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

THURSDAY, 17 MAY 2018

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

By authority of the Legislative Assembly for the Australian Capital Territory

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

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DANIEL, MR MATTHEW, Secretary, Australian Nursing and Midwifery Federation (ACT) **57**

EASTWOOD, MS SUZANNE, Community Development Manager, Canberra Multicultural Community Forum Inc **49**

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Amended 20 May 2013

The committee met at 9.31 am.

PHILLIPS, MAJOR GENERAL (Rtd) PETER

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

Before we begin, I remind witnesses of the protections and obligations that parliamentary privilege entails and draw your attention to the pink privilege statement that is there on the desk. These are very important. I welcome today's first witness, Major General Peter Phillips. Could you confirm for the record that you have read and understand the privilege implications of the statement there?

Major Gen Phillips: I have.

THE CHAIR: Before we proceed to questions from the committee, I would also just like to take a moment to acknowledge that we meet on the lands of the Ngunnawal people. I pay my respects to elders past, present and emerging and the continuing contribution of their culture to this city and this region. Major General, would you like to make an opening statement before we start with questions?

Major Gen Phillips: Sure. I am not sure how I came to be selected for interrogation, but I do not represent anyone except myself. In fact, I should emphasise that I am not here as an expert in anything but I am here as a concerned citizen who believes it is in the best interests of our society not to legislate for euthanasia. All I can offer you is the life experience of someone who is just about to turn 83.

You will see from my submission that I have a special concern for ex-servicemen and women who, by the nature of their training and inculcation into the services, are more likely than most to see the right to die as a duty to die. This was a matter which was debated extensively in the veteran community in the 1990s as part of the discussion over the Northern Territory legislation. I can no longer speak for the RSL or the veteran community, though I did outline my views, much as I have put to the committee, in an article in our national magazine, *Last Post*, which seemed to be well received. At least, I have received only favourable comment.

In my submission—and I just want to correct something—I refer to active and passive euthanasia. These were terms which were bandied about in the 1990s, and on reflection I would want to withdraw that. The issue is quite clear. Active euthanasia is killing another human being by medical means or whatever other euphemisms are used to describe it. The term "passive euthanasia" should not be used. It was meant, in those days, to refer to refusing futile treatment and a pain relief which might inadvertently lead to death.

The use of the term euthanasia in those two connections, I now see, is quite wrong and confusing. Rather, they belong in the realm of palliative care, which is, in my view, incompatible with euthanasia. I say that particularly having seen in the last month two of my comrades pass on out at Clare Holland House.

I would like to say that I am very mistrustful of public opinion polls, because the poll results in this matter overwhelmingly rely on the question that is asked. I am also deeply distrustful of reported outcomes in a few overseas jurisdictions that have gone down this route, and they are only a handful of European countries and a couple of states in North America.

Much publicity was given to Andrew Denton and our own Mary Porter after their visits to these countries when they reported favourably on the overseas statistics. I am sure they were well meaning but I did not find that their reports matched those from what I think are reputable sources that I had read.

In any event, the overseas experience is appalling. When we see euthanasia being offered even to children and to mentally defectives, I would wonder how on earth we in Australia could limit the provision of euthanasia to the terminally ill and provide safeguards against abuse, when the overseas experience clearly indicates that there would be relentless pressure to extend the legislation. I think Victoria will learn this lesson the hard way, starting next year.

In the second paragraph of my submission, I put the question:

> To be blunt, would it be worth assisting even one person to commit suicide if it led to increases in the already high toll of youth suicide and elder abuse?

I thought about elder abuse and I have since noticed the reports of the increasing prevalence of suicide among men in their 80s. I see this as something that is being linked to elder abuse.

I mentioned my concern for the medical profession if it was coerced into providing assisted suicide. I am delighted that the federal president of the AMA, Dr Gannon, and our own ACT AMA president, and their organisations, have stood firm in their opposition.

I mentioned in my submission my experience with wounded enemy prisoners at the Battle of Coral-Balmoral exactly 50 years ago this week. You may see this as a remote red herring, but I do want to demonstrate that introducing euthanasia legislation has far-reaching consequences for the fabric of our culture—collateral damage, if you like. If I were you, ladies, I would not want my name associated with such legislation but would rather be remembered for the promotion of palliative care.

MS CHEYNE: Thanks very much for your time today and thank you for your very considered submission and your opening statement. I just want to tease this out: I think you raise some very valid points about suicide, but would you not agree that there is a difference between the active promotion of suicide and acknowledging that an individual with an incurable terminal disease and in significant pain would want to end their suffering—that there is quite a significant difference there?

Major Gen Phillips: I am as compassionate as anyone about someone who is in end of life pain, but I still do not think that justifies allowing them to kill themselves. I do not agree with you.

MS CHEYNE: In your submission—it is something I really want to understand better—you raised that veterans might be more likely to be prepared to sacrifice their lives instead of being a burden on their families. Do you think there are any safeguards at all or that, by imposing safeguards that would require doctors to make an assessment of all factors when effecting a decision to request voluntary assisted dying, we could ensure that anyone who wishes to die does it only out of a genuine need to relieve themselves of pain and suffering rather than something like depression or a psychological illness?

Major Gen Phillips: I am sorry, my hearing is not the best and I just missed a couple of bits there.

MS CHEYNE: I am happy to say it again.

Major Gen Phillips: Would you mind?

MS CHEYNE: Sure. You raised that veterans might be more likely to sacrifice their lives rather than be a burden on their families. I appreciate your view that voluntary assisted dying should not be allowed to happen at all. But hypothetically, if it were to go ahead, are there any safeguards that could be imposed on a doctor that might reduce this risk to some extent—for example, making sure that anyone making an assessment of that person was considering all factors relevant to that person, including whether they have a psychological illness and making sure that any decision to grant that person access to assisted dying would be done out of their need to relieve suffering from a terminal illness rather than a psychological illness?

Major Gen Phillips: Obviously the issue of safeguards must be paramount in your minds, as it was in Victoria.

MS CHEYNE: Absolutely, yes.

Major Gen Phillips: But my view and what I have read suggest that you are not going to get safeguards that will stand up to the relentless pressure that will be put on governments to extend the use of euthanasia. If I could just side-track here, the Dutch and Belgian experience is that about four per cent of deaths are now through euthanasia, and I do not think it has stopped growing. If you translate that to the Australian scene there would be about 6,000 a year Australians euthanised. That creates a real industry in Australia. Once you have got an industry and a profession there will be, again, enormous pressure to meet their demands. I am not hopeful that you will ever get this right. It is better to stop now.

MRS DUNNE: Major General Phillips, thank you for your submission and your appearance today. I want to explore with you something you touched on in your opening comments about the treatment of prisoners of war in conflict situations. I will put a proposition to you, and I hope I am not putting words in your mouth. What I am hearing from you is that you are saying if we go down this path in a medical context, it creates a permission structure in other spaces. For instance, perhaps the rules of engagement could change so that it would be easier for a soldier to kill a captured prisoner who was badly injured. Also, having regard to your comments in relation to elder abuse and youth suicide, do you see that we are creating a permission structure in that, if it is all right to kill in this circumstance, it becomes easier to kill in another circumstance?

Major Gen Phillips: That is exactly the point that I was trying to get across. My example of the shooting of prisoners might have been a bit way out, but it is a question of how society views life and death. I would not want to weaken our respect for life.

MS LE COUTEUR: You touched upon elder abuse. Clearly, that is potentially relevant in many instances. Clearly, elder abuse happens now. I am sure you would agree with that; clearly, it does. The federal government has recently done inquiries; clearly, there is elder abuse. Can you think of ways that we can reduce the amount of elder abuse? Regardless of whether you regard this potential legislative change as being elder abuse, how can we treat our older people better?

Major Gen Phillips: I have had some experience of this because I chaired for the commonwealth government a veterans' aged-care forum for nearly 10 years and visited something like 120 nursing homes around Australia, including around the Northern Territory. I am very conscious of the fact that even some of the best homes had instances of elder abuse, and it needs very careful management. It is a question of the climate and whether you have a good management climate.

We started something at the Leslie Morshead home, where nurses were encouraged to spend more time off duty chatting with patients. That had a remarkable effect. That is the sort of interaction that I would hope for. I seem to have spent more than enough time at Clare Holland House lately. As I mentioned, several of my comrades have died in the last few weeks. They do a wonderful job, and I would like them to be helped, rather than helping people who want to take an easy way out.

I will add a personal experience. I mentioned in the submission that we lost a granddaughter some years ago. One that sticks particularly in my mind is an uncle of mine who was a senior officer in Customs, a World War II veteran pilot, a great footballer and a great athlete. He had barely retired when he got a lymphoma and had cancer for 13 years. I said to him, "Jim, I'm sorry that you've had to endure all of this." He said, "Don't worry. I've never experienced such great love for my family as I have over the last 13 years." That is at the heart of this, about whether the family looks after the person.

MRS KIKKERT: Thank you for being here today, and thank you so much for your service through the many decades of your life. We really appreciate your service to our nation. Your submission really opened my mind to a perspective that I had actually never thought about while we were having this discussion in the public hearing. Please help me to understand more your thoughts and your experiences, having been a soldier for many decades.

As somebody who lays down their life for someone else or for their nation, how do you feel when a nation leans more towards voluntarily laying down their own life, when you have gone off to war and experienced danger and risky, dangerous situations to protect lives back in your nation? How does that make you feel as a soldier? Also, what impact emotionally would that have on you and your comrades?

Major Gen Phillips: My active service experience was three years in Malaya in the 50s, chasing communist terrorists, and a couple of years in Vietnam dealing with the North Vietnamese. Frankly, I did not go off to war for my country to endorse euthanasia. It is just not in my nature. I wanted better things out of our country.

THE CHAIR: Major General, I note your many years of service. I am the granddaughter of a veteran and I am married to a veteran, so I understand how difficult it can be at times for returned servicemen and women. Putting all of that aside, and just as an Australian, is it not everyone's choice that they can make for themselves? Should people have their own choice? I respect that these are your views, but are there opportunities for opposing views?

Major Gen Phillips: You, no doubt, have opposing views, but I do not support them.

THE CHAIR: That is absolutely okay. My point is that some people chose to enlist. Some people enlisted because their birthdate was drawn out of a barrel, so to speak. We do not always have choices. Do you think that being able to end your life in a manner which you believe to be peaceful should be a person's choice?

Major Gen Phillips: No, I do not think it is manageable. It would be a chaotic situation if everyone is allowed to follow their own choice in anything. There have to be some boundaries.

MS CHEYNE: Major General, how is a doctor being involved in assisted dying inconsistent with palliative care? In your submission you asked why you would want to be treated by somebody who actively promoted or through whom you could access assisted dying. Why is that inconsistent?

Major Gen Phillips: I would not want to be treated by Dr Nitschke for anything.

MS CHEYNE: My broader question is that, with palliative care, proponents of voluntary assisted dying see that assisted dying is one choice at the end of a person's life, and one that not many people would choose to take, and that palliative care is appropriate for people. I would be very surprised if we had a range of "Dr Deaths" emerging.

The overwhelming experience I have had with medical professionals is that the sanctity of life is paramount. They want people to live and to be able to do what they can, while also appreciating that there is a point in a person's life where nothing more can be done. I am wondering how that could possibly be inconsistent with palliative care if a person wants palliative care.

Major Gen Phillips: I can only hope that you will put that to others about palliative care. How far can palliative care go? I think there are enormous advances being made, so it will be interesting to see what the experts offer.

THE CHAIR: Thank you so much for your time today, Major General. I believe the committee has no more questions for you. 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, if needed. On behalf of the committee, I would like to thank you for appearing today.

GREEN, MR MARK, National Director of Mission, Little Company of Mary Health Care

KANATHIGODA, DR SUHARSHA, Medical Director of Palliative Care ACT, Calvary Public Hospital

BROWN, MS FRANCES, Director of Mission, Calvary John James Hospital

THE CHAIR: Good morning. I welcome our next witnesses to the hearing today, from the Little Company of Mary Health Care. On the table in front of you is the privilege statement. Can you acknowledge for the record that you understand the implications of the statement?

Mr Green: Understood.

Dr Kanathigoda: Understood.

Ms Brown: Understood.

THE CHAIR: Would you like to make a brief opening statement?

Mr Green: We begin as the committee has done: we acknowledge the traditional owners and the custodians of this land on which we gather and pay respects to our elders, past and present. We also thank the committee for its invitation to provide evidence.

Our opening statement will be in two parts: I am going to provide a general introduction and Dr Suharsha beside me will talk a little bit about our approach to end of life care and palliative care. As the committee is aware, Little Company of Mary Health Care has been providing accompaniment and support to those experiencing suffering, particularly at the end of their lives, for some 131 years in Australia and 40 years in this territory.

The committee would be aware that our footprint is reasonably extensive. We operate the public hospital at Calvary, Bruce, along with its specialist palliative care unit at Clare Holland House. We also have two private hospitals: the one on the Bruce site and John James in Canberra’s south. And, of course, we provide a residential aged-care service at Haydon Retirement Community, adjacent to the Bruce campus, and extensive home care or community care support. We have a lot of experience of encountering each day Canberra’s citizens at various stages of their life.

Drawing all this experience together, because of our work we are very conscious of people who have difficult lives in our community. We are conscious of people who are at present battling and surviving experiences of institutional sexual abuse who have been damaged by some of our leaders. We are conscious of our First Peoples and the continuing trauma they live with. We are conscious of people who present to all of our services who live with isolation and loneliness. Many battle chronic illnesses and we encounter many people who are fearful of growing old and women and men who every day face their own imminent death.

In our experience it is important that we note and reflect that their grief and loss is not always relieved by medicine. The solidarity of presence, the enterprise of research, imagination and grit, together with multiple acts of service of those who give to those who have not are equally as important. For 131 years this is how we have attempted to assist those who experience loss and grief as they face death every day, whether that is their imminent physical death or the death which is that common experience of not being able to live in a way and manner one desires.

Up until now in our public discourse we have not publicly contemplated eliminating this type of suffering I have been describing by making it lawful for a person to take his own life or for another over the age of 18 to assist such a person. The implications of such a path are huge, and they will impact on our common enterprise as human beings. They will impact on our efforts to build a solidarity, one with another, and on our claim that each one's life is precious and matters every moment of every day.

