and what percentage of the medical profession you represent?

THE CHAIR: Professor Gillespie, did you hear that question?

Prof Gillespie: I must say, I have a very bad line. I think it referred to the fact that other organisations are opposed to assisted dying. Is that roughly it?

MRS DUNNE: Madam Chair, I suggest that this is not a very productive use of the time of the witnesses. Could we suspend and find a time to come back—

Dr Leaf: Can I interrupt, please, because I heard the question very clearly, and I can answer it, and I do not consider this a waste of my time at all. The AMA represents 30 per cent of doctors, probably 28 per cent. The Royal Australian College of General Practitioners, which is the only specialist college that has a position on voluntary assisted dying, represents about 30,000 to 35,000 general practitioners. And whilst not all of them will support voluntary assisted dying, the Royal Australian College of General Practitioners has an agreed position in favour of voluntary assisted dying, as does the national nurses and midwives association.

The AMA tried to do a study looking at its members, which is a biased sample immediately, and they found approximately 50 to 60 per cent of their members were in favour of it if it was legal. That is the best data we have in Australia.

MS CHEYNE: Some of the submissions made to the committee have argued that legalising voluntary assisted dying would be contrary to doctors' duties towards their patients or that it would degrade the doctor-patient relationship and also that it is incompatible with palliative care and—I am paraphrasing here—would almost defeat the purpose of palliative care. Are any of these statements true? If not, how will voluntary assisted dying fit with doctors' duties?

Dr Leaf: If we refer to the evidence again, the evidence from jurisdictions where doctors can offer voluntary assisted dying is that patients have no negative feelings about their doctors whatsoever. In fact, they feel it enhances their relationship. We feel voluntary assisted dying, if the patient wants it and qualifies, is a form of care and, therefore, it fulfils our role. In answer to your question about palliative care, in jurisdictions where voluntary assisted dying is legal, palliative care does nothing but flourish. No-one internationally claims that voluntary assisted dying replaces palliative care, and it never has in any of the jurisdictions. It enhances it and should be used as well as or instead of for those who qualify.

On a personal note, when I am struck by a patient who would ordinarily fulfil the international requirements and probably the Victorian ones, and I cannot offer that, I feel clinically impeded by the law. This is an area where our politicians are out of step with the Australian population. So I feel absolutely the reverse—it would not adversely affect relationships with a patient. And that is evidence based.

Prof Lugg: The whole system is based on the autonomy of the patient. If the patient does not want it, it does not affect them in the least. If they do want it, it gives them an important option. It is the autonomy of the patient which is central to the VAD concept. I do not think it in any way impacts adversely on the doctor-patient relationship.

MS CHEYNE: We have talked a little during our hearings so far about doctors who wish to conscientiously object and whether that should be allowed and, if so, should doctors then be required to refer on to another doctor who might not object or perhaps refer someone to a board, for example, for it to be taken into their hands. Do you have a view on that?

Prof Gillespie: We believe doctors should be allowed to have a conscientious objection to being involved. They previously have been able to conscientiously object to such things as termination of pregnancy. But having said that, in the interests of patient care, yes, it should be mandatory that they refer on to somebody else who is able to completely give the patient full attention to whatever that patient is suffering from. I do not believe it would work if we were allowed to get the situation where doctors said, "No, I'm not involved in that. Go away." That would obviously leave the patient without any choices and they would have to persist in their miserable state in which they would be suffering.

Dr Leaf: The Australian Medical Council, which provides us with guidelines for code of conduct—it is a freely available document—clearly states that if a doctor has personal values which interfere with the free and open practise of medicine they are entitled to those values yet they should be declared to the patient during the consultation and appropriate referral be made on. This is not a question which is open for debate; it is in our code of conduct and should be part of voluntary assisted dying, as it is for every other part of medicine, as Professor Gillespie said, with regard to termination, use of contraceptive pills or various other forms of medicine.

MS LE COUTEUR: My major question is about the time lines for assisted dying. In the initial presentation I think Professor Gillespie said that most people seeking assisted dying were not suffering from intolerable physical pain but existential distress, and that, I could imagine, could occur well before a six-month diagnosis of likely death. Is this a concern to you in terms of the legislation in Victoria and what could be proposed here?

Dr Leaf: The time frame is a question that often comes up. I have regularly had patients who have been diagnosed early on with a terminal illness which is inexorable, meaning that Western medicine offers no chance of survival. Mesothelioma is a good example of that, and patients often die horribly within 18 months of diagnosis. They will suffer right through diagnosis all the way to their death with the notion that they are going to die and it is going to be terrible. Frequently they know other people who have. They also will share that with their families and their families suffer equally if not more and certainly after the person's death.

The time frame is a source of contention for us. I am not sure why six months has been agreed to in Victoria because patients suffer long before that. I would prefer to be able to offer it when it is medically clear that the patient has no chance of survival, whether that is three months before they die or 12 months.

MRS KIKKERT: You mentioned in your submission about the Victorian Voluntary Assisted Dying Act and how the death certificate should mention the underlying illness as well as to record the manner of death of voluntary assisted dying. You also go on to say that you see no reason for Victoria to record this on a death certificate. Could you please clarify which of the two you would prefer not to be included on the death certificate?

Dr Leaf: In New South Wales at least when you write a death certificate there are two components to the cause of death. One is the condition that directly leads to the cause of death—for example, pneumonia—and the next component is those conditions that contribute to the cause of death, and you might say metastatic cancer. I think every jurisdiction around the world where voluntary assisted dying is legal records their data fastidiously, particularly Oregon and the Netherlands. The use of the death certificate is but one measure of doing it. The administrative processes that go on in those countries are external to that and probably more accurate.

If it was legal in New South Wales and I had a patient where that would occur, as directly causing death I would say voluntary assisted dying or injection of lethal substance or something like that, whatever I am allowed to write. And the second component would be metastatic cancer or motor neurone disease or something like that.

Prof Lugg: The description David has given of the medical certificate applies not only throughout the country in every jurisdiction but throughout most of the world because it is a WHO-mandated form of certificate. The whole point of these certificates is to get to the underlying cause of death. To use the example David gave of mesothelioma, no matter how that person may eventually die, the underlying cause of death is going to be mesothelioma, and that should be what is on the death certificate.

MRS KIKKERT: You listed all of the doctors in your organisation. How many of them live in Canberra?

Prof Gillespie: About six doctors live in the ACT who are also members of our group. They are not amongst the most active members of our group, but certainly we keep them in contact with what we are doing and what is going on and certainly with what is going on in the ACT, although they are usually pretty cognisant of that, of course.

MRS DUNNE: Could I ask you to comment on the fact that the legislation in Victoria which has been passed has been passed without the agreement of a modality of treatment? Could you comment on that? Could you also comment on what, in your experience, would be the appropriate modality of treatment and on the contra-indications of that modality of treatment?

Prof Gillespie: David, could you do that one, please?

Dr Leaf: Yes, certainly. By “modality of treatment” I am assuming you are referring to the methods where the person will euthanise themselves. I will go on to the second part first. The preferred modality is whatever the patient can manage or prefers themselves. This is what we call patient focus, which is sadly lacking in our current legislation.

For example, as is most commonly done in Switzerland and the Netherlands, the patient ingests a substance. They just drink it. It is usually a very strong, potent drug called Nembutal. The other method of doing it is intravenous injection triggered by the patient somehow or where someone else is given permission by the patient to trigger an injection. Either way it is the same drug.