The ramifications of the discussion are having implications for our medical profession and our carers because, up until this point, as has been mentioned many times, the essential duty has been to protect life and to do no harm. That must change if a law is passed in any state or territory, as it has been in Victoria, that permits assisted suicide. We are going to have to deal with those tensions and the divisions that will have to be navigated in our therapeutic professions. Others who work in our aged-care sector and our home care sector are particularly worried about people who are lonely and depressed and who may take the momentous decision to seek an assisted death simply because of heartache or loneliness or because they feel a burden to their carers or children.

These deliberations are momentous, and it is important that all of us bring our best thinking to them. Calvary will seek to assist the committee in any way it can. It might be appropriate to say some things about our approach to end of life care and palliative care before you ask us some questions.

Dr Kanathigoda: Thanks for giving us the opportunity of expressing our opinions. I have quite a few hats, and one of them is the director of palliative care at Calvary. Wearing that hat, I have to say that palliative care as a whole is about preventing early, detecting early and managing symptoms—they could be physical, psychosocial or spiritual—of a patient who is at end of life. They could be having some kind of life-limiting illness or they would be at end of life, but, whatever the situation is, if somebody has a life-limiting illness, managing their physical, psychosocial as well as spiritual wellbeing is what palliative care is all about. It is actually about optimising life; it is not about death.

Even though a lot of people have been talking about death, if you look at the WHO definition of "palliative care", it is about managing these patients. You prevent the symptom from occurring first; you try to do that first. Then you detect things quite early, you anticipate things before they happen and you put things in place so that it does not happen. Then, once you get the symptom, whether it is physical or otherwise, then you manage that symptom impeccably—impeccably. That word "impeccably" is in the WHO definition. And that is what we have been doing over the last so many years, as Mark said.

Through our institutions like Calvary hospital, as well as Clare Holland House, we look after the majority of the patients in the ACT, as well as some surrounding areas in New South Wales. We have an inpatient unit which is second to none; at the moment it is rated as one of the top 10 inpatient units in the country. Within Australia it is recognised as the jewel in the crown of palliative care, and worldwide it is a recognised unit.

Our home-based palliative care service, which is functioning with the greatest of difficulties at the moment because of lack of funding, even with all that, we have managed to actually look after all the patients within the ACT who actually require home-based palliative care.

Now, is that enough? I am not saying that; we need more. If the federal government as well as the state government can come to the party and provide us enough resources, I can guarantee you that we can provide quality palliative care and end of life care to all the patients within the ACT and the surrounding areas.

The issue we have is, to give you an example, our home-based team work because they love what they do. They have a room probably one-fourth the size of this room in which to have their meetings. That is the home-based palliative care service. That is the space they have got, but they do not complain. They have their meetings, they look after the patients and they do a phenomenal job.

But what I am trying to say is, even if you look at our outpatient clinics, we have only two rooms. We can definitely look after more patients. With the limited physical resources we have as well as the human resources we are doing a pretty good job up to now, but we can do more. If you provide us the opportunity, we will show you that we will be able to do even do better. Just like the Australian cricket team, we can always be better.

My feeling, in terms of what we provide for our patients, is that our reputation precedes us. I have hardly seen anybody complain about our service. Whenever there is an issue it is handled very methodically and in the correct manner. The majority of our patients love the service. I have told my staff that I would book a place there as well if I had a life-limiting illness, so what else can I say? That is what I can actually tell you. But I can give you a very safe guarantee that, if we have enough resources, end of life care for all patients within the ACT and the surrounding areas is totally possible.

MRS DUNNE: Thank you, Mr Green, for setting the scene in a high level way and reminding us that these deliberations are extraordinarily serious. In a sense, there is a prevailing view that there comes a time for particular people when their life is not worth continuing. Could I have the perspectives of both you, Mr Green and Dr Kanathigoda, on that proposition. That is a simplified proposition, but do you see that with modern palliative care and a modern approach to the whole person—not just a medical approach but a whole-person approach—we are in a position to eliminate that sense that this is not a life worth continuing?

Mr Green: We shall start with the clinical experience.

Dr Kanathigoda: I will give you a very simple example to explain this. I met a patient—and this was not in the ACT but in New South Wales, while I was working there—who was a high level fashion designer and who was living at home. He had a family but he had not much contact with them so he was living as a recluse. When our home-based team went and saw the patient, the patient was very grumpy and was having lots of physical and other issues. He did not want to engage with the nurses who were going in and seeing the patient. After a few visits the nurses came and told me, “Unfortunately, we don’t seem to be getting anywhere. Can you go and see this patient,” which I did.

Even before I walked in I saw the garden was not kept well, so I knew that he was not looking after that, obviously because of physical and other needs. He was living alone. You walk in through the doors and you can see pictures, beautiful artistic pictures hanging on the walls, so I knew that he loves art. This is something that we always teach our registrars and junior doctors: it starts before you go in and as soon as you walk into the place. Even before a word is uttered, you need to look at the whole picture, the whole person.

I did not talk to the patient about his pain. I did not talk about his symptoms at all; I just had a chat with him. I wanted to find out more about him and what his background was, because nobody had asked that question previously. I found out he was a great fashion designer who had a major business in Sydney, and he was thriving, travelling all over the world doing that. But, unfortunately, due to different circumstances in his life he was estranged from his family, and now he has this lung cancer which was preventing him from doing the things that he liked to do. He was living as a recluse, in pain and discomfort without much dignity, and because of the anger and the resentment he had had towards himself and others, he was feeling miserable. He said, “I want to end my life. There is nothing for me to live for.”

While I was having this chat with him, he slowly started smiling for the first time because I was asking him about his past. Once he knew that I was interested the conversation continued. And then I asked, “What would you actually like to do? Is there anything, any unfinished business, you want to do in life?” And he said, “One of my greatest regrets is I always wanted to do gliding but I have never been able to do that. I am feeling miserable because of that, apart from all the other things. If I could go gliding at least once in my life I would be extremely happy.”

So, apart from being estranged from his family and all that, this was his main issue at the moment. And I felt, “Okay, is it something we could provide?” With his permission I called his son, who he was estranged from, and I said, “Is there a possibility of you coming?” His bones were riddled with cancer. If he fell down, he would break every bone in his body. But the son volunteered, and the son was very happy to come and take the father gliding. So as soon as I got his confidence I was able to manage his symptoms so that his pain was well-managed, and then I sent him gliding with his son. I have to say, that was the happiest moment of his life. After he came back he thanked me profusely and we managed him very comfortably at home on his own. Eventually he came to the inpatient unit and then had a very peaceful death.

What I am trying to say is: palliative care is not about just managing a symptom or just talking to somebody or being there; it is about knowing what makes them tick. Once you know what makes them tick and once you know about the background of the patient, even if they are requesting to end their life because of those issues, you can still use it as an opportunity to find out what is the core problem and sort it out. And when that happens the patient can die very peacefully and comfortably.

The example is basically to show that maybe a lot of people would like to have the right, according to the polls, to end their life, but very few will ever request it, even if they have the right. My feeling is most of the people who request it will also change their mind, mainly because we have not identified what their problem is.

When this whole debate came up I felt there was a lot we could do if we were to get a person to go into a home of a person and have a chat with them about their life and what is going on—which takes time—in an activity-based funding model that we are moving towards. How are we going to check the quality of life or how are we going to check the quality of what we are going to provide if we do not have the time and resources to spend with our patients?

Without doing that I think it will be rather unfair by our population to allow them to just take the easy way out in a way, because they might not be optimising their life otherwise. That is something that I want to clearly demonstrate to you. There are lots of examples—I can go on for 24 hours talking about these situations—but that is basically what it is, yes.

MS CHEYNE: I have a supplementary on that.

Dr Kanathigoda: Yes.

MS CHEYNE: I have a few. I am just trying to sort my thoughts out here. In this case, for this person—thank you for the example; I think it is a very good one—I do not think anyone is suggesting that it is either/or with palliative care and assisted dying. I think that proponents for assisted dying are saying that is just one choice that is at the end of someone's life, and a choice that they might want to have access to but not necessarily exercise. In the example that you gave, I cannot see why that person could not have been accessing both—in terms of having made that request and potentially having been granted the drug—but equally still be very well serviced by palliative care, and indeed so well serviced that they decided not to take the drug.

Dr Kanathigoda: That is a very good question. I did ask him that question once he went gliding. When he came back I did ask him, "Would you still like to end your life?" and he said, "No." Because he now had a friend. He now had a service which was actually providing the service he required. He was a human being again. Earlier he was just a number. Now he was a fashion designer at the end of life who was recognised as such, and his needs were recognised. We identified his needs and we provided for his needs.

THE CHAIR: Yes. I guess what you are saying—again, I am not trying to put words into your mouth for my own means either—is that the two could potentially exist side by side. You could still be providing that excellent palliative care to a point that a person decides that they do not want to go down that path. I absolutely see that that is the role of palliative care. That is the idea: you want someone to be in that space.

But, equally, with your example, that is someone who is very conscious. He still has great cognitive abilities. I think there are surely plenty of examples where people’s lives are prolonged near the end of their lives with no benefit. They are not necessarily able to get out of the house or the hospital bed or they are in incredible pain. The quality of life reduces. In my own experience, I have seen someone who, in the last eight days of their life, was not conscious but was in incredible amounts of pain any time they were touched. Why should that person’s life, their suffering, be prolonged?

Dr Kanathigoda: I think there was a question that the panel asked the major general who was here about when nothing can be done. There is always something that can be done. We never say nothing can be done. I never have had a patient that we could not do anything for. Never—in my last 20 years as a doctor and probably five to 10 years in palliative care—have I come across a situation where there was nothing I could do for a patient. There is always something that you can do. Palliative care is something that you can do. Palliative care is actively actually managing these patients’ symptoms at end of life as well as during their lifetime, during that life lived with the illness. There is always something that can be done.

I am sorry to hear about your experience. What you just described is allodynia, which is where, as soon as you touch the patient—it is neuropathic—anywhere on a part of the body you get pain. There is a particular medication that you have to give for that, for example, methadone. Subcutaneous methadone—a small dose of 2.5 milligrams—would have sorted that issue straight away. That is where our specialist palliative care knowledge comes in. A normal general practitioner or any other doctor like a cardiologist would not know that.

MRS DUNNE: I did want to follow up. I think you partly answered that. There is a perception that, even with modern medical practice, there are circumstances in which patients are in un-relievable pain. What I am hearing from you is that that is not the case.

Dr Kanathigoda: Let me—

MRS DUNNE: We all hear stories in this environment. People will tell stories of personal experiences they have seen. Rather than my putting words in your mouth, what are you saying in response to that?

Dr Kanathigoda: What I am saying is that, with adequate resources in palliative care, we can manage any symptom. There is nothing that we cannot manage. You asked a question around how you would manage a patient who was given every possible conventional medication but still had intractable existential distress or other symptoms like nausea or pain. Palliative care has an answer for that as well. It is called palliative sedation.

Again, I have to say that a lot of people in the community do not know what palliative sedation is. People think palliative sedation is something you give somebody with intractable pain to end their life. That is not the case. That is far from it. Palliative sedation is all about sedating the patient so that they do not feel uncomfortable but we do not take their life.

I recently had a patient at Clare Holland House. There was intractable existential distress in this patient. All possible things were done. We then had to use palliative sedation. When we use it we do it in a very incremental, evidence-based way. It is a gradual increase. The whole idea is to sedate the patient so that the patient does not feel those symptoms. Once the sedation is done, you stop. If you continue any further that is when it could be considered euthanasia. The patient lived for another seven, eight or nine days and passed away quite comfortably. So the patient did not have any symptom and the family was extremely happy. That patient actually passed away quite peacefully.

I had a patient who lived like that for 21 days without food or drink. At that moment in life, if you give fluids to the patient, IV or otherwise, you hasten the death of the patient and make the patient uncomfortable. It would cause pulmonary oedema, because at that time in the life of that patient they do not need that much fluid as their body is shutting down. If you give fluids to that patient, it will go the lung or go around the heart, causing oedema of the body. You are basically making the patient uncomfortable by giving IV fluids or hydration.

Food is the same. If you try to feed that patient orally, obviously they will get pneumonia by aspirating that food. They are conserving their energies, so you do not need to feed them. They are not uncomfortable because they are not eating or drinking. If they get hunger pain we manage that with opioids, quite effectively. It is very easily managed. Palliative care has an answer for everything.

MRS DUNNE: Just one follow-up: I suppose that one of the points that Ms Cheyne was making—I do not necessarily want to put words in her mouth—is that the option of assisted suicide is another weapon, so to speak, in the armoury of palliative care. Is that roughly what you were saying?

MS CHEYNE: Not a weapon; an option.

MRS DUNNE: An option. Thank you because I said it for want of a better word.

MS CHEYNE: What I was talking about here is choice. Are there choices available?

MRS DUNNE: Is it part of the panoply of services provided and what is your response to that?

Dr Kanathigoda: The simple answer is no. I will tell you the reasons behind that. The reason I say that is, if we had a situation that we could not manage in a patient—I am talking about symptom-wise—then that could have been an option. But in the palliative care situation we can manage any of the symptoms that any patient gets, with the adequate amount of resources.

There are situations where the resources are not enough. The home-based team might not be able to access the patient at the right time and the patient might have symptoms due to that. That is an issue with the system where we do not have adequate resources. But my feeling is—in palliative care as a whole, as a rule, through ANZSPM or otherwise—it is not something that we would ever have in our armoury.

MS LE COUTEUR: You said you had palliative sedation for this particular patient who was suffering from existential distress.

Dr Kanathigoda: Yes.

MS LE COUTEUR: My question is this: how do you know that that relieved the distress for the patient or whether it just meant the patient was not in a position to visibly express the distress? The impression I get from what you were saying is that they were in a position and were basically not communicating with the outside world. How do you know that, in terms of their suffering, it made any difference?

Dr Kanathigoda: You do not take palliative sedation lightly. Initially, when a patient has existential distress or other distress, we always refer to social workers and get psychological opinions. Sometimes a psychiatrist is involved. All those avenues are looked at when we look at existential distress. We look at all social aspects of that patient as well. Sometimes it could be a social issue more than a spiritual or other issue. We look at the spiritual-psychosocial issues and try to manage them as much as possible with all optimal resources we have in our armoury, as you call it. Once that happens and you still feel that it is not a physical symptom causing this patient to have the distress, that is when we tend to use it.

When we use it, our idea is to sedate the patient. To answer your question directly, we would not. Our idea is to sedate the patient so that the patient will not have a physical or spiritual or psychological symptom. No studies on that will ever be done because there would be no approval to do a study like that.

We know when we look at the patient physically—if the patient is looking comfortable, without distress, without moving their arms and legs around too much, and not feeling; even with those patients who are sedated or unconscious we have a way of seeing—whether or not they are distressed. We use those criteria to see whether the patient is distressed or not. Sometimes the patient might grimace, might make a face. Sometimes they might moan. These are things that we keep an eye out for. My feeling is that, with palliative sedation, we can manage all those symptoms. But a study on whether we definitively know that this patient is completely out of distress is something that has yet to be done.

MS CHEYNE: There is something I am really keen to hear from you. You said that palliative care needs more resources. Can you give us a dollar figure or at least expand on what is needed? I think you mentioned that home-based palliative care is an area that we want to do better at.

Dr Kanathigoda: Yes.

MS CHEYNE: But how we do better at that needs something.

Dr Kanathigoda: Yes.

MRS DUNNE: Could I interpose? The chair and I have just been discussing this. Could you give a brief summary and then come back to us in writing about, if you ruled the world, how much money you would need?

Dr Kanathigoda: I would be more than happy to do that, with Mark and the rest of them, yes.

THE CHAIR: Yes, just noting the time also. I had a few queries that were the same as Mrs Dunne's.

MRS DUNNE: I think that delving into the dollar figure is an important one for us.

Dr Kanathigoda: Yes.

MS CHEYNE: Could you give a three or four sentence answer just to stimulate us for future discussions.

Dr Kanathigoda: Yes, in two or three lines I have to say that, as I said, we need more money in mainly home-based palliative care, outpatient clinics and infrastructure as well because the infrastructure we have at the moment is not very well equipped. We need more money to expand the service. We have a research unit functioning at Clare Holland House which is run in one room. Education is run in a small room. We need more infrastructure resources as well as human resources. For example, we need a psychologist. We need more social work hours. We need a gym. At the moment there is an inpatient gym, which is a very small room. But we need an outpatient gym.

THE CHAIR: As in "gym"?

Dr Kanathigoda: Yes.

THE CHAIR: Sorry, I just wanted to clarify that.

Dr Kanathigoda: We need an outpatient gym so that our patients can come and feel that they are living and also improve their quality of life. Also, we need a diversional therapy service, which is operating in all other jurisdictions except in the ACT. I can go on, but I can only do as you suggested. We will go through all those things.

MRS DUNNE: Provide to us, on notice, what your budget submission would be.

Dr Kanathigoda: Yes.

Mr Green: May I add a couple of dimensions to that? You would have noticed from our submission that the projections suggest that by 2027 we are looking at a home-based or non-residential special palliative care service which is double that of the present; so that is a significant change.

Suharsha mentioned activity-based funding. Following the discussion, if we move to activity-based funding, as many jurisdictions have, in this dimension of end of life care we need to make sure that that activity is holistic so that we are not funding, if you like, just the medical dimensions of it but we are looking at the whole of the psychosocial allied health components.

When we look at the unit of activity, there must be enough allowance made for the human dimension—in other words, that these interactions that people are having, which are the last interactions they are having in their lives, are not five-minute commercial exchanges. They are actually opportunities for people to ask some very serious questions about their life and to reflect on some very serious things. To offer that dignity in the dying time and presence are as important as the actual physical time and presence—

MS CHEYNE: Time and presence of people.

Mr Green: of people and so on. It is interesting. Probably one of the reasons that we are sitting around having a discussion in our society in this time is that our society has changed. We do not live in a village. People’s lives are much more complex. The milieu in which we live our lives is much more complex. Our understanding of choice has changed. All of these dimensions, as with any change journey, have to be negotiated individually as well as collectively. What the individual is going through as they live the last 12 months, six months, three months, weeks of their lives is not dissimilar to the journey that all the people around them and our community at large are going through. So we have to have time.

MRS DUNNE: Is part of that that we do not now normalise death?

Mr Green: Yes, I think that is very accurate. We have lost a familiarity with death that once perhaps we had. I spent 3½ years in my recent life living in Timor-Leste. The primary care services there were very inadequate. So death was a familiar companion. People lived with it every day. Those of you who know the history of East Timor would know that for 400 years the Timorese were living with the constancy of death, dying and violence. But because of that people have a resilience and a capacity to navigate that change and that trauma that perhaps is different from ours. They are more practised in its everyday reality, whereas in our world that we live and move in, death is much more remote from us. It is managed differently. It is not a personal, familial thing. There are funeral homes. We have found ways, if you like, to separate ourselves from the experience.

I also think that, in this conversation we are having, if that is the case, how do I befriend death? How do I befriend my own death? How do we help people on that journey when our actual experience of it and our craft, not at a specialist palliative care level but just at a human level, have diminished? If that is the case, like in many other craft groups, we turn to the specialist to help us navigate a space which is unfamiliar and I think we need to resource that.

MS CHEYNE: Following on from that, could you perhaps provide, on notice, some suggestions? How could we be better at familiarising, or re-familiarising perhaps, people with death? I think some of the evidence given this morning might come as a surprise to people about what dying looks like and why fluids are withheld—things like that that family members might find distressing. What resources or options might be available to make that a better experience for people and make people more comfortable with death, dying and ageing?

Mr Green: We are having a conversation about this precise topic this afternoon. One of the things Calvary is hoping to do is provide a resource. It might be video footage or a storytelling suite of resources to address these very things.

MS CHEYNE: Thank you.

THE CHAIR: Before I go to Ms Le Couteur’s substantive question, I note in your submission that, on page 12, you talk about the fact that 75 per cent to 80 per cent are in favour of voluntary assisted dying. But, basically, what you have just said now is that in Australia we have little understanding about death. Therefore, as Ms Cheyne has just asked, it would be great if you could provide us with some of that information on notice.

You also mentioned advance care planning in your submission. I personally believe that that is something that is not talked about enough in society. There was only a short bit in your submission about advance care planning. Could you also expand on that in your response to Ms Cheyne?

Mr Green: Yes.

THE CHAIR: That would be fabulous, thank you. I am asking you to do that so that I do not take up too much time.

MS LE COUTEUR: Talking about time, I am actually concerned.

THE CHAIR: We have spoken to our next witnesses and we have let them know that we are running a little over time.

MS LE COUTEUR: We will need at least a half hour to allocate to them.

THE CHAIR: Absolutely, yes.

MS LE COUTEUR: There was a thing in your submission that I was surprised about. You thought that the most significant problem with the Victorian legislation was their failure to say exactly what the drugs were.

Mr Green: A significant failure, yes.

MS LE COUTEUR: My computer is closed down. I will find it in a second, but I thought you said it was the most significant. Anyway, whether it was “a significant” or “most significant” I was very concerned, very surprised. Yes, you said it was perhaps the most significant failure of the Victorian system. Can you say a little more about why you think that is the most significant? I would have assumed, obviously as a layperson, not a medical person, that this was something that it was possible to research and a good answer found, that it probably was not particularly appropriate for the parliament to say, “We actually know the best way of doing this.” The people who are drafting the legislation are not medical professionals.

Mr Green: I will say a couple of things as background. I think in our submission we referred you to submissions that we have previously made to both the New South Wales and Victorian parliaments. The context of saying that was that when the

Victorian legislation was being discussed by the AVMA panel, and even when the bill was first introduced, the medical or the clinical regimen—in other words, what is the substance that a person would ingest that would assist them to die, to kill them—was not determined.

In other words, there was no data being presented in any of the conversation about what that regimen should be. At the time, you will recall, there was considerable controversy going on in some jurisdictions in the United States with respect to the concoction that was going to be used to execute by lethal injection prisoners who are on death row. You will remember those conversations. There was also at the time the Supreme Court decision in Canada. The supreme court in that jurisdiction found that there was a human right to have access to patient-assisted suicide, patient-assisted dying, and that the government had to make provision for that. There was a time limit running.

Some of the clinical regimens for providing that service were coming out. They are reproduced; so we will not labour the point. They are reproduced in our submissions to both the New South Wales and Victorian parliaments. If you look at that regimen, it is quite a complicated protocol. This is an intravenous methodology. If you read it, it has a certain effect on you. It would have a certain effect on a person.

Actually knowing what is the substance that is going to be used is an important factor, we were arguing, in thinking about this whole question. I do not agree with it, nor does Calvary, but if your argument was that you were introducing this because you wanted to help people to die in the most efficacious and pain-free manner possible, to actually then introduce a substance which caused vomiting, seizure and other physical symptoms which are distressing would be actually to militate against the very thing that you were trying to achieve. That was the context in which we were making that point. I hope that helps a little. Did you want to add anything?

Dr Kanathigoda: The thing is, in some respects it is not easy to kill a patient.

MRS DUNNE: That is the second time someone has said that to me in the last 24 hours.

Dr Kanathigoda: It is very hard. My feeling is that, in doing this voluntarily, people think that it is easy, but it is not. If this legislation is passed and if this is going to happen here, one of the greatest concerns that we have is what happens when the patient does not die and then has all these other symptoms going on and continues to live. In that case, we will not abandon the patients. What I am try to say is, for example, if somebody—our patient—takes this medication at home, as per the legislation, and they might be one of our home-based patients, we will still look after that patient's symptoms until the patient passes away.

What I am trying to say is that that is why I say palliative care and EAD are two completely different things. Because EAD is EAD but palliative care will still continue even after the EAD. How can we not look after a patient who is in distress, who is still suffering? That is our job. We will continue to look after them as a home-based patient or an inpatient, as the case may be.

But my concern is if you do not know how to do it properly and if the patient suffers—palliative care patients do not know how to do it properly. I am telling you now straight away, because we are not taught those things in medical school, nor are we taught this at the specialist level. We do not teach this to our registrars. It is a hard thing to do. So my feeling is that eventually, if this is passed, whoever does this will have to know exactly what they are doing or else the patient is going to have enormous suffering. This has happened previously and it will happen in Victoria.

MRS DUNNE: I want to follow on from that. When the committee travelled to Victoria we discussed this: that there is still no modality of treatment. At some stage for the legislation to become effective in Victoria there has to be a modality of treatment. I think that most unqualified people think that you just take a pill or have an injection and you sort of drift silently off into the next life. I understand that there is considerable literature about the contraindications. The contraindication seems to be death but there are a whole lot of other, lesser contraindications. There is substantial literature that indicates that sometimes the death is protracted, uncomfortable and the like. Could you provide references to that to the committee, on notice?

Dr Kanathigoda: Yes.

MRS DUNNE: Thank you.

MRS KIKKERT: I have been very impressed with the discussion. Dr Kanathigoda, you are fantastic palliative doctor.

Dr Kanathigoda: Thank you.

MRS KIKKERT: Thank you for your service. How many palliative doctors are there here in Canberra?

Dr Kanathigoda: If you look at the full-time equivalents, we have got 4.0 FTEs for the whole of the ACT plus New South Wales.

MRS KIKKERT: In Calvary?

Dr Kanathigoda: No. Calvary has 3.2 FTEs, whereas the Canberra Hospital has 0.8 FTEs.

THE CHAIR: And that is a palliative care specialist?

Dr Kanathigoda: That is a palliative care specialist. I am talking about palliative care specialists. Plus we have two advance care registrars only based in Calvary and Clare Holland who are full time. And we have a resident palliative care specialist who works at Clare Holland on a full-time basis who comes from the Canberra Hospital.

MRS KIKKERT: Is that enough to provide the service that you want to provide?

Dr Kanathigoda: No.

MRS KIKKERT: How many more palliative specialists do you want to get on board?

THE CHAIR: Sorry to interrupt, and I am happy for you to answer—

MRS KIKKERT: You could take it on notice, yes.

THE CHAIR: But I just thought that might be part of the information you provide to us.

Dr Kanathigoda: Part of that, yes.

MRS KIKKERT: You were talking about projections.

THE CHAIR: Sorry to interrupt, Mrs Kikkert.

MRS KIKKERT: Most of my question were answered before.

THE CHAIR: Thank you so much for coming in to speak to us today. I am sure that we, as a committee, could continue to speak to you. But unfortunately we have gone well and truly over time. Thank you for also taking some of our questions on notice and agreeing to provide information to us. I will just very briefly ask if it is okay, as we may, as a committee, have more questions, that we provide those in writing to you as well for your feedback?

Mr Green: That is fine. Sometimes when you get a question in writing you want to clarify the context or get a bit more information. If there could be a bit of argy-bargy or a bit of toing and froing to make sure we have understood it, that would be helpful.

MRS DUNNE: Mr Green, you are not Canberra based?

Mr Green: No. I am based in Sydney. Frances is Canberra based and so is Suharsha.

THE CHAIR: Thank you for travelling to be here today.

Ms Brown: What time frame do you want these questions back?

Mr Green: Yes, that would be helpful to know.

THE CHAIR: As soon as practicable.

MRS KIKKERT: Could you also add in there how much funding you currently get?

Mr Green: Yes.

THE CHAIR: A proof transcript is provided to you to read and provide an opportunity for you to check the transcript and suggest any corrections that may be required. Generally speaking, we ask for questions taken on notice to be provided back to the committee 14 days after you receive the proof transcript, noting we are not going to hold that deadline steadfast.

MRS DUNNE: I think that we might take Mr Green's point that there may be a conversation about exactly what it is that we want.

THE CHAIR: Yes. I thank you for appearing today. As I said, a proof transcript will be provided to you. Thank you so much.

MOBBS, MS JENNIFER, Chief Executive Officer, Council on the Ageing (COTA) ACT

FELDMAN, MR PAUL, Chair, Policy Committee, Council on the Ageing (COTA) ACT

THE CHAIR: Welcome to today's hearing, the first hearing. Before we get started, could you just confirm that you have read and understand the privilege statement that was forwarded to you. It is sitting there on the table if you would like to refresh.

Ms Mobbs: I have read it and I agree to that, yes.

Mr Feldman: Yes, I agree to that also.

THE CHAIR: Do you have a brief opening statement you would like to give to the committee?

Ms Mobbs: I wear many hats and deal with many topics at times, but today we would like to just talk about end of life, particularly end of life care. My concern is that everyone needs a choice in life. We get choices right from the beginning of our existence, and I think we need choices at the end. One of the things that we put in our submission concerned the fact that we might consider a move from concentrating on saving people no matter what to giving them a choice of their wish to die. And the national recognition of advance care planning is something that we need to incorporate in our thinking.