The end result is the same. The patient will simply lose consciousness and stop breathing. It is very similar to the drugs like Pentone that are used every single day in every hospital right around Australia to put people to sleep for general anaesthesia. It is a very fast-acting sedative which, firstly, puts you to sleep and, secondly, stops you breathing. It is long enough acting where the heart will eventually stop. That is the best method of doing it. I think the Victorian legislation, if my memory serves, only allows for the oral medication to be administered.

MRS DUNNE: Yes, I think that is right.

Dr Leaf: That is where I finish.

Prof Lugg: I add that it is probably not desirable for legislation to attempt to spell out in detail the modality-of-dying matter. It is really a question that is best sorted out by medical colleagues such as the college of anaesthetists or other colleges that have experience in the use of these drugs and establish protocols on a clear, checked basis. I think attempts to legislate these details probably would not be the best way to go.

MS CHEYNE: My questions are related a little more to palliative care. I noted quite strongly throughout the submission that palliative care is deficient in some circumstances. We have also heard evidence so far that some people have wanted to access the palliative care system or have been quite close to dying but have been quite negatively affected by some GPs' or by their treating physician's lack of understanding about palliative care and the support that that person requires.

With your combined experience, do you have any comment on that? If so, what do we need to be doing better to provide a better palliative care experience as part of the broad suite of end of life choices in the ACT?

Prof Lugg: I would like to answer that by saying that palliative care is always going to look after the vast majority of people towards the end of life. So it is very important that we are properly resourced and properly supported. Voluntary assisted dying legislation offers no threat whatever to palliative care. As David has indicated, palliative care flourishes where voluntary assisted dying is also legal.

In terms of what could be done in the ACT, I think one of the things you should consider is the development of a domiciliary-based palliative care service, a home-based service. I come from the city of Perth where we have an excellent service like this. It is conducted by a body called Silver Chain. My understanding is that it is somewhat the envy of other cities that do not have such a well-developed home care palliative service. That would be my recommendation for what you could consider in the ACT.

Dr Leaf: I have nothing much to add to that except to say, once again, that in every specialty, there are people who do it well and people who do not do it well. Palliative care is of course an area where we should be doing it well as often as we possibly can. I would like to reiterate that voluntary assisted dying should not be seen as any kind of threat to palliative care but as an addition to the suite of options that should be open to patients at their end of life.

MS CHEYNE: I think what you are saying there is that it is not an either/or. It is not voluntary assisted dying or palliative care—that they can exist together quite comfortably.

Dr Leaf: No, and they do in many jurisdictions around the world. One point I would like to make is whilst every jurisdiction is entitled to hold meetings like this and consider its own position, we are very lucky in Australia in that we can point to at least 15 jurisdictions around the world now where there is considerable experience and published papers on this.

We do not, to some extent, have to reinvent the wheel every time. We can look at those other organisations, other countries around the world. The Victorian parliamentary inquiry visited some of them. In doing so it gave valuable insight into other aspects of end of life care such as palliative care.

MS CHEYNE: Finally, a good portion of your submission deals with the complexities and particularly the legality regarding palliative sedation. Do you believe that any legislative changes need to be made to clarify that and what occurs?

Prof Lugg: I would like to make a comment on that. Our submission describes some of the deficiencies of palliative terminal sedation. I think it does so very graphically and very well. In general, when you compare palliative sedation with voluntary assisted dying, both of them end up with exactly the same outcome. They end up with the death of a patient.

But the journey by which the patient gets there is completely different. Terminal sedation we considered to be inferior in virtually every respect. There is no control over timing. It is often extremely distressful for relatives and it does not have the sense of control that voluntary assisted dying offers.

While we acknowledge that terminal sedation will probably persist to some extent, we would hope that the option of voluntary assisted dying, being a much superior option from the point of view of the patient and the family, would ameliorate those adverse effects to a considerable extent.

Dr Leaf: I add one more thing in repetition of something I said earlier. Using international data, in those jurisdictions where voluntary assisted dying is legal, the medically bad decisions such as terminal sedation without reference to the patient or the family occurs less in jurisdictions where voluntary assisted dying is legal. That is very clearly demonstrated. In enacting these laws, all by itself we are increasing the freedom of discussions between the patients and their treating doctors and nurses where those discussions can be had. So involuntary terminal sedation occurs less.

MS CHEYNE: You just flagged having those better conversations. Outside legislating for voluntary assisted dying, do you have any other recommendations for how we could improve the conversations in our communities and with health professionals around death and dying and ageing generally?

Prof Lugg: This introduces a whole question of advance care planning, advance health directives and that sort of thing. Around Australia, while they are available in every jurisdiction, they are notoriously poorly taken up by patients. One of the reasons is that doctors do not have the time for the proper in-depth discussions that are required with patients.

What we would advocate—we strongly suggest to the ACT that you also pursue this with the commonwealth—is to get proper medical benefit recognition of the importance of professional discussion with patients over advance care planning matters. With the presence of a medical benefit for advance care planning discussions, we think there would be a much better discussion, much more acceptance in the community, a much wider uptake of those things and a generally beneficial effect when patients come to their end of life episodes.

Dr Leaf: I would like to add that today I spent 20 minutes with an elderly lady and handed her the New South Wales government version of the advance healthcare directive. She had never heard of one before. I had to educate her about what it was, how it should be done, and let her go home and do it. That was 20 minutes on the end of a consultation of 15 minutes for other things. I will get no financial recompense for that at all. A Medicare benefits item number would be a good idea for that.

THE CHAIR: I would like to thank you all for appearing today. I note that we had some technical difficulties. Particularly with Professor Gillespie, as the author of the submission, we would reserve the right to follow up on a few questions that were unable to be heard. We may have a few more questions as we move through the series of hearings and then move on to the committee's deliberations. We would like to be able to contact you again if necessary.

Prof Gillespie: Yes, I did not have much to say here but I speak on our behalf now. We would be pleased to have further communications. Fortunately for today, I am blessed with two eloquent colleagues who could more than give responses to your questions.

THE CHAIR: Thank you so much again for appearing today. When available, a copy of the proof transcript will be forwarded to provide an opportunity for you to check the transcript and suggest any corrections where needed. I note that there were some questions that we will be providing to you. On receipt of those, the committee would hope that you could respond in approximately two weeks. I thank you again for appearing today and I apologise for our technical hiccups.

Dr Leaf: Delighted; no problem.

Prof Gillespie: Thank you very much and I thank you on behalf of the doctors group.

PROWSE, ARCHBISHOP CHRISTOPHER, Catholic Archbishop of Canberra and Goulburn

KIRK, MRS LARA, Coordinator, Marriage and Family Relationships, Catholic Archdiocese of Canberra and Goulburn

STUPARICH, MR JEREMY, Public Policy Officer, Australian Catholic Bishops Conference

THE CHAIR: I would like to welcome our next witnesses to the hearing today. Before we get started can I just confirm with the archbishop and his associates that they have read and understood the privilege implications of the statement?

Archbishop Prowse: Yes.

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

Archbishop Prowse: I am very happy to be with you today. Thank you so much for enabling us to address you. I come not only as the Archbishop of Canberra and Goulburn but also as a priest of 38 years. I have been with many people over the years in their final years, months, days and moments before and at their death, and also with their families and loved ones afterwards. I think that is an important aspect that I would like to bring to this discussion today as well.

All of us here today want to have a good death. We wish that our friends and loved ones too will feel free from distress and pain. Sometimes this does not happen, which is why some people think that a lethal injection is the best way to somehow cheat death by either killing patients at their request or by assisting their death by suicide. I think this is a fundamental mistake. That would, with the aim of avoiding distress and pain, put vulnerable people like the sick, frail and elderly at grave risk.

We have good evidence from the experience of euthanasia in different parts of the world to show some of the dangers of lethal euthanasia and we have set out some of that evidence in our submission to you, which I presume you have got access to.

Firstly, we see what happened in the Northern Territory in an Australian setting. In the nine months euthanasia was legal there the so-called strict safeguards in the territory were treated as hurdles to overcome rather than as protections for vulnerable people.

Secondly, looking at the experience overseas, we have seen an expansion in the reasons for euthanasia. For example, in Belgium we saw in 2013 adult twins seek euthanasia because they were deaf and then found they were going blind and thought life had nothing more to offer them. The twins obviously faced a terribly sad and difficult situation but one that could be addressed in another way.

We have seen euthanasia introduced for minors in the Netherlands and Belgium and we have also seen a disturbing increase in the number of people seeking death in places like Oregon, the Netherlands and Belgium.

The last important point that I would like to raise with you at the beginning here is to stress to you the importance of ensuring that everyone has access to good quality palliative care when they need it. This is very much a matter of social justice. It is a matter of social justice in the sense that in seeking the good of our neighbour and in comforting our neighbour in times of distress and trouble we should be outraged that palliative care is still not available to everyone who needs it.

Palliative Care ACT makes the point that there are “still many people who are unable to access services”. How can it be that we are contemplating lethal injections for patients when we are still not able to offer excellent standards of care to all people who need it? Once again, thank you for enabling us to address you and I would be more than happy to respond to any questions.

MRS DUNNE: Your Grace, can I start where you concluded and that is what you have characterised as our social responsibility to provide the best possible service to people when they need it. In your experience of—as you say, 38 years?

Archbishop Prowse: Yes.

MRS DUNNE: In 38 years of being a priest you would have seen lots of people approaching death and lots of people who had varying access to palliative care. Would you like to reflect on your experience of people’s access to palliative care from your point of view?

Archbishop Prowse: Yes. First of all, 38 years is a long time. I have seen a virtual revolution in the end-of-palliative-care modalities and access and the types of drugs that are available now for a whole host of illnesses, where even a few years ago there was very little available. I presume and hope that that projection will continue. My dream, my hope, for the community and this wonderful country of Australia, particularly in this beautiful city of Canberra, is that every illness in the fullness of time will be able to have sufficient and proper palliative care drugs to be able to respond. We understand there are gaps there at the moment.

Secondly, if I could speak more personally, I come to you not as an expert in medicine nor an expert in politics nor law; I come to you as a pastoral person, a human being. I like to see myself as a bit of an expert in humanity, after being with people on the rollercoaster road as they approach death. And that is a good image that I would like to use. It is a rollercoaster road.

I remember one wonderful parishioner I had when I was a parish priest in Melbourne, and she contracted a terminal disease. For about 2½ years not only I but our community accompanied her—and that is an important word for fragile and very vulnerable, elderly people, particularly with a terminal disease, to be able to walk with them.

The rollercoaster is that sometimes, yes, the pain is unbearable. “I want the quick fix.” Then a few days later, “No, I was just overreacting.” Then, deep lows of depression, deep lows of shock, denial—all these phases as we move towards death are there. To me, in more recent years, when that happens and I am with people I find that the palliative care services are generally, once sought, able to be accessed—and what a wonderful job they do too, working with the local community to provide all sorts of remedies, medically—and also being with people.

Here in Canberra, rather than talk abstractly, one of the great gems of the Catholic Church here in this fair city is Clare Holland House. I understand you have had explained what happens there. Many of these services are done in a hospice. But so many of them are done by that wonderful community going out in teams to people in their homes.

There is a sophistication today that was not there in palliative care only a few years ago. As I say, and I will finish on this, I do hope that in the years ahead this trajectory which is rising—more funds for appreciation in the community of palliative care—will dispel the terror of the night and make the disastrous option of euthanasia something that is seen, perhaps 20 years from now, as rather, to say the least, dehumanising, anachronistic and not needed.

MRS DUNNE: Could I reflect on that? You have already spoken a little about what you saw as the medical side. The palliative care specialist that we had from Calvary LCM yesterday spoke about the holistic, social and spiritual all being part of a whole. One of the issues I think that many people experience is the existential stress of confronting death. How do you see the role of the churches, the community, the social side of our society accompanying people to address those issues?

Archbishop Prowse: I am glad you brought up the spiritual side. You will notice in our submission that I am not using religious language and I am not using language that would only be suitable to, say, Christians and not to others. I have deliberately not done that. I would believe that the spiritual aspect would give greater energy to the motivation. But really the issues at play here are ethics, reasons, common sense perhaps, which is not so common these days.

But I do believe that people that are approaching the twilight of their life and are in a terminal situation must be accompanied by community and the medical side, yes of course, and the family. But sometimes the family is not there.

In regard to social justice, as you mentioned, there is a plea from the heart that in a good society that says it is a mature society respecting human dignity, we would rally around our most fragile. Indeed I would like to think that the litmus test of whether a society or community is a mature one and one that really does uphold human dignity and basic human rights would be able to be accessed and judged by the way they treat their most fragile and their most vulnerable members. And certainly one of the categories would be the people with terminal disease. It is a community effort.

To look at this particular issue in silos—the medical side, the political side, the other side—I think has a great danger there. It has to be—and you used the word beautifully—holistic. Looking at it in that regard is a pathway to really resolving a great human need at the moment.

MS CHEYNE: Your Grace, what is a good death? What does it look like?

Archbishop Prowse: I will go back to my personal experience, and I am thinking particularly of the lady I mentioned indirectly before. What was a good death to her was that the ups and downs, the rollercoaster of two years of coming to terms with the fact that her life was coming to an end sooner than she wanted and in a manner that she did not want, was causing her incredible existential alienation from herself first of all and then to others as well because of the anger and all the different emotions of this rollercoaster.

But the good death—and it is a great question—looked like this: we were there with her family and some of her friends in the community. I was able to be there as her parish priest. Yes, she was sedated because of the pain, but the pain was such that we were able to at times speak to her and then she went back into a deep sleep. But the hand; I always remember her hand. Although she was not able to speak or look there was the squeezing of the hand. For a while she held my hand. Because I got to know her so well after two years of being a visitor and becoming part of her family—and I still am—I knew that she was on a journey and how grateful she was that she was with us together. She was ready to go, ready to accept death, although it had all the things she did not really want.

It is a tragedy when a person dies like that. It is something the family still have not got over. Society I think gives you about six weeks to get over a significant grief, but six years is only the beginning of it. They will have this forever, but they have the memory that when their mum died she was not able to talk and kiss them and cuddle them as she would have done and she did do earlier when she was able to, but at least with the hand she was saying to us, “It’s okay; I’m ready to go. Thank you for all you have done.” That is a great death. That is a good death.

MS CHEYNE: I am not sure, Your Grace, if you were here for the final bit of the questioning with the doctors and professors we were speaking to before, but they raised the issue of terminal sedation or palliative sedation, which you have also written about in your submission, probably given to patients where palliative care is not otherwise working. The strong view, it appeared to me, that came from that evidence was that palliative sedation is the less good option, I suppose, when compared to voluntary assisted dying, not least because of the distress it can place on families. Reading through and thinking about many of the submissions we have received, it has been those cases of the sedation and what that looks like that has had lasting effects on families, and that has been their final memory of their loved one. Do you have any comment on that? We talk about families and grief and getting over it, but it strikes me that terminal sedation, rather than being able to say goodbye to somebody at a time when they are able to communicate in some way, actually leaves the family in a worse position.