A little while back, when we were planning our work plan for COTA ACT, which constantly goes off the rails, we thought that we would have Wednesday afternoon education sessions for older Canberrans, this group of Canberrans that is increasing. We planned a whole heap of Wednesday afternoons from now until almost November. Two weeks ago, we ran a session on end of life planning, thinking that we would be lucky if we got 60 people. Well, 120 people enrolled in that particular afternoon's course, run by ACT Health and people from the Canberra Hospital. People did not even RSVP; they just walked in. It was an interesting afternoon. Anyway, the session was well attended, so obviously that is a really big issue in Canberra. We have decided to slot another session in in three weeks time, and already 70 people are enrolled to come to that particular session. We can take 100 people in the hall comfortably, but 120 is a very big squeeze.

So that is one of the issues that COTA, representing older Canberrans, will have at the forefront of our thinking on this particular issue. Paul, do you want to say anything to lead in?

Mr Feldman: Yes. I chair COTA ACT's policy committee, which is a group of people that meet to consider issues of policy relevant to the welfare of older Canberrans. I would just like to say that our submission is basically in two parts. We do have a developed position in relation to the provision of palliative care. In relation to the provision of assisted dying, we have really done no more than attempt to map out the risks and the possible mitigation strategies that can be used to manage those risks with assisted dying.

In relation to the first part, our position on palliative, it is being informed by our colleague organisation, the Health Care Consumers' Association of the ACT, who have done a lot of work in that area and have, like your last set of speakers, pointed to the need for the expansion of palliative care services in the ACT to include the home setting, aged care and a more enlightened approach to the delivery of palliative care in the hospital setting.

We see that in the hospital setting there is still a residual kind of cultural problem where medical practitioners sometimes see themselves as having a mission to prolong life at all costs. At a minimum, we would like to see that where a person's advance care plans provide that they receive palliative care rather than a succession of heroic, life-prolonging treatments right at the end of their life, their wishes be respected.

In relation to the rest of our submission, which concerns assisted dying, we take a much more objective, distanced approach, you might say. The guidelines for the submission quite properly invite respondents to identify risks associated with assisted dying and strategies to manage those risks. The identification of those risks is a common-sense process that any of you could have conducted, and similarly, with the strategies for management, there is no special education needed to identify and enumerate those.

What we think we can bring to the table in relation to consideration of those risks and strategies is the capability to conduct a survey of older Canberrans, who are obviously the people who are most likely to be impacted by or to benefit from the availability of assisted dying. We are confident that we can frame the survey questions in a way that would result in a fair kind of assessment of popular views on those issues.

THE CHAIR: Thank you.

MS CHEYNE: Thank you very much for appearing and for your very considered submission. I think it is quite clear where you stand as an organisation, but I did want to tease out that it could be argued that the Victorian legislation is too restrictive in that particularly the last-minute change to get that legislation through reduced the likelihood of passing away from 12 months to six months, and naturally that rules out some conditions which are terminal and can have quite a lot of pain associated with them.

From the sessions that you have had with your members or the conversations that you have had more generally in your committees, what has been the view that has been put forward there? If an assisted dying scheme were to operate in the ACT, what would that time frame ultimately be, and should it be only for time-limited life prognoses? Should that be tested? Are you able to expand on that a bit?

Ms Mobbs: You can talk to that, Paul. Personally, I do think it is quite restrictive, and I have talked with COTA Victoria about their input into that, but it is something that is in place now.

MS CHEYNE: Yes.

Ms Mobbs: I would say that that is probably better than nothing in place.

MS CHEYNE: Yes.

Ms Mobbs: Paul might expand on that.

Mr Feldman: I was going to ask you about consultation. I imagine that people who attended the forum that you referred to would have expressed some views about the availability of assisted dying.

Ms Mobbs: They have not in particular. That has not been an issue that we have taken up more broadly with our constituents. But the fact that people want to have a say about what is going to happen to them later in life is interesting. In fact, a lot of the 120 people who came in two weeks ago have made individual appointments. We work with the Canberra Hospital. The staff come down and I find them spaces in our office, often in my office, so I go somewhere else. They come down individually and work through that end of life planning, which is not an easy thing to do. I took the forms home myself and got to question 2 and thought, "This is all a bit hard; I do not think I can do this."

So we have actually worked with the Canberra Hospital. They work through that form, which is about 19 pages long. It takes considerable thought about what you really want. I would like that to be more recognised. I have heard from people who come into our office, and their relatives, who say that the doctor has not respected that particular plan and they have made the decisions for the family and have said to the family, "Leave it with me. I am the one who knows what your parent wants or needs." That is an issue we deal with all the time.

THE CHAIR: We heard about this when we were in Victoria as well. They have recently made some changes to their legislation separate from voluntary assisted dying.

Ms Mobbs: Yes, that is an issue that we hear about.

Mr Feldman: In relation to the possible deficiencies of the Victorian scheme, what led us to spell out some of those were the personal experiences of acquaintances and friends who had suffered things like motor neurone disease, Parkinson's disease and a certain form of multiple sclerosis that involves a deteriorating quality of life over many years.

We think the question at least needs to be asked as to whether the availability of assisted dying ought to be extended beyond the time limit specified in the Victorian legislation. In the case of dementia, there is the added factor that if a person reaches the period specified in the Victorian legislation of 12 months for a neurodegenerative condition, they may well at that stage be incapable of giving conscious consent.

THE CHAIR: Yes, absolutely.

Mr Feldman: These are not easy issues, but we think that the committee should have the courage to put them on the table rather than regard the Victorian legislation as a kind of safe option.

THE CHAIR: Or a template.

Mr Feldman: Yes.

THE CHAIR: Thank you.

MS LE COUTEUR: Do you want to say more about the dementia issue? I thought that was one of the most interesting issues in your submission. My experience is that many people who are getting close to end of life are not as mentally acute as they used to be. They may or may not have been diagnosed as having dementia; they are not what they used to be. They may have had very clear views earlier in their life—I suppose I am speaking here from personal experience—and have had absolutely no qualms whatsoever in people knowing that a few years ago they would not have wanted to be there, but they are significantly not capable. Do you have any views, given that this is, as your submission said, an ever-increasing problem and it is not likely to change, because as people deteriorate physically they deteriorate mentally as well?

Ms Mobbs: From my point of view, it is about encouraging people to think about the fact that every day we get a day older. While we plan lots of things—we plan our wedding, we plan this and we plan that—we do not plan to get old. Being old is not terribly trendy, particularly not in Canberra. We really do have to get the word out to people about planning for your life and that the end of life needs to be planned. I am not sure how we get that message out to people in their 30s, 40s and 50s, but we must, because if we do not, we will end up with a lot of people in that situation where they will have things done to them that perhaps 20 years ago they would never have agreed to. Paul knows a lot more about dementia than I do. Do you want to speak about that?

Mr Feldman: Just to pick up Caroline's point, there is certainly such a thing as mild cognitive decline, progressive cognitive decline, which is something medically distinct from various forms of dementia. As you would know, there are forms of dementia which are quite aggressive. Frontal lobe, Lewy body dementia incapacitates people quite quickly. Alzheimer's takes a period of years. But mild cognitive decline can be present for many years, and it is a progressive thing.

This, to me, underscores the importance of people in their 50s framing advance care plans and reviewing them regularly, and for those advance care plans to be expressed in a way that is simple enough for them to be able to grasp the essentials as they look at it year by year. That, to me, would extend beyond expressing preferences for palliative care as opposed to what you might call heroic medical treatment in the last weeks of life, to questions of assisted dying, if there is community support for that. That has to be part of the ballpark consideration, I think.

MS LE COUTEUR: I could talk more about that issue because I think it is one of the most fundamental issues. The Victorian model is basically only for people who are mentally absolutely fine and clear. My experience within my own family, and wider than that, is that by the time the end of your life is getting nearer you are unlikely to be in that position. You are likely to have problems. The advance care directives are not going to go to that level. At present an advance care directive would not be able to say, “Five years ago I said what would happen if I was in this situation.”

MRS DUNNE: I did. I want to go to the thrust of your submission because I am a little unclear. What is the formal position of COTA on the issue of voluntary assisted dying, simpliciter, as opposed to the range of other things? Reading your submission and hearing your comments today, I feel that there is a disconnect. Is there a formal position by COTA in relation to voluntary assisted dying, not taking into account the other things?

Ms Mobbs: No, there is not. It is a matter of choice.

MRS DUNNE: That is what I thought, but there were some things that you said, Ms Mobbs, that were from a personal point of view, and I wanted to clarify that COTA does not have a formal view.

Ms Mobbs: No, we do not.

MRS DUNNE: But you have spoken and written extensively, and you have given examples of how important the ageing community takes the issue of advance care planning, and you have said that it is complicated. Does COTA as an organisation or do you as individuals have views about how that might be simplified and made more effective?

Ms Mobbs: I am not sure that it can be simplified because there are so many issues there that people have to think through medically. The other thing is that if someone from the ACT prepares an advance care plan and then moves to live on the south coast, which many do, the ACT plan does not apply in New South Wales. That national issue needs to be tidied up.

THE CHAIR: I think we heard evidence of that in Victoria as well, about how it does not transfer across boundaries.

Ms Mobbs: That is right, and it is the same with people moving to the ACT. If they bring one from another state, it does not apply here. I do not think people know enough about them.

MS CHEYNE: While it is an individual choice about whether COTA members support voluntary assisted dying, does COTA have a view about overturning the federal legislation that restricts the ACT in making its own legislation on this matter?

Ms Mobbs: Individual members have their own point of view.

MS CHEYNE: Same again?

Ms Mobbs: Same again.

MS CHEYNE: I just wanted to check.

Ms Mobbs: We have not canvassed the whole of the community, and we would do that if we wanted to ask that question.

THE CHAIR: Thank you for appearing, and thank you also for allowing us to run a little bit over time with our previous witnesses. I want to declare that I have quite a strong affiliation with COTA nationally, just to put that on the record.

I have lots of questions about your submission, but when you were giving your opening statement, Ms Mobbs, you noted that you had 120 people arrive at the seminar or information session that you provided. I would like to know a little bit more about the information session. Was that really targeting end of life choices, including assisted dying, or was it literally about thinking about choices for care at end of life?

Ms Mobbs: It was not particularly for end of life. It was about planning. As you said in the last bit of that statement, it was thinking about all of the things that you need to think about to plan the end of your life, including health. It covered some other issues like power of attorney, but only minutely. It was mostly about thinking about all of your health options, finding people that you trust and having them around you.

THE CHAIR: Leading on from that, you also noted, and you have provided evidence today, that the advance care planning system is not great.

Ms Mobbs: It is difficult.

THE CHAIR: Have your members expressed views to you? I know you have your own personal view, but have your members expressed views to you about how it could be made more simplistic? Are your members even aware that we have those care directives and plans?

Ms Mobbs: It is an interesting thing. Until the 120 people turned up, I had not thought specifically about asking that question, but it is something that we will address now. I will take it back to our very active policy committee as an issue. I think it is bigger than I thought it was. We could ask people about that and also publicise it more than we have. We have advertised our sessions that we run, but I have not actually asked the question: do you know what is in it? How can we make it better? We could work on that, but we have not done that yet. That is something to add to my never-ending work plan.

THE CHAIR: Exactly. How many members does COTA ACT have?

Ms Mobbs: We have about 5,000 now.

THE CHAIR: It is growing.

Ms Mobbs: Yes, it has grown since I have been there. It was about 2½ thousand when I started and now it is about 5,000. So we are doing well.

MRS KIKKERT: My question goes back to your submission, in which you stated:

> An official policy emerges of encouraging assisted dying as a means of containing costs.

> This could be managed by criminalising deliberate instances of this, and by public education.

I am curious: how can you prove that a criminal act has been conducted in a situation where assisted dying is being dealt with?

Mr Feldman: I think you are referring to one of the social risks—

MRS KIKKERT: That is right.

Mr Feldman: and an official policy emerges of encouraging assisted dying as a means of containing costs. There is evidence of that in the American context. For example, people in the state of Oregon have had the option of assisted dying extended to them in a rather callous way by the health bureaucracy in that state as an alternative because they do not qualify for expensive, potentially life-prolonging treatment. I would consider that to be a kind of bureaucratic malpractice rather than a criminal act. It is an instance of where the judiciary could act to circumscribe the way the bureaucracy, health insurers and nasty entrepreneurial medical practitioners could start operating in that space. That is the only instance I am aware of. I am not aware of shocking instances where it has been abused. They may exist in places, in totalitarian societies.

MRS KIKKERT: Let us hope not. Thank you.

THE CHAIR: Thank you so much for appearing today. We really appreciate everything you have had to say. For your information, when available, a copy of the proof transcript of today's hearing will be forwarded to you. You will be provided with an opportunity to check the transcript and suggest any questions, if need be. On behalf of the committee, I again thank you, Ms Mobbs and Mr Feldman, for appearing today and for letting the committee ask questions of you.

TAYLOR, MR ANDREW, Public Trustee and Guardian
THOMPSON, MS CHRISTINA, Director, Guardianship Unit, Public Trustee and Guardian

THE CHAIR: I would like to thank the Public Trustee and Guardian for appearing today. Can you confirm on the record that you understand the privilege implications afforded to you and that you have read and understand the statement in front of you?

Ms Thompson: Yes.

Mr Taylor: Yes.

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

Mr Taylor: We appear here as Public Trustee and Guardian and a deputy public trustee and guardian. In the role as public servants and independent statutory office holders we do not appear in a personal sense at all and any of the points or comments or submissions that we made were purely made in relation to our own role as public servants and statutory office holders. Some background: the Public Trustee and Guardian is a relatively new agency, formed in 2016. It was a result of the merger of the public trustee and the former guardianship role of the former public advocate and is the only jurisdiction in Australia where the two roles are combined in one single decision-maker. However, they are kept quite separate.

We represent around 200 people for guardianship purposes and a small number of people as attorney, under power of attorney, for what you might call guardianship, personal and healthcare matters. We represent around 700 people with a decision-making disability in total in the sense that we are decision-makers for those 700 people.

In respect to guardianship we can only be appointed as a guardian as a last resort. The legislation prefers that an individual be appointed and where an individual is either unwilling or incapable or not proximate to the person then the ACT Civil and Administrative Tribunal will defer to the Public Trustee and Guardian as the person’s guardian. It is also interesting to note that once a direction is made appointing the Public Trustee and Guardian we are immediately active as that person’s guardian and that, under a power of attorney, when the person appoints us as their attorney for similar matters the person must make that power of attorney in their capacity and it commences on their incapacity.

The roles of guardian and of attorney are quite distinctly separate and different, although they do involve similar thinking and discipline. The types of decisions that we would make as a guardian are entirely in accordance with what the tribunal’s order is for us to do. And they may include things like accommodation, where the person lives and with whom; medical, consents to giving treatment; legal, Family Court, family provision matters; health and welfare, NDIS and mental health.