Archbishop Prowse: Yes, and that is understandable and that has been the experience of many. I will make two comments. The first one is a long-term approach to this. For a person who is terminally ill well and truly before they reach that particular stage at the moment of their death and the moments before their death that discussion ought to be held not only with their medical practitioner but with the family to talk about this and to perhaps appoint an attorney, a family friend or somebody who can speak on their behalf when certain medical conditions happen unexpectedly so that we know the mind of the person. That is the long term. Short term, though, nothing should be done by either direct methods or very significant omission of what ought to be reasonably offered. That should never happen. That is what I would say is the classic definition of euthanasia.

You mentioned terminal sedation. The big issue there is intention. What is my intention or the doctor's intention? I am not a medical practitioner but am I putting the person in a comatose situation and in a sense denying the goodbyes and all that? What would the person want? Have we discussed that earlier? What is the intention? Is the intention to relieve the pain and then a consequence which we did not intend being that pain might move them rather quickly to death? That is the important issue.

Terminal sedation is a regrettable one in the sense it is true—it denies the person. But at the same time I have been with people who have died who have been terminally sedated and communication has many different forms. I mentioned about the hand a moment ago, and it is not just the person who is terminal but their families—they can touch. It is just not a verbal thing and looking around and saying, "I love you and goodbye." That would be wonderful, and please God, this would be the optimum way for us to meet a good death. But there are other ways of communicating too. The stroking, the patting on the forehead, the kissing, the silence together, knowing that mum or dad or my loved one has already indicated to me a year ago that tentatively this is what they want and there is somebody there that is able to interpret what she would want or he would want at this time.

I know that is rather a vague answer, but then we really do not have a handle on what can happen in these very precious moments at the end. I do not know whether Lara or Jeremy might want to talk about terminal sedation. It is an important topic.

Mrs Kirk: I would like to pose a question that has come to me in this issue of grief. Grief is difficult for all of us and for most of us we can experience grief in any experience of loss of control—it could be a car accident, it could be somebody dying. That whole feeling of having circumstances taken out of our control and we have to go through that human experience of grief. I do not know how much study has been done into how grief is impacted when the control is actually taken by another person with whom you are in a relationship either therapeutically or in the family.

I only have one experience of a friend whose mother summoned the family to another country where she had decided that she was going to end her life medically. It would be naive to think that everybody in the family is on the same page about how they feel about that experience. I know for that family people had different reactions. I know one of the sons later took his own life not long after that. It is a whole area of human grieving. We know from post-traumatic stress situations that when people are somehow implicated in grief that it compacts and complicates the grief.

I was posing that as a question for us to consider as a community. We do not know yet how we are going to grieve as human beings when it is not nature or taking control away from us but somebody with whom we are in relationships and the fact that the community will have different feelings about that.

MRS DUNNE: I am trying to get my head around the point that you made. A lot of the discussion about voluntary assisted dying, euthanasia, is about the patient. But you are actually saying that we do not look at the implications for the people left behind. In much the same way when someone is terminally ill there are two groups of people:

there is the ill person and then there are the close family and friends who are left behind who have quite different needs. Am I interpreting you correctly as saying that in these circumstances we have not looked at the impact this would have on those people left behind? Some people would agree and think that was a reasonable course of action, but there will almost inevitably be in any family group people who would be offended, outraged, upset—any number of negative emotions about that course of action.

Mrs Kirk: Yes, and I am putting it out there as something we need to consider as a community when we consider this issue.

MS CHEYNE: This is a really delicate question, and I understand it if you cannot answer it, Your Grace. You are in a very privileged—I think that is the right word to use—position of being with people and their families at the point of their passing or during their sickness. Do you have many people say to you, "I just want to die"?

Archbishop Prowse: On the journey towards their death, yes, and more often than you would think. But then the next day or the next few weeks, "I'm just shooting the breeze," or, as those might say from an Irish background, "I feel a lot better today." As I say it is a rollercoaster ride. When people are at their low ebb, to then move in with a legislative arrangement, "Okay. Well, if that's the way you feel, off we go. Can you sign this?" "Yes. I'll sign anything." To me this is reckless and a very ill considered and dehumanising way of treating people in their fragilities. That is the way I feel. Like all of us—I am not talking about terminal illness—some days we have good days and some days we have terrible days. As the song goes, some days are diamond and some days are stone. One of the big principles of right decision-making is when you are down in the dumps, wait till tomorrow. Do not make a decision. We even have that expression, "I'll sleep on it."

The major decision about my life and whether to continue or not should not be made impetuously. I notice the proposed legislation is trying to bring that in. But it needs to be done not only on their own but on a whole variety of levels. You know, "That's not you, mum. You think like that, but you've had that before." "Oh, yes. I know." That is why counselling is very important, if it is not professional then at least truth speakers in one's life.

This is the difficulty in the very isolated, atomised society we are becoming. All of a sudden we feel it is all of my choice; it is all about giving me options. On one level that is right but we are in this together. There is a communal aspect about good human living. When it is dumbed down, all of a sudden if it is your choice and you really want it, then off we go. That is an ethical argument that is very shallow given the complexity of human nature.

We are here to love and to be loved; to be forgiven and to be healed. We are not here to be judged and all of a sudden, "Look, I'm feeling I'm a burden on my family. I think I'll go for this option. I'm on my own at the moment. They're busy with their life. They're not visiting me as much as they used to. I'm feeling depressed. Give me that form, I'll sign it. I think they'll probably be happy with that." To me it is a very lonely society that encourages that.

The euthanasia option here is a very lonely policy that only an atomised society would even seriously think about. We are greater than that. We are a society that should be able to really care for each other. And Australians are famous for this. But our family life is becoming very different to what it was even a few years ago, and I think one of the casualties of it is that this topic comes up, and it is a sad topic to talk about. The real issue is the breakdown of family life and friendship and really being intimate with each other, not in an erotic sense but in the sense of having people that really know me and understand me and can say, "That's not you. This is what you are."

There is the difficulty. We are all busy. Everybody is racing around. If people ask, "Are you busy?" and you say, "No, I'm actually having a day off; I'm reflecting," you feel like you are a slacker. Anthropology is the word. That is a good way of moving towards this type of legislation because it is done in isolation and it must be done in community.

MS LE COUTEUR: Your Grace, I do not disagree with your commentaries about people being part of a community rather than individuals. I think that changes in our communal life are undoubtedly one of the things that have caused this to be an issue. Of course, there are another lot of big changes, which are medical advances. These have meant that people are staying alive. One hundred years ago they simply would not have. My parents were both in that situation. They both lived a lot longer with their conditions than they possibly could have, had they been born 100 years ago.

I think it is not as simple as community. We have changed our medical technology so that people are staying physically alive, but that is about all you can say. They are in a situation where it is not clear that they understand anything that is going on around them. That is even before terminal sedation. I am speaking from personal experience. If these people want to change, want to end this, do you feel that is still unreasonable when there does not appear to be any option for them to be a full, or even a reasonable, member of this community again?

Archbishop Prowse: Yes, that is a great question. I have pondered that. I was not so long ago in a nursing home. I was speaking to a lady who was 104. We had a very good conversation. She said that her daughter was also a patient at the nursing home. The daughter was 80. The daughter was in not such a good state as mum was. Yes, we are living longer; so there is the physical side. But then there is the issue of purpose in life—the existential side, meaning in life. We have all opted for a pretty high standard of living. It means that you have to work hard. We say, "You have to get that job." It is more than just Monday to Friday. Then there are all sorts of other pressures.