There are a few more relevant points. During the 2016-17 financial year when we represented as guardian, the breakup of male to female was 63 per cent female to

37 per cent male. Of the 200 people that we represented as guardian, 63 per cent of them were female and 37 per cent were male. In the same year the largest cohort of those represented were those with a mental illness, 38 per cent, and people aged between 66 and 90 years of age formed 68 per cent of those that we represent as guardian.

THE CHAIR: Maybe the committee could ask you some questions?

Mr Taylor: Yes, for sure.

MS LE COUTEUR: I will not ask you about voluntary assisted dying because it seems fairly clear from reading your submission that you are not in a position where that would be something that would be relevant to your decision-making, and that is quite possibly appropriate. I am wondering about your role, obviously, in palliative care issues, where people are approaching their end of life and there can be some quite complicated decisions as to whether or not this treatment is futile or desirable. How do you find managing that part of end of life but not the actual—

Mr Taylor: Our decision-making is confined strictly in terms of a guardian by a set of decision-making principles that are established in the Guardianship and Management of Property Act. As an attorney, however, we are there to represent the person's wishes totally. We act for them in terms of their wishes, and we are not guided, necessarily, or responsible to or reviewed by any other agency as an attorney. Having said that, though, an attorney cannot do something that is unlawful, even if requested to by the person.

If I just step through, in answering that, some of those principles, the most important of those principles is that the person's wishes, as far as they can be worked out, must be given effect to. In giving effect to the person's wish, if that would significantly adversely affect the person's interests the decision-maker must give effect to the person's wishes as far as possible without adversely affecting their interests. If the person's wishes cannot be given effect to at all, their interest must be promoted. It is person centric.

The decision-maker must also consult a person's carers, unless by doing so this would adversely affect the person's interests. I cautiously give an example that perhaps, say, a person's carers were of a particular religious belief and the person themselves were not, and consulting with the person's carers, they may say, for example, "We would not want our son to have a blood transfusion," but you know that the son's views and wishes are that he would, then the decision-maker may not have regard to the carers' views.

In practice, for example, a guardian could be requested by a doctor to make a decision in respect to a person's medical treatment where the person did not have decision-making ability and was subject to guardianship. If, for example, the doctor's request was for a decision, giving the previous example, to give a blood transfusion and the guardian was aware that the person objected to such a procedure, for personal reasons or religious reasons or whatever, the guardian is placed in a position where, on the one hand, they are required to give effect to the person's views and wishes and, on the other hand, abiding by the person's views and wishes might significantly adversely affect the person’s interests, as it may result in death. In a situation such as this, a guardian does not try and balance the respective interests or wishes of the doctor against those of a guardian because quite simply the guardian cannot make a decision which might assist or be seen to assist or result in a person’s death.

In a situation like that, we would refer the matter to the courts. A matter was referred to the courts in 2009, similar but slightly different, where a person was fasting, amounting to starvation, and it was life threatening. The doctors were employed by the territory at the time. The territory brought the matter before the court for a declaration that it is unlawful for the medical practitioner to desist from affording other than palliative care to the person. The court found the territory is no more entitled to refuse treatment to this person than any other person in its care who is unable competently to refuse it. In effect, the person remained under a regime that required competent and effective treatment. The court did not enhance the person’s wish or right to refuse to eat.

MS LE COUTEUR: Was the person forced to eat?

Mr Taylor: Sorry?

MS LE COUTEUR: Did this end up with the person being force fed? Do you still allow the person’s right to not eat?

Mr Taylor: I think the result was that the person had to be treated, which included being forced to eat. A guardian is quite outside that stage of decision making but I make the point to the committee, because we are drawn very, very close in everyday decision-making to those kinds of decisions, at the present moment the law is such that a guardian is not and perhaps should not be the person that makes decisions of that kind.

A power of attorney situation is quite different. There are not the decision-making principles in the Powers of Attorney Act that there are in the Guardianship and Management of Property Act. However, there are some guiding principles in the Powers of Attorney Act but the role is quite significantly different. The role of an attorney is to represent the person, to do what they want you to do, unless of course it is unlawful.

MRS KIKKERT: Thank you both for being here today. You relate on page 5 of your submission to Dr Karen Hitchcock’s story in the March *Quarterly Essay* 2017 about Fred, a man with quite severe heart failure who thought himself a nuisance and wanted to go to a hospice and die. And then his situation changed. Do you think it is dangerous to allow for the legalisation of assisted suicide for people such as Fred, who may have chosen to take the option of euthanasia or assisted suicide had it not been for the intervention of someone willing to listen to him and also provide him with practical care?

Ms Thompson: I think that is a very difficult question, because the idea of danger means that you have to weigh up a number of factors, and each individual situation is different. In relation to Fred, there certainly were some aspects to his original decision or his original comments that could be counteracted by some other intervention at that point which then changed his mind. For some people, that will be the case, that there are drivers that lead them to think along those lines and some kind of more positive intervention can change it. But others will hold fast to that original decision. It is a difficult question to answer, because I actually do not know Fred. But as a theoretical comment it really would depend on the individual circumstances.

THE CHAIR: Regarding the Medical Treatment Planning and Decisions Act 2016 in Victoria, we heard a lot of information about the changes that were made to that act during the debate on the assisted dying legislation. Are you aware of that particular act and, if so, do you have any comments on some of the changes to the act?

Mr Taylor: We are certainly aware of that, but we are well aware, too, that the Victorian legislation has not provided any ability for the guardian to take any greater role than they might previously have had. It certainly had regard to the submission made by the Public Advocate, but it has not gone any distance at all towards giving the Public Advocate, in their role as a public guardian, authority to consent to administer medication to cause death.

MRS DUNNE: The Medical Treatment Planning and Decisions Act, which is what Ms Cody was talking about, in shorthand terms is about advance care planning. Does the Public Advocate or the equivalent in Victoria have a role in that process? In the ACT, even if as a public guardian you were not a decision-maker but as someone involved in decision-making in that space, would you see there is scope for law reform in that medical decision-making space, short of voluntary assisted dying?

Mr Taylor: It could be that there had not been a guardian, but in the case of a person with a decision-making disability only it is likely a guardian would have been appointed. It could have been a private person; it could have been the Public Trustee and Guardian. I think a distinction has to be drawn to the actions of the guardian leading up to that, but I do not genuinely believe the guardian should be involved in that ultimate decision.

MRS DUNNE: Sorry, Mr Taylor, you have misunderstood my question entirely. I am not asking about voluntary assisted dying; I am talking about the structures you have as a decision-maker in that space of making decisions about people’s medical procedures, in the limited way that you do. As a decision-maker and as a public servant, do you see the need for law reform in the ACT in relation to medical decision-making? I am talking not about voluntary assisted dying but about the other panoply of medical decision-making. You say in your submission that there are odd interactions between the legislation in place in the ACT. Do you see there is a need for law reform to address those and, if so, how would you do it?

Ms Thompson: We are involved in advance care planning in the ACT up to a point. We certainly do a lot of education sessions advising people around the various options. We work closely with the advance care planning unit at the Canberra Hospital. Obviously we help people make an enduring power of attorney, which is one of the options here. It is difficult because guardianship in its purest form is a substitute decision-making paradigm. There is movement internationally as well as locally to remove guardianship in favour of upholding the United Nations convention on the rights of people with a disability, particularly article 12, and moving towards more of a supported decision-making environment. That works in well with the advance care planning. At the moment we have a number of options you can take. A statement of choices can be made by the person with capacity or can be made after the loss of capacity, in conjunction with an attorney or a guardian at that point. So there are avenues to actually interact.

I do think there should be legislative reform because at the moment what we see is too many options arising in too many different environments that mean people do not know what is available to them. But, more than that, the people who are receiving the consent and the decisions, the people like health professionals—we are talking specifically around medical at the moment—will often get called by the doctors, asking for advice. They have in their hands an enduring power of attorney, but they do not know how to read it; they do not open it; they do not know what to look at.

THE CHAIR: The doctors do not know how?

Mr Taylor: No.

Ms Thompson: Frequently. One of the things Mr Taylor is part of is an incorporated company called the Australian Guardianship and Administration Council, and all the public guardians, public trustees, public advocates and heads of tribunals around the country are part of this incorporated company. They are looking very closely at and advocating for a single consistent enduring power of attorney across the whole country. That is obviously difficult because every jurisdiction thinks they have the best legislation. But I think that would help because doctors and medical professionals would actually know where to look and what they are looking for. There would be some consistency in that regard.

I think we can improve on the legislation, but I think we also need to improve on people’s ability to reference the legislation and have a look. If people are not opening the documents that we already have under legislation, if they are not looking at what appointments the attorney or the guardian has, what limitations the person has put on those attorneys or the limitations the guardians have, then we are still a long way from having successful legislation.

MS CHEYNE: We heard this in Victoria as well, that sometimes doctors were not even opening things or were not aware that they existed. That was a good point you made. We get medical practitioners routinely saying, “Oh, hey, we’re going into palliation. Is that all right?” It is a fundamental human right; you do not need to seek consent. So there is that lack of knowledge. It is a kind of two-pronged approach here: we need legislative reform because too many acts are confusing things, but we also really need to bump up the education of our people who are receiving that consent.

Ms Thompson: Definitely.

Mr Taylor: There will be statutory change arising out of the recent review of the ACT’s guardianship laws. The government is still trying to determine how it is going to implement the recommendations contained in that review. One of the significant changes, as Christina mentioned, relates to this concept of supported decision-making and whether that should be something that might be introduced in a less formal way through the tribunal and through the actions of guardians and managers or merely just a change in definitions of what the role is.

Certainly around this Australian Guardianship and Administration Council the federal government has tasked the council and funded the council with the job of harmonising power of attorney laws around Australia as well as establishing a national register of enduring powers of attorney or powers of attorney. It seems that every state and territory wants to rush towards establishing a national register. I guess it is appropriate for me to say that I have my doubts about whether that is the best thing, and I am on record as having expressed what those doubts are.

I think it is going to get down to who runs the national register, whether it is the commonwealth or the states and territories. With the best of intentions, it is never going to be up to date. For example, somebody might have revoked a power of attorney at law, but how long is it until that gets on the register and becomes subject to public notice? Do you really believe that at 2 o'clock in the morning a doctor is going to get on a 24/7 register and pretend they can understand what a person was attempting to say in a healthcare power of attorney—that they specifically wanted this to happen—and to interpret that? I do not think that is going to happen.

We find now that, faced with an emergency situation, a doctor will do what a doctor has to do, and that even may be the case where a person has a power of attorney in place. But I am talking about emergency situations where it is life and death decision-making. Doctors make decisions, even now.

Interruption in sound recording from 11.49.59 to 11.53.21—

THE CHAIR: Is there a difference between a personal guardian and the role of a public guardian under legislation?

Mr Taylor: Not under the legislation.

Ms Thompson: The guardian is appointed under the same legislation, the Guardianship and Management of Property Act. What we see in practice is that, largely, family act as family who also have decision-making ability under the Guardianship and Management of Property Act. Those lines get skewed, and we do a lot of education with family guardians who are asked to do things under the guise of being a guardian and feel that means that they cannot push back or say no, and so they get quite worn out. So we do a lot of education to let them know what their role specifically is as a guardian.

As a family member they might be more inclined to say, "No, I'm not doing that," or "I'm not getting involved in that," but when they feel it is their obligation as a guardian they do, and then they find it difficult. So when they learn that the role does not encompass those extra duties they often feel quite willing to stay involved. The only way a statutory guardian is different to other guardians is because of the Public Trustee and Guardian Act. That confers upon the office different authorities.

MRS DUNNE: My substantive question is about the legislation that underpins decision-making. In a sense the Public Trustee and Guardian is only one player in that.

It goes back to my original question, I suppose: because you are the public service policy people, you must have some policy overview. You alluded, Mr Taylor, to the coming together of all the public guardians in a policymaking way.

I am interested in fleshing out what legislative changes would make these decision-making powers—which are not easy—easier, more transparent and more liable to be implemented according to the wishes of the person making the decision. What we are hearing, and we heard it from COTA, is that it is too complicated and that they cannot see how to make it less complicated. What we are hearing from you in particular, Ms Thompson, and we have heard it elsewhere, is that doctors do not have regard for them—whether it is because they do not know how to read them or there is a level of arrogance, perhaps. How do we make it more likely that people can effectively make a plan and have that plan implemented if the need arises? That plan might be made now, and the need may not arise for 20 or 30 years.

Ms Thompson: One of the most important ways is education, whether that requires legislative change or not. In a former life I went through the university system, in psychology. It was always spoken about that you must have informed consent before you could engage in any treatment, but there was never any discussion or training on what to do if somebody required the treatment but did not have that capacity to give informed consent. There was never a discussion that I was aware of—and I went to a number of different universities—that talked about any substitute or alternative consent provisions. I understand that it is the same for medical training as well. We often find that doctors do not have a good sense of guardianship, enduring power of attorney or any of the other provisions.

My main concern is that we could change legislation and improve it, but unless we actually train people in how to use it we could have the best legislation and it still will not be enacted. I do not know whether going to universities and having more education around those different provisions would assist in that—I suspect it would—but certainly there should be more education and training.

Some of my colleagues in different jurisdictions, in particular, see each different area come up with its own statement of choices. We certainly have one at the Canberra Hospital, but I know that other places, like different nursing homes, for example, will have their own different forms that they may use. Instead of having a whole range of different options available, we could have it all contained in one area, and people could have those discussions and decisions can be made.

We have it in a medical environment but we also have different consent provisions in mental health. The new Mental Health Act has nominated persons and advance consent directives. It also has the advance agreement, which overlaps with the advance consent area in health, but they are slightly different. It is about having them all form one document, and people can consider it.

Legislative change is not really my forte. I do not have any legal background to talk about that. I can just see in practice that we could have the best legislation but we need to make sure that people are educated in how to enact it.

THE CHAIR: Just to follow on from Mrs Dunne’s question, COTA appeared just before you. They ran an information session, for want of a better phrase, about choice and planning for your end of life, including health rules—all those sorts of things. They were expecting a very small turnout and ended up with 120 people who wanted to know about this stuff. Possibly a broader public education campaign could also assist.

Ms Thompson: We are involved in a lot of education as well. We recently put on a forum with Imagine More and ADACAS, where we spoke to private guardians and people with young children who were coming up to being adult age and they were looking at guardianship. We have certainly done a lot of training and education in that space as well, as do a lot of other agencies around Canberra, such as ADACAS and Imagine More—those kinds of agencies. There is a lot of information, and there are people out there willing to educate people on it. We do rounds as well, at each of the hospitals, to try and give that information to as many medical and health professionals as we can. The advance care planning unit also do a lot of training in that space. Public education is always a really big part of that as well.