I think that people are bit more unreflective today than perhaps a generation ago. As the philosopher would say, a superficial life is not worth living. People do feel superficial once they have stopped their work. They say, "I am no longer in that job and my whole identity was in my occupation. Now I am in retirement I do not know what to do. I am bored. I feel that I have let down all sorts of people." This could be if they retire at 70 or 75 and they might live to 100.

A large part of life now is spent trying to come to terms with the life not led properly yet. How do I start again without giving up and basically saying, "I am depressed now and I am going to be forever depressed. It is going to be a downward hill." This is where people need some help. If they cannot get it from loved ones then they must have some help from professional counsellors and others to be in a community that treasures this.

But I can see your point and it is true. I am listening to people all the time. You can tell by the way they are talking that although they have probably got another 20 years left, their life is already finished in many respects. But is life simply the breathing and the physical side and the active side? What about the contemplative side? There was a lady that I used to visit for many years. She was very sick. But she would not go to a nursing home. She was going to tough it out at home. She spent most of her life on her own but she went through the pain barrier.

When I visited I felt that I was speaking to a mystic. She was there on her own for most of the day and she never imposed herself on anybody. But she came to terms with who she was: "Who am I? What am I doing? Where am I going?" In her way she came to terms with that. We need to slow down and ask people to assist people to understand that when life's activity finishes there is a new chapter of their life awaiting them. It is not literally a dead-end sentence.

Mr Stuparich: Could I add something? I think your question probably goes a little to medical technology as well. I wanted to make a point that there is no obligation to pursue extraordinary means to stay alive. In particular, if technology is being used to keep you alive and that becomes burdensome, you are quite free to cease that particular treatment and allow nature to take its course. But that is quite different from accelerating death through a lethal injection or some other means like that. There is no obligation to maintain life beyond its natural phase. It is quite ethical to let that go.

Archbishop Prowse: Yes. I remember once being with a family whose loved one was on a ventilator. Clearly, the prognosis was focused towards death. We gathered around them. It was simply like that. The treatment was burdensome. It was very expensive and you could tell that it was causing a great deal of unrest in the person. So we gathered together. Doctors and family were there. They turned off the machine and within 20 minutes the person died. That is completely different from a direct intervention. There is nuance here.

I think there is a lot of ignorance in the community. When we start to talk about palliative care and other ways, there is ignorance about that. There is a good way of dying and there is a bad way of dying. When death is evitable and treatment is burdensome, expensive and futile, then let us gather together and say goodbye to our loved one. That is a different scenario from what is envisaged with certain types of legislation in regard to euthanasia.

MRS KIKKERT: Thank you for being here. My question relates somewhat to the effect, if assisted suicide is legalised, upon the vulnerable people in the community—the disabled and youth who are depressed, vulnerable and lonely. With your experience of helping so many people over so many decades of your life, how easy is it for someone in that vulnerable position to be influenced by external decisions?

Archbishop Prowse: I think it is more difficult now than it was in the past, with the break-up of family life. People are all busy and the family might have members all around the world. Their loved one might be able to telephone them or use modern social media, but generally that person is on their own. It can have all sorts of impacts on them. Their own friends start to die. This has an effect: “I will be next.” We need to be able to create an environment, through community, to say, “Yes, it is challenging but it is a new life phase. Let’s work it out together.” It is easy to say that. But when you are elderly and sickly it can be hard.

A lady said to me once when I was visiting her, “Bishop, it takes me most of the morning to get out of bed and get myself ready. By the time I have done all of that I have to start thinking about getting ready to go back to bed.” So her whole day was basically taken up managing herself.

But the good thing now is that communities and governments are able to bring all sorts of things into the home, where people prefer to be. They can do that like never before. It is wonderful. The ACT should be really complemented on so many resources that are now available to people who are sickly, elderly and very frail. They can access these services if they wish. But there is the thing: if they wish. Who is going to help them to access it? If they are on their own and their family are overseas, it is lovely to get the phone call, but you need somebody on hand.

Even with neighbours today, do we really know who our neighbours are? So the real illness is loneliness and atomisation of society. The unfortunate effect sometimes is a death wish: “Maybe everybody, including me, would be better off if I did this.” To me, the issue is not the issue here. The deeper existential issue is paramount.

THE CHAIR: I note the time. Do committee members have a burning desire for a very quick question?

MRS DUNNE: I have a burning desire for a—

THE CHAIR: Very quick.

MRS DUNNE: It was the point that Mr Stuparich raised, which I was going to raise anyhow. I know, Your Grace, you said that you have not presented a submission in religious, theological terms. But there is a philosophical point that Mr Stuparich touched upon about the difference between ordinary and extraordinary means of sustaining in life. Given your 38 years of pastoral care, would you like to give us a brief exposition on this?

Archbishop Prowse: Yes, it is quite true. We should do all that we can to provide ordinary means of health and medicine. But when does it become extraordinary? We need to have discernment about that. Jeremy, could you make a precise definition about what is extraordinary? Pastorally, to me, it is when the person’s treatment is overly burdensome, very costly and rather futile. Then we have to start to think, but there might be other issues.

Mr Stuparich: I think that beyond ordinary is when you are providing something that your family, that your ordinary carers, might provide. Extraordinary is when you are moving into particular types of extra technology and things that you would find in hospitals. Those things can become burdensome. There are a number of reasons that they can be burdensome. They could become painful. Sometimes tube feeding becomes very uncomfortable and painful for the patients. It becomes too disruptive.

There are different situations for different patients. For example, travel may take them away from a sick spouse. They decide that that travel for their health treatment is burdensome and they decide to forgo that so that they can stay with a sick spouse. It can also become too expensive. The costs are much more than the family can bear. They are some of the reasons that it might become burdensome.

MRS DUNNE: I think one of the things that we have heard about from time to time, mainly from medical practitioners, is what might be called heroic endeavours towards the end of life. People are told that this might be the treatment or that might be the treatment and this perhaps unreasonably raises people's expectations. But it is also quite invasive in a way that creates a high level of discomfort for the patient. There is also the stress associated with repeated operations or something like that, for the family around them. It not is the physical stress but also the emotion stress.

Archbishop Prowse: Yes.

MRS DUNNE: Is that the sort of the thing that would be classified as extraordinary means? I suppose that in our current legislation, the medical treatment directions—I have forgotten what the legislation is called, sorry—

THE CHAIR: The Victorian one?

MRS DUNNE: No, the medical decision-making legislation in the ACT that allows people to make those sorts of general decisions in anticipation that there are certain things that they do not want to happen. Do you, as a pastor, have a problem with that kind of legislation?

Archbishop Prowse: No. Really, the extraordinary is changing so much. What was extraordinary a generation ago is now definitely ordinary. It is the normal thing. We need to make sure any legislation we bring in is not going to be set in some sort of—

MRS DUNNE: It has to be calibrated for the time.

Archbishop Prowse: concrete. It has to be quite dynamic because the area is dynamic. The medical care and the access to medical care is very dynamic. I think that is an important point to keep in mind—the tentativeness and the generality that ought to exist in legislation to promote a good life and not to hasten unduly a death by direct means.

THE CHAIR: Thank you so much, Your Grace. I note the time and I thank you for allowing us to continue this afternoon. 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 thank you again for appearing, Your Grace, Mr Stuparich and Mrs Kirk.

Archbishop Prowse: Some of the little stories I have told I have actually written in a little booklet of reflections. If it is appropriate, I have five copies I can provide to the committee.

MRS DUNNE: That would be great, thank you.

THE CHAIR: Thank you.

MRS KIKKERT: Thank you.

SWANTON, DR DAVID, Chapter Coordinator, Exit ACT
WHELAN, MR TONY, Member, Exit ACT

THE CHAIR: Thank you appearing before the committee today. We are looking forward to talking with you and hearing your responses to the questions, and to you providing us with your insights. Can you confirm that you understand the privilege statement and the implications of it.

Dr Swanton: Yes.

Mr Whelan: Yes, I do.

THE CHAIR: Do you wish to make a brief opening statement?

Dr Swanton: I do. Thank you for seeing us at the end of what has been a very long day, and thank you for inviting the ACT chapter of Exit International to your committee's hearing today. Exit considers it is a fundamental right for every adult of sound mind to be able to plan for the end of their life in a way that is reliable and peaceful and at a time of their choosing. Importantly, this means that a person need not be ill to act on the end of life decision. Consequently, many Exit members, including in Canberra, have already acquired the means to end their lives peacefully if they so choose. This is because of and despite the absence of regulated voluntary euthanasia in the ACT.

Exit supports the human rights model for voluntary euthanasia. This model does not require the intervention of doctors in the end of life process. Doctors, the clergy, Archbishop Prowse, politicians or anybody else should not deny people of sound mind the right to end their own life at a time of their choosing. Most Australians recognise that the option of voluntary euthanasia is morally right simply because it is voluntary. Given euthanasia's sound ethical footing, Australian governments, including in the ACT, should develop a voluntary euthanasia policy that builds on the best systems overseas to help those that are suffering.

Such a system exists in Switzerland, where, on 10 May 2018, 104-year-old Perth academic Dr David Goodall requested and received a lethal dose of Nembutal. A dramatic and compassionate and rational suicide caught the attention of the world's media. He had impaired eyesight and mobility. He had lost enjoyment in his life, but he was not terminally ill. Exit supported Dr Goodall, who was a long-time Exit member. Dr Nitschke provided information, and Exit members provided funding for Dr Goodall to achieve his objective. I am fortunate to have the letter Dr Goodall wrote to all Australians:

> To my fellow Australians,
>
> I would have preferred to end my days in Australia, the country of my adoption.
>
> Unfortunately the dominant forces of the medical profession have exerted every effort to thwart any attempt at independent actions by the elderly in ending their lives.
> Luckily, the medical profession in Switzerland have a more enlightened view, and so I am travelling there - a beautiful country but not my own.

It was signed “David Goodall, 29 April”. It is exasperating that at 104 Dr Goodall was unable to have the death he wanted in Australia and had to travel to Switzerland. What possible problem could there be with a 104-year-old choosing to die peacefully, when the time is right, listening to Beethoven after saying goodbye to relatives? That is a peaceful death. We do not die in our sleep. We would all wish to go that way. This procession of suffering Australians overseas will increase without appropriate regulation. It may soon appear in the media that an 80-year-old couple who are not well will similarly choose to go overseas.

Australian governments, including in the ACT, must establish appropriate supportive regulatory systems for the sake of all Australians. They can no longer ignore the fact that unregulated voluntary euthanasia is currently occurring in Australia, including in the ACT. Within Australia, Victoria’s Voluntary Assisted Dying Act 2017 is a notable first step in a state, but it is unduly conservative. It does not meet the needs of ACT citizens now. To qualify under that act a person needs to be a resident for 12 months in Victoria and have less than six months to live. That is impractical for ACT residents. The most effective drug, Nembutal, cannot be used as it is currently illegal to import or produce in Australia.

As you would appreciate, the Australian government has prohibited the ACT from legislating for voluntary euthanasia. The Exit ACT submissions presented three options for the ACT government, two of which are actionable. First, the ACT government should seek to have the Australian parliament repeal the federal government’s Euthanasia Laws Act 1997. Even though that outcome is out of the ACT’s control, we should pressure the federal parliament whenever possible. Second, the ACT government should consider adopting Exit ACT’s solution to circumvent the Euthanasia Laws Act, although there are political implications. That solution is outlined in our submission.

To conclude, Exit would like your committee to recommend that the ACT develop a world-leading regulatory regime for voluntary euthanasia. This is your opportunity. Please do not introduce medical and regulatory hurdles, as in Victoria, that are too high to jump. Reducing suffering for Canberrans is your responsibility. If you abrogate that responsibility, please be assured that Exit will continue to support people in their end of life decision-making.

As another new initiative, Exit is developing a legal, portable and biodegradable end of life device that is easily constructed from ready available material. That device can render ineffective voluntary euthanasia regulation—obsolete. That said, any supportive voluntary euthanasia regulation would be highly desirable and appreciated. Please take this opportunity to seize the moment and act to help suffering people at the end of life. Exit ACT is willing to help. Thank you.

MS CHEYNE: I note there are some other members of Exit International here today. I am not sure if you can speak on behalf of the people in the gallery, but did everyone here provide a submission?

Dr Swanton: Exit ACT provided a submission for everybody. Individual submissions were provided as well.

MS CHEYNE: That might just help the other conversation we are having.

THE CHAIR: I already was on to that, Ms Cheyne. Thank you.

MS CHEYNE: Your submission really highlights the importance of personal autonomy and that voluntary assisted dying is ethically sound. In the last two days of hearings the tension points between people we have heard from have been about autonomy and whether people are really autonomous. Others say voluntary assisted dying is not ethically sound. Could you expand on both those points about why it is so important to have the freedom to choose the method and timing of our death and what makes voluntary assisted dying ethically sound.

Dr Swanton: It is ethically sound precisely because it is voluntary. Nobody knows more about my life than me. Nobody here knows my ailments. Archbishop Prowse does not know my ailments. He does not know how much pain or suffering a person can bear. Ultimately it should be a decision for everybody. We decide who to marry, how to spend our finances, where to go on holidays. We should decide when we should be able to end our life, and a peaceful ending is the appropriate way to go. If we do not die in our sleep, the way Dr Goodall died is very appropriate. I would rather not be terminally sedated for four weeks or have dementia for two years before I die. That would not be good for me; it would not be good for my relatives. What was the second part of your question, Tara?

MS CHEYNE: It was about personal autonomy. Why is having the freedom to choose the method and timing of our death so important?

Dr Swanton: Again, because that is what we want. In Australia at the moment people are using Nembutal and various gases. There is no voluntary euthanasia regime in place because there is no regulatory system and they need to use something. Nobody knows what is right for somebody's body except that person themselves.

Mr Whelan: I have been a member of the ACT chapter of Exit International for 10 or 12 years. Growing up as a gay man with the potential sentence of 14 years' imprisonment hanging over my head in the three states that I lived in prior to coming to the territory, I know a little bit about ideological directions implemented in law that constrain people from acting in a way that should be acceptable but was not considered acceptable. We have a history in the British colonies, if I can call us that, of restricting and constraining and directing a whole range of personal activities, and that has been dismantled to a great extent over the years. When I joined the public service, women who married were immediately dismissed, for example. We are still going through that process of re-evaluating what is appropriate for people to make their own decisions about. Even in the churches, substantial numbers of congregations now are in decided disagreement with their church leadership, and that is something that has been overlooked a bit.

Dr Swanton: I should add that many Exit members are religious but they reject the views of the mainstream religions in terms of: is voluntary euthanasia acceptable or not?