Mr Taylor: Could I add a point about legislative change? There is a significant problem across a number of areas of legislation relating to capacity. Whilst in the case of a guardian being appointed it is fairly clear, in black and white, what a person’s capacity would be at the point of appointment, because the tribunal determines a person’s capacity, capacity does not relate to one thing. You need to understand that there is capacity for different things. A person who might have a guardian appointed can still have a job, can still get a licence to drive and can still marry a person if they want, but they have a certain kind of incapacity.

If you move outside the guardianship area for one moment, a major problem is in determining that a person has a capacity to make an enduring power of attorney, because it is not governed or oversighted by an organisation. You might, for example, say to your dad, “You need to have a power of attorney; you’ve lost capacity.” You might be pushing him a little bit and he might say, “Okay, that’s fine.” And you start making decisions on the basis of his lost capacity. Or he might have made the power of attorney to say, “It comes into effect when I lose capacity.” The margin in between capacity and when he loses capacity can be blurred as well. Given that we are only dealing in the field of incapacity ourselves, that is a significant issue. It is even more significant when you start dealing with financial and property matters, and fraud associated with that.

I should also mention that, in terms of policy, the Australian Guardianship and Administration Council, which we are a member of, prepared and reviewed recently national standards for guardians. They apply principally to public guardians but they are aspirational as well in terms of non-public-trustee guardians. That is a fairly extensive document prepared, as we said before, having regard to the United Nations Convention on the Rights of Persons with Disabilities, particularly article 12, which makes it very much a person-centric matter.

In the ACT, probably unlike other states and territories, we have a much more centralised form of government. Lawmaking is a lot more cohesive in the sense that one agency, one government, is looking at the matter from a holistic community perspective, whereas in other states and territories the communities are not quite so connected, if you like.

MS CHEYNE: I have two questions. We have touched quite a few times on how the Victorian act only enables the person themselves and does not empower guardians and powers of attorney. In respect of that legislation, could I get absolute clarity from you about whether that is a good thing or deficient?

Mr Taylor: That the guardian does not have a right—

MS CHEYNE: Yes.

Mr Taylor: We would aspire to that same view.

MS CHEYNE: I just wanted to be super-clear on that.

Mr Taylor: I do not think that the Victorian guardian was looking to have that authority and power.

MS CHEYNE: I just wanted to make sure there was no confusion there. My second question relates to a similar part of your submission, talking about the two jurisdictions of the ACT and New South Wales and how problems might arise if New South Wales were to legislate, given that the ACT services so much of the New South Wales region. I see that as a problem if New South Wales were to legislate first and we did not have a similar scheme. Looking at that in reverse, are there similar issues if the ACT were to legislate but New South Wales did not, or did not for a long time?

Mr Taylor: We are dealing with the problem now but more in relation to will making. We are dealing with this with the New South Wales Cross-Border Commissioner. The ACT has a cross-border collaboration agreement with the Premier of New South Wales. The outcome there is that we need to make some changes to legislation to allow the ACT public trustee to make wills for residents in close communities on the other side of the border.

A reality with people who find themselves in the ACT in hospital is that the ACT has regional hospitals. In the ACT the Canberra Hospital and Calvary hospital are regional hospitals. They have people brought in here every day—people who are normally resident in New South Wales. Many people who are brought into hospital or other health institutions in the ACT are not going to return home. The question is: where are they resident at the time decisions are made? Are they residents here? Have they moved here? Are they now residents of the ACT for the purpose of the law and decision-making?

We take the view, in the sense of a person needing a will who has not long to live and they need to make a will, that we make it. We take the view that they are living in the ACT and we are making the will on that basis. Similarly, if a person became a resident of the ACT in that way, they may have a guardian appointed in New South Wales who can still make decisions for that person although, in some cases, it may be necessary to have the order registered in the ACT with ACAT before that can have effect.

You do have this cross-jurisdictional issue. AGAC and the Cross-Border Commissioner in New South Wales are also looking at the effect of trying to harmonise laws relating to powers of attorney and the effect of jurisdiction of tribunals, to the extent that hypothetically a tribunal in the ACT might, subject to an agreement, have authority to allow a person appointed in the ACT to have authority across the border in New South Wales. There are issues that prevent that, in that one law might allow coercive treatment and another one might not.

MS CHEYNE: That is a really interesting point that you make. For a lot of proponents of the Victorian legislation, the fact that you have to have lived there for the last 12 months to access the scheme has been seen as a really positive safeguard. Particularly when we are essentially an island in New South Wales, for us I think it raises some issues. Certainly there are some questions for Victoria, but for us especially it raises some questions about how that safeguard would work in practice.

Mr Taylor: It is a much more pressing issue here because we cannot divorce ourselves from the fact that our border is uniquely with New South Wales. Another way of saying it is that, in bringing people to Canberra with chronic, life-threatening conditions, they may be bringing people here to die, effectively. What happens in Victoria may not necessarily—except for Albury-Wodonga—be appropriate for the ACT.

MS CHEYNE: Equally, New South Wales could legislate but have an entirely different scheme. We could both legislate, but the schemes, the safeguards and whatever could be entirely inconsistent powers.

Mr Taylor: Just as we look for harmonisation with power of attorney laws, it would make eminent sense that there was harmonisation between New South Wales and the ACT in this space, for that very reason.

MS CHEYNE: Yes. Thank you; that is a really important point to make.

THE CHAIR: Thank you so much for appearing today. When available, a copy of the proof transcript will be forwarded to you, to provide an opportunity for you to check it and, if needed, suggest any corrections. On behalf of the committee, I would like to thank you again for appearing today, Mr Taylor and Ms Thompson.

STEVENS, MS GLENDA, Chief Executive Officer, Palliative Care ACT

THE CHAIR: Could you please confirm that you have read and understand the privilege statement that is there in front of you.

Ms Stevens: Yes, I have.

THE CHAIR: Do you have an opening statement that you would like to provide to the committee or are you happy for us to get going with questions?

Ms Stevens: I do have an opening statement. Thank you for inviting us to talk and to be able to put in a submission on voluntary assisted dying. Whilst voluntary assisted dying is an avenue for some who are in intolerable suffering, the government still must ensure that everyone has good end of life care. Palliative Care ACT's submission focused on good end of life care, that being palliative care. Your instructions focus told me that I could expand on what I had written in our submission. I shall do that to give a bit more rounded understanding of palliative care.

The word "palliative" itself means to cloak. It is not a cure; it is cloaking or alleviating or relieving symptoms. Palliative Care Australia's standard says that palliative care is provided for people of all ages who have a life-limiting illness with little or no prospect of cure and for whom the primary goal is quality of life. Palliative care does not hasten death. It helps people's lives so that they can live as full a life as possible. It is provided by a range of people and it is a very complex and interwoven system. Those people vary from specialist palliative doctors to GPs, nurses, volunteers and physiotherapists. The whole gamut of the medical profession is involved in palliative care.

Palliative Care Australia has written some standards, which were released at the beginning of this year. There are now nine standards. They focus on care, decision-making, and care planning that respects the uniqueness of patients, their caregivers and their family. The needs and wishes of the patient, their caregivers and the family are acknowledged and guide the decision-making throughout the person's end of life journey.

Palliative Care's primary aim is to provide the right treatment at the right time in the right place. It differs from end of life treatment in that palliative care can commence from the time of diagnosis, which for some people is many years before their actual time of death or expected time of death.

For some it commences not long after birth, unfortunately. At the moment, Palliative Care ACT cares for a young baby. He was diagnosed several weeks after birth. We expect him not to be an adult, never to be a teenager, but he is receiving palliative care for the duration of his short life. That palliative care is ensuring that he has as good a life as possible and also that the life of his parents and siblings can continue and be full of as much quality as available.

Palliative care treats the symptoms. It is not just the physical symptoms; it is also the emotional, spiritual and social needs of the person. It is a very holistic approach. It is very hard to gather figures, but in my submission I think we said that between 60 and

82 per cent of people in advanced countries would benefit from some form of palliative care. That means that people that die suddenly from car accidents et cetera are not going to be in a position to benefit but pretty much all of the rest of us will.

Palliative care is provided in a number of settings. It could be the person's home, and that is generally what we aim for, if that is their wish, for as long as possible. Most people are most comfortable in their own home. To do that needs quite comprehensive support systems around them. It could be in a specialist inpatient hospice, such as Clare Holland House, the one and only here in Canberra, and there people will receive specialist or clinical support; in the hospitals; or in residential aged care facilities. We have limited palliative care available in our hospitals, just due to lack of training and capacity. And in the residential care facilities, the level of palliative care is very varied. Crucial to all this is our GPs, who are the linchpin and are very much involved in primary palliative care, which is what most people need for most of their end of life journey.

Palliative care does not include euthanasia or physical assisted dying, physical assisted suicide. It is completely separate. Dying is a natural part of life, and declining or withdrawing aspects of treatment is acceptable if it aligns with a person's wishes.

I go to point 3. I apologise for all these pieces of paper, but technology beat me this morning, so I am on plan B here. I want to give a bit of extra information about Palliative Care ACT. Our mission is to influence, foster and promote the delivery of quality care. We try and do that equitably and without cost to our clients and patients. The ACT government funds us to provide one program, our volunteer assistance program. For everything else we do, we scrape together the money through fundraising and from donations.

In 2016-17 we provided more than 13,000 hours of palliative care to the members of the community, and demand for our home-based support program grew by 120 per cent in that one year. Going to the sorts of services we provide, there is the volunteer program. We also provide a relaxation massage program, which is provided by volunteers or paid staff. We are just introducing a music therapy program. We provide companionship and basic help in the home, making a meal or a cup of tea. And there is companionship and transport to appointments. A lot of work also provides relief for the carer so that the carer can go and do things and life can continue for them. Their quality of life, their mental and physical health, really impacts upon the person they are caring for. So we are helping to address the physical, social and psychological needs of our members of the community.

Let me go to point 4. I have some examples of different things but hopefully they will come up and I can use those during questions. The final point is about access to palliative care in the ACT. We know that about 80 per cent of people want to die at home but only about 14 per cent do. That is due to lack of knowledge of the people around them, not having advance care plans in place saying that, and just the system not working as well as it can.

Access to Clare Holland House is a problem. There appear to be issues with referral pathways and issues with bed numbers there. We do not have another hospice here in the ACT, and we do not have a short-term hospice which is non-clinical, somewhere

where someone can just go for a rest. Clare Holland is a clinical environment, which means that there are a lot of medical interventions.

Primary palliative care is where you are just caring for the needs of the person and it does not have medical stuff. As I said earlier, our GPs are crucial to the implementation of primary palliative care. We at Palliative Care ACT and Palliative Care Australia receive between us probably at least 10 phone calls from members of the public and from GPs not knowing where to go or what to do, having to support them through decision-making and give them information. We feel that is crucial for good palliative care: more education for the community and for our GPs and health professionals. Given the nature and the size of our jurisdiction, we can be leaders in this, because we have a defined area. I really look forward to us being able to build something that is world class. Questions?

THE CHAIR: Thank you, Ms Stevens.

MRS KIKKERT: My question goes to page 9 in your submission. You express a genuine concern that if the bill is introduced and passed, your work will be done and palliative and end of life care will be a casualty of voluntary assisted dying. Could you please elaborate on that? And where did that come from, that fear of the unknown?

Ms Stevens: I think that is actually not our personal view. That is a general view that came from reference 29; there are references on the bottom. I can always send that through to you if you wish. Overseas it has been expressed in that report that people will think, "We've addressed this, so we've taken care of all that." It does not translate well into the transcript, I know. The idea is that by addressing one small part of an issue, they have solved the problem for the whole part. We know that voluntary assisted dying is only going to be an option for a very small number of people, but death is not an option for the rest of us. But that is a concern that has been expressed: that we are ticking one small box and therefore we have ticked every box.

MRS KIKKERT: Thank you.

Ms Stevens: If you like, I can send you through that paper.

MRS KIKKERT: Thank you.

MRS DUNNE: Is that "Pereira, J. 2011. Legalizing euthanasia or assisted suicide: The illusion of safeguards and controls. Current Oncology. Ottawa." Is that where that comes from?

Ms Stevens: Yes.

THE CHAIR: But you did just make a commitment to provide the committee with the actual paper.

Ms Stevens: Yes; I will send you through that paper.

THE CHAIR: Thank you. We had some earlier witnesses who were talking about palliative care in the ACT, a palliative care specialist doctor this morning. From your perspective, as Palliative Care ACT, how are we situated in Australia? Are we Australian leaders at the moment? Do we provide great service?

Ms Stevens: We provide great service when people can get the service. That is the answer. It is when they can get the service they need or they want. That is another question too. In the paper I talked about choice and preference.

THE CHAIR: I was about to come to that.

Ms Stevens: Isn’t that a great point?

THE CHAIR: Yes. My next question was: can assisted dying or assisted suicide—people call it many different things—be another option in the palliative care suite?

Ms Stevens: It would not be an option within the palliative care suite because, as it stands now, palliative care does not include that option. It is an option in the end of life suite. It is a fine differentiation, but it is a differentiation.

THE CHAIR: Can you just expand on the differentiation briefly?

Ms Stevens: Yes. Palliative care covers from time of diagnosis and helps the person journey through the process to death. It supports them; it manages pain; it manages symptoms.

THE CHAIR: That could be an extended period of time in some cases?

Ms Stevens: Oh, yes. Yes, as I said, it can be several years. In the ACT we do support quite a few people who have five or six years. There is a lady at the moment we have been looking after for several years who has hydrocephalus; that is a life-limiting illness.

THE CHAIR: So the end of life care choices you mentioned—

Ms Stevens: End of life tends to be that last 12 months of life or less. That is the terminology.

MS CHEYNE: So palliation can occur at any time in your life, but end of life is the last 12 months?

Ms Stevens: Generally, yes. Then it gets more intense.

THE CHAIR: Thank you.

MRS DUNNE: I want to drill down into that a little. You were saying that that sort of voluntary assisted dying was not in the panoply of tools that were used in palliative care but that it was an end of life option. Where does Palliative Care Australia stand on that end of life option?

Ms Stevens: I have those statements. If it is okay, I will read from Palliative Care

Australia. Palliative Care ACT, of course, is a member of Palliative Care Australia:

> Our priority is to engage and educate the Australian community about palliative care and raise awareness about palliative care services across the country. We accept that this is a complex and difficult emotional issue, and there are many views. The practice of palliative care does not include euthanasia. Our position is that all legislative change is a matter for the elected members of the parliament.