MS CHEYNE: Do you have a percentage of how many of your members are religious?

Dr Swanton: We do not ask that question.

MS CHEYNE: Anecdotally?

Dr Swanton: Anecdotally, I would say 20 per cent.

Mr Whelan: Yes, I would agree with that. I know that, once or twice, people speaking at meetings have said things that basically imply that all Christians, for example, were opposed to voluntary euthanasia and they have been shot down very quickly by a number of people in the room because they are committed Christians and they support assisted dying, just as many Christians supported same-sex marriage equality, as demonstrated by the plebiscite recently.

MS CHEYNE: I know Exit has a more wide-ranging approach to what a scheme could or should look like in the ACT. Dr Swanton, you said we should be world leading in that respect. Is it better to wait for a perfect model or a world-leading model or is it better to produce a model or a scheme now that might be more restrictive or have quite a lot of safeguards in it, like the Victorian scheme?

Dr Swanton: Many Exit members are split on that issue. A lot of them would want the best possible scheme now, something like the scheme in Switzerland which allows for a drug such as Nembutal to be prescribed to a person. Others might take a step-wise approach, where something is in place in the first instance that might be appropriate. I know many jurisdictions around the world allow voluntary euthanasia for terminally ill people. Of course, Exit wants to go further than that because it is a right we think that everybody should have, and there are instances now with David Goodall or people not being terminally ill. I think we are split between a perfect solution straight away and anything to get there eventually. I think that would be a fair summation.

MS LE COUTEUR: Clearly you are not happy with the Victorian legislation. Do you have a model set of points or model legislation that we could look at? I have looked at your submission and it has some of the points that would be in legislation but you could not write legislation from it. Have you done that work?

Dr Swanton: Not as an organisation, no. It is something I will be chatting with Philip Nitschke about. As a person with some regulatory experience, I think we could write some drafting instructions in a week or two, going flat chat. But there are some important principles we would follow. First of all, we would set that a person could make a voluntary written request for voluntary euthanasia. We prefer self-administration of a lethal drug, although in some cases if the person needs a doctor to use an intravenous injection we would also be happy with that.

We would like Nembutal to be permitted. Of course, that is not possible in Australia at the moment, although, as I said, many thousands of people around the world are accessing Nembutal regardless of the regulatory regime in their jurisdiction. What they do in Switzerland is record the event, and there are a whole range of standard regulatory provisions regarding penalties and compliance and enforcement and eligibility criteria et cetera. They record the death in Switzerland on a video to make sure it is voluntary and the person acknowledges all the right things and makes all the right statements.

MS LE COUTEUR: Which leads me to my other question: do you have a view about mental capacity at the time of choice of death? One of the issues clearly is that many people as they get older may get mentally as well as physically frailer and lose capacities. You have people who may at some time in the past have been very clear about the circumstances they may find themselves in where they would wish to die, but they are not regarded as mentally component to make that sort of decision. Do you have a view on that?

Dr Swanton: Exit's position is one that you need to be a person of sound mind, so that means mentally competent.

Mr Whelan: No regulatory system and no unofficial ad hoc system can ever guarantee all of us an outcome that we might find acceptable. I have had the experience of an elderly friend who had obtained Nembutal. She did not use it because after the first couple of strokes she thought she would get better. The third stroke sent her blind. She was immediately sent to hospital then to a nursing home, where she still is. She begged me to go to her home and get that Nembutal. And I had to say to her, "It's too late. It can't be done." It would be a crime, and I certainly do not want to spend the rest of my life in prison. So some people are going to fail to be able to avail themselves of any scheme that might be regulated or legislated, and there is really nothing we can do about that.

MRS KIKKERT: Is Philip Nitschke the director of Exit?

Dr Swanton: Dr Philip Nitschke is the director and founder of Exit International, yes.

MRS KIKKERT: In the past he has made some comments that he supports child euthanasia. Do you support child euthanasia?

Dr Swanton: Exit's view is "every adult of sound mind". "Adult" implies over 18. From a philosophical perspective we could have debates for another two days, but that is Exit's position—you need to be an adult.

MRS KIKKERT: You need to be an adult of sound mind. So if somebody who is 19 years old expresses that they are depressed and they want to end their life, would you consider them as being of sound mind and that they are—

Dr Swanton: I am not a medical practitioner. We would have to leave that to medical practitioners to determine. Even though we prefer a human rights model, it does require doctors to be involved to assess the mental state of somebody when they are 19 or 20 and they have just had a break-up and they are depressed. I think that would require two doctors to assess their mental capacity.

THE CHAIR: In your submission you talk about Exit ACT members and Exit members internationally preferring the human rights model, which you have just noted. I am not sure if you had an opportunity to hear this morning on ABC Radio or giving evidence here today the ACT Human Rights Commissioner.

Dr Swanton: Yes, I think she was supportive of the right for the ACT to legislate for voluntary euthanasia.

THE CHAIR: She believes it is a fundamental human right to exercise choice.

MRS DUNNE: To have a debate.

THE CHAIR: That is correct. Thank you for correcting me. She obviously has her views, from a human rights commissioner's perspective. Can you just expand a little more on where you see the human rights model?

Dr Swanton: There are two models Exit has considered of voluntary euthanasia. One is the medical model, and that involves doctors being involved either by inserting an intravenous drip or by being physically engaged in the death process. A lot of Exit members do not like that process; we do not want doctors involved. Often it is a tedious process to convince the doctors. In the Victorian situation and many other jurisdictions overseas it is a massive process to get a doctor on side who says that you are terminally ill. Then you have to get other doctors and then there is a cooling-off period and then you have got to see the doctors again. This is an onerous process when you are in the terminally ill phase of a terminal illness. No-one wants that.

We in Exit have all seen many loved ones die in terrible situations. We do not want that to happen. We want to die in the most peaceful way possible. If we can, we want to remove doctors to the maximum extent possible, understanding that there might be some doctors required, as in Switzerland for Dr Goodall, to assess the mental capacity of the person. If we remove doctors as much as possible, that is the ideal situation and we get to the human rights model where the thousands of Exit members around Australia and the many thousands overseas—many of whom might have something other than a rope in their garage to help cause that peaceful ending—have something they can just drink when the time is right. Most of them do not drink it, but it gives them comfort knowing that is there just in case they are at a stage where it is unbearable.

THE CHAIR: What would you consider a good death? I am not sure whether you heard the evidence earlier—

Dr Swanton: I probably do not agree with Archbishop Prowse. What did he say?

THE CHAIR: It was a very extensive response, so I would rather not rehash that.

Dr Swanton: Okay. Good death is the following: peaceful. Preferably in one's sleep, but otherwise "peaceful" means calm, without pain and suffering, hopefully in the presence of loved ones. That would be better than any prolonged stay in palliative care, as my mother had. Despite the best possible palliative care in Sydney, there were still two instances of unbearable breakthrough pain that could not be palliated. That is always going to be the case with some forms of cancer, and any doctor who says otherwise is misleading you.

MRS DUNNE: Dr Swanton, you touched on this a couple of times. You talked about a human rights model. What are the underpinnings of that human rights model? What is the law—the international law, the Australian law—that says that people have a human right to choose death?

Dr Swanton: Suicide is legal now in Australia. Voluntary euthanasia has evolved into suicide. People have their Nembutal or other substance or substances and they can take them. Actually, that is a suicide. Suicide is legal.

MRS DUNNE: Suicide is not legal in the ACT.

Dr Swanton: Suicide is legal in the ACT.

MRS DUNNE: Oh, sorry—

Mr Whelan: It certainly is.

Dr Swanton: I am quite sure it is.

MRS DUNNE: We will have to beg to differ and I will come back to it.

Dr Swanton: I would be very interested to hear the outcome, through the secretary.

MRS DUNNE: We heard evidence today referring to cases in the UK which were eventually elevated to the European Court of Human Rights. All levels of jurisdiction through the UK, including the House of Lords and finally the European Court of Human Rights, have actually said that the proffering of the recognised human right of the right to life does not create in and of itself a right to die.

Mr Whelan: But I raise the comment—

MRS DUNNE: That is the established law in the UK and under the European Court of Human Rights. I am trying to get a feeling—you have used the term “human rights model” a number of times. I am wondering whether there is a legal underpinning for your position.

Mr Whelan: I will just quickly respond to Mrs Dunne. The issue that I mentioned earlier of progressive changes in society means that at some point or another there is no underpinning by the law of a position. It does not mean that it is not right. From my point of view, my autonomy demands that I should have the same right to die as I have to drive on the left side of the road, or not. The fact that legislatures do not necessarily at this point recognise that right does not diminish my right, in my view. That is all I want to say on that.

Dr Swanton: Mrs Dunne, can I ask you a question? Do you agree in principle that a person has the ethical right to determine what is right for his or her own body?

MRS DUNNE: Apart from the fact that I am asking the questions, I am happy to answer the question. That is a somewhat nuanced question. I think there are things that people's personal autonomy allow them to do and I think we probably have a philosophical disagreement about where that line is drawn.

Dr Swanton: But I would say that nobody else knows more than anybody else about what is right for them.

MRS DUNNE: I do not think I would necessarily agree with you. You might know that philosophically but not necessarily physically or metabolically. But I think that I am on the questioning side of the table at the moment.

Dr Swanton: Yes. I understand.

MRS DUNNE: My question to you was this: what is the legal underpinning, if any, for your contention that your approach to voluntary suicide at a time of your choosing is a human right?

Dr Swanton: The legal underpinning has been more explored elsewhere in the world. But I would say that the legal underpinning now in Australia is that suicide is legal. Now, if I am correct on that, I presume that means that you would agree that voluntary euthanasia has a sound legal basis.

MS CHEYNE: You are correct.

THE CHAIR: It actually states that suicide is not an offence.

MS CHEYNE: Yes.

Dr Swanton: So if you commit suicide, there is no offence.

MS CHEYNE: It is not to commit or attempt to commit, but what is an offence is aiding.

THE CHAIR: Aiding and abetting.

Dr Swanton: Yes, and that we do not do. The fact that suicide is legal, not an offence, means that that is the legal underpinning. The philosophical underpinning goes back to John Stuart Mill when he wrote *On Liberty*. He said:

> Over himself, over his own body and mind, the individual is sovereign.

It is about the legal underpinning here in the ACT and Australia and an ethical underpinning which goes back to the 1870s that is understood.

MRS DUNNE: Thank you.

Dr Swanton: I know you might not agree with that. The views of Archbishop Prowse, from what I heard from the room next door, seemed to be from my perspective rather arrogant—that we must have his view, when all we are asking for is individual choice. I am not demanding that anyone else have voluntary euthanasia. I want everybody to have that choice. I might not have voluntary euthanasia. I might be happy with palliative care. But we all want that choice and want people to have that choice. I do not want to have Archbishop Prowse holding my hand, because that will not suffice.

MS CHEYNE: Talking about the concept of a good death is something I have explored with a few of our witnesses over the past few days. You mentioned before that Exit is made up of a lot of people who have witnessed the deaths of loved ones. What would a good death look like from the perspective of those who are left behind?

Mr Whelan: Can I comment on that?

Dr Swanton: Yes.

Mr Whelan: I lost my mother in 1995, my father in 1997 and my sister just a few months ago. My mother's death was appalling. She wanted to be at home and then she went into a stage of shocking pain as her organs deteriorated. It was midnight and it took us two hours to get medical assistance. That was the worst two hours of her life and of mine. My father, mercifully, was sedated in hospital so that when his kidneys failed he died peacefully. I had a similar experience with my sister in January, who was sedated—in fact, unconscious with morphine—when she died. I felt that the deaths of both my father and sister, whilst sad, were not something that I was going to be feeling damaged about for the rest of my life, whereas my mother's death left me stuffed up for months afterwards. I was a mess. I guess it is a bit like asking: "Is it good for the person who is dying?" If it is, then it will be good for us. I think that is how I see it. I am not sure about David.

Dr Swanton: For the survivors, a good death will be different for every person. Everybody is going to die. All I can hope for is that the people I see die, die in the best possible way after leading the best possible life. Whether in pain or suffering or dementia or incontinent or whatever, if a person is distressed that is not good. I have heard doctors say that they should do no harm. Keeping the people alive in some instances is doing harm. It is up to the person themselves. If it is what the person wants, there is a little bit of satisfaction we can get out of that death—that the person got what they wanted in the end, peacefully.

MS CHEYNE: We have heard quite a lot today that people change their mind a lot. One day it might be, "I definitely do not want to be alive today." But the next day they are saying that they are doing okay.

Dr Swanton: Tara, thanks for telling us that, but I think that is an extremely arrogant position. They are saying that they change their mind; therefore, you cannot do that. People change their mind on who they want to marry, which house they want to buy and which car they want. These are things that we do in life. The joy of being a person is the fact that we make decisions about our own lives. But you are the regulators. You are the politicians who can pull the regulations together. If we have a situation where you can actually say, "These are the conditions that you need to fulfil before you can have voluntary euthanasia," that might help.

THE CHAIR: Thank you. I note the time. I know Ms Cheyne could probably go on all afternoon. I am sure we all have more questions, but it is a rather late hour.

MS CHEYNE: Can I please ask one that is very short—it is really short.

MRS DUNNE: You think so?

MS CHEYNE: I think it is. I will ask our witnesses, because I do not have any other questions except this. Are there members of Exit who have accessed Nembutal or anything else and then not taken it because having the drug in itself has given the palliative effect of knowing they could exercise that choice at some point?

Dr Swanton: I know at least one.

Mr Whelan: Yes, I have certainly known of people who sat on their Nembutal for a substantial period of time, and some who still are. I think one, when her condition went really, really, severe, reached the point where she did use it. Another never used his because he ended up at the hospice, in palliative care, and he died there. It is not necessarily the case that people will use it. But there is certainly an element of feeling, as I do, that I have an insurance policy there that I might be able to call upon if I need to. That makes me feel that I do not have to. If things started to look bad, I do not have to act precipitately.

Dr Swanton: One other thing: I have two books here that I would like to provide to the committee. One is from Dying with Dignity New South Wales. The other is *The Damage Done*, produced by Andrew Denton’s group Go Gentle. There are some very explicit stories, which are heartbreaking and certainly worthy of a solid read.

MRS DUNNE: Thank you.

MRS KIKKERT: Thank you.

THE CHAIR: Thank you for coming and talking with us today and for providing your insights. I remind you that a proof transcript will be provided to you, to check and to suggest any corrections if required. I do not think any questions were taken on notice.

Before closing the public hearing today, I remind all witnesses that have undertaken to provide further information, or who took questions on notice in the course of today’s hearing, that, whilst the committee has not set a deadline for receipt of responses, answers to these questions would be appreciated within two weeks from the date of the proof transcript. I thank everyone for their input today. I now close the hearing. The next hearing will be on the Thursday, 24 May.

The committee adjourned at 5.21 pm.