Does that answer your question?

THE CHAIR: I think so.

MRS DUNNE: So, in a sense, Palliative Care Australia does not have a position?

Ms Stevens: Mute. Yes, we are mute on it.

MRS DUNNE: Okay, right.

Ms Stevens: We focus on palliative care. It is up to the government and the people to decide whether voluntary assisted dying is appropriate.

MRS DUNNE: On a substantive issue, you made a very important point about the proportion of people in the country who would eventually benefit from palliative care. I think that there is possibly a perception that palliative care is for people with cancer.

Ms Stevens: Unfortunately, yes.

MRS DUNNE: But there are many other people who would benefit from palliative care.

Ms Stevens: Yes.

MRS DUNNE: It has been put to me—it was certainly put at a seminar that Ms Le Couteur and I attended at the hospital—that one of the important things is to get palliative care specialists in at the beginning of the process, early after a diagnosis, and that it has great benefit in terms of providing not just a service but a sense of reassurance as well. For people with long-term illnesses, say degenerative illnesses, what role does palliative care play in someone with MS or Parkinson's, which is a longer term, gradually degenerative condition? Are we doing that well now? If not, how do we better inject palliative care into those scenarios?

Ms Stevens: There are quite a few elements to your question. I will answer the ones that I remember. We can then pick up the others. First of all you said "specialist". Most people will not need the support of a specialist. If I can go back a step: palliative care is divided into two sections. Did you all see the diagram on the back of our submission?

MRS DUNNE: Yes.

Ms Stevens: We developed this diagram because what is available in the ACT is quite complex. The first column is "primary palliative care". That is what most people will need for most of their period of palliation. That does not involve a specialist generally. You are managed by your GP. That is why GPs are so crucial. The GPs need the knowledge to be able to manage a person's palliative progression. They need the understanding of: "Now this is too far. Their pain management and symptom management is beyond what I as a GP can prescribe or do. They need to engage with a specialist." For most of the time, it is through the GP and the community nurse in a primary role. That is the first thing. It is different treating between primary and specialist or clinical.

The other thing is being engaged as early as possible. It makes a world of difference. To receive that diagnosis is, as you can imagine, emotional and very traumatic for the person and their family. Working out that plan and having an understanding of how it all works from the beginning is extremely important. I cannot stress that too much. So people, say, with MS can understand that they have a long journey. But if they engage in practices and look after themselves health wise, that journey will be longer and, for whatever length it will be, it will be a healthier, more holistic journey.

It also addresses things like bereavement. Bereavement does not start at time of death; bereavement starts at the time you recognise loss. There is bereavement of the person themselves plus there is the bereavement of their family members. It helps with the family members' mental and physical capacity so that they can continue, whether it is by contributing through work or understanding that now they need to reduce their workload and will have more time as a carer, engaging with Carers ACT et cetera.

It is understanding what is available from as early as possible. There are simple things like having different sorts of chairs to sit in to help with your physical health. I am talking very detailed, low level things, but they are the sorts of things that help a great deal with a person's physical and mental health as they go through this journey. Are we doing it well now? In lots of ways yes and lots of ways no. It tends to be that if somebody accesses and has a good understanding, they will get good palliative care. But because most people do not have a full understanding, it is piecemeal.

MRS DUNNE: Is it because people think palliative care is a narrow, end of life service rather than a more holistic service?

Ms Stevens: Yes; that is part of it. That comes down to community and medical education to understand the word. If we could have another word it would be great because that word has been earmarked to the very end of life.

MRS DUNNE: To dying.

Ms Stevens: To dying and it is not about dying. It is about not having other long-term alternatives.

MRS DUNNE: I suppose part of the question is—because it is seen as an end of life process rather than a maintaining the patient process over a longer period of time—are we being effective in those longer term degenerative diseases? If not, how do we interpose or insert palliative care into that process more effectively?

Ms Stevens: Again, it comes down to supporting the medical profession with knowledge. I am not an expert on this, but my understanding of how medical professionals choose their areas of speciality is that palliative care has not been an area available for a speciality for a particularly long time.

Oncology has been around for a long time. The concept of being a palliative care specialist has not been in existence for that long. Most doctor university courses et cetera do not have a discrete unit on palliative care. It is sort of popped in amongst everything else. It is not perceived by them as being important because it does not have its own discrete unit of training. James Cook University in Queensland has recently started rotation of its residents into palliative care units. That is helping greatly up there. Once again, these are small things where the awareness of the medical professionals about what they can do is really important.

THE CHAIR: Can I just ask, hopefully, a very quick follow-up?

Ms Stevens: Yes.

THE CHAIR: I know Mrs Dunne suggested MS and Parkinson's.

MRS DUNNE: Just as examples.

THE CHAIR: Yes, absolutely. I have known a number of people with MS, some of whom are no longer with us. I understand that it is great to get in early. How do we help people—maybe that was part of your answer—who will not accept the fact that this is a potentially life ending, long journey, a terrible thing?

Ms Stevens: It is part of the process, really. That is part of having those conversations. Once again it comes back to the medical professionals having the wherewithal to say, "That penny hasn't dropped," because it is such a huge concept. That conversation may be need to be reiterated in X number of weeks. The continuity of working with your medical professionals is really important.

MS CHEYNE: What is late palliative care? You say that it is a missed opportunity to do better for patients, families and health services.

Ms Stevens: That is starting palliative care and a palliative care program or treatment plan at time of diagnosis or shortly afterwards. I will give you an example. About six weeks ago we had a phone call from a lady who said, "I have pancreatic cancer. I am in extreme pain. I have been back to see my GP. He won't prescribe me more opioids because he doesn't want me to get addicted. I have three months to live. I said to him, 'I think I need some palliative care.' He said, 'You're not ready for that yet.'"

This lady had a very short life expectancy. She was in extreme pain. Where is her quality? Where is her ability? That extreme pain of course will reduce her life expectancy. By waiting, her life span is shortened, her enjoyment of her life is greatly shortened because her GP thought she had to wait to be at very end of life, as opposed to being palliative.

MRS DUNNE: There is a lot of education for doctors of that—

MS CHEYNE: It keeps going back and back, does it not?

Ms Stevens: Yes. I want to use the word “support”. I do not want it to appear to be a blame thing. It is just that there is so much that doctors need to know and there is so much we expect of them, and this is one more thing. I do not want them to feel as though it is a blame or anything. It is like we need to support you so that you can support your patients.

MRS KIKKERT: As a follow-up to that, why do you think there is a delay in it? Palliative care has been around for many, many years. Why is there is a delay in doctors getting educated on the importance of this?

Ms Stevens: That is a very good question. Some of it I addressed in the paper with regard to some GPs. Our medical professionals are trained to cure and to make better. It is very hard when someone comes along that they cannot do that for. They want to continue with interventions to try and make that.

We had an example—and this one was about 12 months ago—of a young lad who was very ill. He was in his teens and the doctors kept wanting to send him to Sydney to have more treatment. “Maybe this will work; maybe that will work.” His mother said, “I think we just have to make the decision now that my son has no quality of life. He is just having more treatments after more treatments and he’s a very sick child. I think it’s time for me to take him home and let him have some time to enjoy being a child and to die.” And that is a really hard call for any parent. But the doctors kept thinking, “What if we did this? Maybe we could cure him with this.” There was no guarantee. There were no percentages. It was just a very slim maybe.

MRS KIKKERT: And palliative care can coexist with treatment from the doctors or referral from doctors?

Ms Stevens: Yes. You can still be undergoing chemo and radiotherapy et cetera if you have cancer and be on a palliative program as well.

MS CHEYNE: Before I go to my other question, the example you gave me reminded me of a submission we received from John Paynter, who chronicled his wife’s decline in the final days of her life. When he asked for more relief to stop her needing to cough up the liquid—this is a seven-day period; this is day six—he was told, “We can only give her that three times a day and she had some an hour ago.” He said, “My God, were they afraid it might make her sick?”

Ms Stevens: That is the mindset and the difference between good palliative care and non-palliative care. It is a different mindset. We had an example from one of the hospitals here recently with the family of someone who was in hospital and dying. They used to refer to the one nurse who had been trained in the palliative way as the good nurse and they would wait until she came on shift so that they could ask her the questions. That was really sad, because the other nurses were good nurses. They were not palliative trained nurses.

MS CHEYNE: Clearly it is an area where we can already see some recommendations coming forward.

Ms Stevens: And I can give lots more examples.

MS CHEYNE: Please feel free to send those through. It all helps. We have asked Calvary to take this on notice as well. Being conscious of the time available, you mentioned there are some areas where you would really need more resources. I think what has come through quite clearly this morning from both you and Calvary is the home-based palliative care. Perhaps on notice, are you able to expand a little on exactly what is needed there and the kinds of resources that you are aware of that could support that better in the ACT? Was it around this that you said the desire for it increased by 120 per cent in one year?

Ms Stevens: The demand.

MS CHEYNE: The demand, sorry.

Ms Stevens: In that 12-month period the demand on our services, which is the volunteer home support service, increased by 120 per cent. And we want to continue to meet demand. My staff work very hard to meet demand but there is a big capacity issue there amongst the staff. We are a very small organisation. We have three full-time staff members and two part-time.

MS LE COUTEUR: I was going to ask that question as well, because clearly that seems to be the biggest problem, but I thought maybe I would ask about a smaller problem with Clare Holland House. You were talking about the difficulty for people getting into it. The other issue that I have heard is that there are people who do not wish to go to a religious organisation, particularly at that time, when they are feeling more vulnerable.

Ms Stevens: To address the first one, difficulty accessing Clare Holland does appear to be a problem and we do know that it is not always the access issue—I am trying to be politically correct—it is not always a bed issue, that other factors are affecting the non-acceptance of patients. Last week we had a phone call from the Canberra Hospital from one of their palliative nurses, "We've been trying since Monday to get this man into Clare Holland. He is very close to death. He is a young man and he needs to not be in hospital for this and why can we not get him in there?" They rang us to see if we had any ability and after our phone call he was admitted the next day. But we did know that during that period he had not been admitted there were beds available. Perhaps the committee needs to do a little more unpacking as to why.

MS LE COUTEUR: Have you any comments about the religious issue? That is what I have heard many times, that it was—

Ms Stevens: Again, anecdotally we hear that. We have not had anything official but anecdotally we hear that some people are not accepted for various reasons. Clare Holland can be actually—

MS CHEYNE: Not accepted?

MRS DUNNE: Not accepted?

Ms Stevens: Not accepted.

MS CHEYNE: It is not just a choice of not going but they want to go and are not accepted?

Ms Stevens: We have heard anecdotally that that is correct. But within the facility itself, even though it is run by Little Company of Mary, it is not an overtly religious environment. There is a chapel but it is a non-denominational chapel. My perception is that, walking in the door, you would not perceive it to be a religious establishment.

MS LE COUTEUR: I guess more generally, taking it out of Clare Holland House—and this might be part of the answer you are going to give to Ms Cheyne's question—how many more in-house or palliative care beds do you think Canberra actually needs?

Ms Stevens: I think we would need to do a lot more research on that to actually answer that question, to answer that properly. I would prefer not to guess at this stage.

THE CHAIR: I would truly, on behalf of the committee, like to thank you for your time today. When available, a proof transcript will be provided to you with an opportunity for you to check the transcript and, if needed, suggest any corrections. For the questions that you have agreed to take on notice for us, generally speaking the committee asks for a 14-day turnaround time from receipt of the Hansard transcript. As I said before, thank you again for appearing today. It has been quite interesting and enlightening for the committee, I am sure.

Hearing suspended from 12.48 to 2.30 pm.

WONG, MRS CHIN, Chair, Canberra Multicultural Community Forum Inc
HUNG, MS YELIN, Secretary, Canberra Multicultural Community Forum Inc
EASTWOOD, MS SUZANNE, Community Development Manager, Canberra Multicultural Community Forum Inc

THE CHAIR: I welcome the next witnesses to our hearing today. Before we start, I ask you all to confirm that you understand the privilege implications of the statement in front of you.

Mrs Wong: Yes, we do.

Ms Hung: Yes, we do.

Ms Eastwood: Yes, we do.

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

Mrs Wong: Yes. I am the chair of the Canberra Multicultural Community Forum. Thank you for the opportunity to speak to the inquiry on end of life choices in the ACT. We are the peak community organisation, representing over 120 organisations in Canberra. We are a volunteer organisation. We are governed by elected committee members.

Our opening statement is that our submission highlights the diverse views from the multicultural communities generally about life, about taking care of their community and taking care of the individual's life. Multicultural communities do not see ourselves as vulnerable communities. As such, like any other communities with heightened needs, given support and information in our people's own language that we can understand, we can be well-informed to make our own decisions, our own individual decisions, just like anybody else.

We can make our own decisions if we use point No 4 of our submission, just like those from the Jewish community. The Jewish say that, from their point of view, life belongs to God, but every person has free will to make their own decisions. Based on that statement, the Canberra Multicultural Community Forum does not have a policy that suggests voluntarily assisted dying. In the multicultural communities in Canberra we have a wide range of religions, cultures and personal views on this issue. Within the individual communities, there can be a wide range of views and belief. Therefore, Canberra Multicultural Community Forum sees our role as representing the breadth of the views that are expressed by our own community.

We do have some points that we would like to make. We see this inquiry as an opportunity to support and encourage our multicultural communities to discuss end of life issues. That includes helping our multicultural communities to develop a better understanding of how to take care of the communities who are dying, in the sense of their being ill or they are getting old. In terms of the palliative care and advance care planning that the community now is encouraged to look at, we need the government's support to help our community with good resources and with good opportunity for wider consultation. End of life is not an easy thing to discuss now in some communities because of the culture and faith, as you can read in our submission.

Canberra’s multicultural community is very concerned that our communities do not misinterpret the intent of this proposal because of a lack of understanding and information not really accessible to the community in the community languages that they can understand. We need to be able to read the information in our own language so that people have the opportunity to fully understand and make their own decision. We give an example of the Victorian inquiry and the information available on their website in a range of community languages. We have shown that to you in our submission.

The other point that the CMCF would like to make is that we would support the project with Palliative Care ACT to train and encourage volunteers from the multicultural communities to promote a higher level of participation in using palliative care services from the multicultural communities.

As you can see, the multicultural communities form their own organisations. They are close-knit and they support their communities. Some communities do have low health literacy about the process of dying—there is no doubt about that—and they have a reluctance to engage with palliative care. This is because they do not understand palliative care and what it can offer. For some communities, palliative care can mean accepting you are dying. That can be a very difficult thing to understand. Before I pass on to Yelin, my secretary, I want to emphasise that end of life is not something that the multicultural communities will accept, but we would like to work with the government to ensure that our community understands it and can make their own decision.

Ms Hung: The next point we would like to make is that the Canberra Multicultural Community Forum is very concerned about the disbanding of the multicultural diversity policy unit at ACT Health. This unit used to focus on multicultural, refugee and other diversity issues such as LGBTIQ. Our point on this issue and this restructure of the ACT Health unit is that there are multicultural issues that are not embedded within ACT Health. CMCF is concerned to make sure that multicultural health issues are looked at and are not lost without proper leadership within the health system.

Introducing a complex topic such as this requires a high level of trust and faith in the system. It is essential that the needs and concerns of the multicultural communities continue to be heard and championed with Health. CMCF want a clear understanding on how that is going to happen with the disbanding of this dedicated unit, which used to be looking after specific issues within the multicultural community. An example is issues with accessing translator and interpreter services, which continue to be a high issue within the whole multicultural community accessing health services. This will lead to people with chronic conditions not getting the right information when it comes to their end of life choices.

THE CHAIR: Thank you so much for those opening remarks. Ms Cheyne will open the questioning.

MS CHEYNE: More broadly, I think, a theme that has probably come through relates not to the assisted dying conversation but to health generally. It is that we need to be doing better there in terms of involving the multicultural community. I think you mentioned, for example, an education program for professionals. You said that you would be willing to assist with that, including with Palliative Care. What would an education program look like from your perspective?

Mrs Wong: I will hand over to our community development officer.

Ms Eastwood: I work on the community development program. We are interested in increasing the cultural competency within the health system at all levels. There are issues about professional development for staff, which is a different issue from the work that might be done with individual communities about improving their health literacy. Yelin and I both worked at the Health Care Consumers' Association. We did the community consultation when the migrant health unit changed to the thing that has just been abolished.

I think our experience is that the multicultural communities are keen to have information to understand what is going on. People have come to every consultation that we have run. The Canberra Multicultural Women's Forum has just run some workshops on domestic violence with some communities that I think Canberra did not even know existed here.

I think the main message is that the multicultural community will come. They are incredibly interested if the information is given in appropriate languages and the information is distributed in an appropriate way. Caroline came to the consultation that we ran for this inquiry. People were very interested and really wanted to know all the information. They keep wanting us to run another one. We will do that as soon as we have finished giving evidence here.

I think the other thing I want to say is that Chin, Yelin and all of the other executive members and members are all volunteers. The amount of time that they put in to actually supporting the community, running programs, is incredible. A small amount of money was given to Canberra Multicultural Community Forum to support a community education program. Palliative Care spoke at the forum that we ran that Caroline attended. It is obvious from speaking to Palliative Care that there is a very low uptake of using palliative care services. There is a low number of volunteers from a multicultural background who are palliative care trained volunteers.

So the Canberra Multicultural Community Forum is really interested in working with Palliative Care, as well as with the advance care directives unit. There is a really low uptake of advance care directives as well within the community. Basically, it is a lack of understanding, it is a lack of information in other languages, and it is a lack of ability for organisations like Canberra Multicultural Community Forum to keep running forums on a voluntary basis. A small investment would really help—or a large one—

THE CHAIR: You are not fussy, are you, Chin?

Ms Eastwood: It would really assist in that ability to disseminate information that people are really interested in receiving.

Mrs Wong: What I really want to emphasise is that the way to access the multicultural communities is not just put up a notice saying, “Come to a forum.” We actually have identified the different groups, identified the people that speak the language and identified the volunteers that can bring the community together. The Canberra Multicultural Women’s Forum uses the approach that the Canberra Multicultural Community Forum is also using. We manage to disseminate the information to the right people, to the right community, and we then get them to disseminate it to their own community.

One of the very successful programs that we are running is the SMILES program. The senior multicultural leaders’ network is running that once a month. We rely on the community who attend the meeting to disseminate information. When you talk about continuing education, whatever education program that it is that we are going through needs to access the community, be able to reach out to the community. That is the first thing that we need to be able to do.

MRS DUNNE: Apart from saying that you would need an injection of funds to run these sorts of information programs, do you see that there needs to be a slightly targeted program, depending on the cultural background and depending upon how a particular culture deals with death and end of life issues generally, not just in the Australian context?

Mrs Wong: I think both. From the conversation forum that we run, we have people from different religions, different backgrounds and different cultures, and they get together—there are nearly 40 or 50 people—and they share. We can share and understand each other’s culture. The Jewish community raise issues; the Greek community raise different issues. So, in a sense, as I say, it is both. You need to target the groups who have their own beliefs, because we do have multicultural communities who do not wish to have this end of life practice. But we have other communities who can understand it. Also, with the younger generation and the older generation, there seems to be some gap there in terms of understanding. One of the comments made at the conversation forum was that the older generation is a little bit concerned about the younger generation—that when they can no longer look after the older generation, they might use this as a way to end their own parent’s life. That is very sad.

MRS DUNNE: Ms Eastwood, you said it was clear that there was a lack of participation from people with a multicultural background in palliative care. Is that because of a lack of understanding? Is it a cultural thing about how people deal with death, or is it a language barrier?

Mrs Wong: It could be both. Palliative Care ACT did make a very strong statement that they do not have the resources to reach out to the multicultural communities. That was very clear. Certainly, from our experience of working in the community, some of the service providers do not know how to reach out to the multicultural communities. Some of them may have the funding, but in general they do not know how to reach out to the community.

I emphasise that if the government wants to be really strong in reaching out to the multicultural communities it needs to involve the multicultural communities. The multicultural communities will speak for themselves. We speak for ourselves. We do not need other organisations to feel sorry for us or to speak as if we are vulnerable people. We are not. We are migrants and refugees who contribute so much economically and in every way. We want the government to recognise that there are special needs or heightened needs, and the multicultural communities need some support so that we can contribute and be part of it.

Ms Eastwood: Palliative Care made it quite clear that the current strategies that they are using to recruit a very amazing group of volunteers are not working for the multicultural community currently because of the very low level of multicultural volunteers that they have. They would love to have more multicultural volunteers.

The other issue is that people from multicultural communities are offered palliative care and do not understand what they are being offered. The way that the explanations are being given is not in a framework so that people think, "Yes, I really need this; my family needs this." Work needs to be done on how to explain palliative care in a multicultural context. Palliative Care were quite clear that they would love to run a project with us, but it would have to be a specific project looking at developing resources that actually speak to the multicultural community.

You were asking how this could be done. For things like advance care directives and palliative care, usually you could produce some resources and the communities themselves work out how it fits in to their context. You do not have to produce a Russian version and an Islamic version; you produce the ACT government version, and the community themselves, when they have access to that information, work out how it is relevant for their context.

MS CHEYNE: This handout mentions that the Victorian legislation, with the mandate in terms of being quite specific to end of life choices, requires there to be a professional interpreter there at all times.

Ms Eastwood: Yes.

Mrs Wong: Yes.

MS CHEYNE: Do you think that, with any legislation that was developed in the ACT, it would need to be a real part of that as well?

Mrs Wong: I think it would be really good to include the fact that it should involve not only volunteers but people who specialise in understanding the whole process about the end of life. One of our concerns about interpreting services, especially in the health area, is that they interpret the question. They do not interpret the meaning. There are a lot of languages where the meaning is not expressed. It is not just a matter of the question being interpreted in the way that the language is being spoken.

Ms Hung: A big issue within the health services is their usage of translating and interpreting services. With respect to that project with the women's group, the Canberra Multicultural Women's Forum, I was part of it. We were running seven different groups in seven different languages. We were looking across all of the issues, at what the issues were with accessing different services like legal, education, employment and housing. Across the board, with all of the services, language was an issue. There is a lack of interpreters in different languages in the ACT.

Not only is there a lack—sometimes only one interpreter in one language—but the organisation only allows the person to go 40 kilometres or 25 kilometres; other than that they cannot go to the client. That is not acceptable. That means you are leaving the client or consumer without that service because there is only one interpreter in the ACT.

That is a huge issue, a huge burden, that we are dealing with in ACT Health in this regard. That is why I mentioned that when this multicultural policy unit disappeared, CMCF was really concerned. We already had issues with this unit. Now, with the unit disappearing, the issues will increase even more. I can give the example of when I requested information regarding different visas and access to different health services. It has been four weeks and I have not had a response.

For me, this is not acceptable. I work voluntarily with the Canberra Multicultural Community Forum, but in my work with the Health Care Consumers' Association I find that to be appalling because I am a community educator. I educate multicultural communities on the best way to access health services. But if I do not have this information on how those on different visas access different services—you get charged here; you get charged there—that means I am not giving even half of the information to them. I am not wasting my time but I am wasting their precious time. They are here and they want to have this information. It is important that we collaborate with the government to make the system easier for people to access. But if I do not have this information, I cannot do so.

Ms Eastwood: Since we did the consultation on the changes to the migrant health unit, there have been big improvements in the level of the use of interpreters within ACT Health. This is not a criticism of Health. Health has actually put in a huge effort to increase the level of interpreters and to make sure that people understand that they can ask for an interpreter. We also had a speaker from ACT Health at the forum who said that with any end of life discussion or cancer discussion they always use an interpreter. That is a very good thing.

THE CHAIR: That is very positive, yes.

Mrs Wong: But that is only one area.

Ms Eastwood: One area, yes.

MS LE COUTEUR: You talked about material being available—that that was all you wanted. You did not want more than that. I assume you are talking about materials translated into the various languages?

Ms Eastwood: Yes.

MS LE COUTEUR: Then you would put whatever cultural requirements on that as a second layer?

Mrs Wong: Normally, there are different ways of getting through to the community. When the government put out information, it is printed in such a way that there are no other languages available. We ask the government to put out the information as simply as possible in the language, and the community will then explain things in their own language. The other thing is about translating it into the language. There is some information that definitely needs to be translated into other languages. If they consult the community, certainly the community will say, “Don’t worry about this; we can disseminate this information in our own language.” But there is certain information that must be translated, and it is not translated. That is what our concern is about.

Ms Eastwood: I think there are different levels. If you look at the Victorian legislation and the Victorian website, from the very beginning of the discussion they had all of the brochures translated into 30 different languages. From the very beginning of the end of life discussion, it was available for communities so that they could read it in their own language. That is an issue. There is also health information that would need to be translated into other languages—about cancer, for example. There are a couple of different levels that this translation needs to operate at.

MRS KIKKERT: Thank you all so much for being here today. We really appreciate your time. I have been thinking about the amount of hunger for knowledge and understanding that the multicultural community has. The committee members can all relate here, in that we are in need of knowledge and understanding about this particular topic. To an extent, we can understand where the multicultural community is coming from, because there is absolutely no information given to them. That is why we are having this inquiry.

Is there something else that you would like to discuss that multicultural members in Canberra are in need of, apart from translating health information into their own language and having regular information sessions? Is there something else that you want to add to this discussion?

Mrs Wong: Yes. As the peak organisation representing the multicultural communities, we like to be recognised as the peak organisation by the government. We work as a volunteer organisation and we do not want to be put as second cousins. At the moment it is very hard to obtain information from the government on what the government needs the community to do, unless you go online. We ask: how many multicultural communities have time every day to go online, go on the government’s line, go on the information line and go on the communication line and say, “These are the things that we need input on”?

On top of that, a lot of the multicultural communities are not very good at writing submissions, and we do not have the resources to write submissions. We would like to have open forums, face-to-face forums, conversation forums. You get so much out of a conversation forum, rather than everything having to go online: “Put your submission online; tell us online.” This might be okay for the younger generation, but with a lot of multicultural communities, especially on the end of life issue, they are older communities. They like to be informed, they like to discuss and they like to have conversations and workshops so that they can express their point of view personally and have their stories listened to. We want to encourage all politicians to listen to the community more. That is all we want to say.

Ms Eastwood: There was another issue that came up in the community consultation where some members of multicultural communities were feeling a level of frustration with their religious organisations. They had been to consult their religious leaders. I refer, for example, to a grandmother and mother who wanted to do an advance care directive because the mother was very concerned about not wanting to have her life extended in intensive care. This person went to her religious leader. He basically did not want to know—did not understand and did not want to know. I think there is a level of frustration within religious communities. A good project would be to offer some support to religious communities to engage with the issue and discuss it within the Australian context.

The other issue that came out was a tension between younger community members who might be more inclined to support something like this and older community members who feel quite fearful of what could happen if this type of legislation happens.

THE CHAIR: Thank you so much. I think we could have gone on for ages. I would like to thank you all for appearing today. Your information has been very insightful. If you do think of the extra point you wanted to make, Ms Eastwood, please feel free to send it through to the committee. A copy of the proof transcript of today’s hearing will be forwarded to you, to provide you with an opportunity to check it and to suggest any changes, should they be required. On behalf of the committee, I would like to thank you all for appearing today and thank you very much for the information that you have provided to us.

Ms Eastwood: Can I just say what it was? I have just remembered. If a person decides to take this opportunity, if it becomes legislation, will the church bury them? That was a big question that came up for quite a lot of communities. If young people particularly decided to use this legislation, would their conservative religious institutions actually allow burial? That was a real worry for people.

THE CHAIR: Thank you so much.

DANIEL, MR MATTHEW, Secretary, Australian Nursing and Midwifery Federation (ACT)
CORRADINI, MS CLAUDIA, Member, Australian Nursing and Midwifery Federation (ACT)
PELL, MS TRACEY, Member, Australian Nursing and Midwifery Federation (ACT)

THE CHAIR: Welcome to today's hearing of the end of life choices committee. Can you confirm that you have read and understand and agree with the privilege statement in front of you.

Mr Daniel: Yes.

Ms Pell: Yes.

Ms Corradini: Yes.

THE CHAIR: Would you like to make a brief opening statement, Mr Daniel?

Mr Daniel: Yes. Good afternoon, and thank you to the chair and the members of the committee for inviting the Australian Nursing and Midwifery Federation, ACT branch, to appear before you today to assist the committee with its inquiry. I am a nurse and the secretary of the ACT branch. With me I have two ANMF members: Tracey Pell, a nurse working in palliative care, and Claudia Corradini, a nurse working in an acute hospital setting.

It is vital that nurses are actively involved in the public debate around end of life choices, including palliative care, advance care directives and assisted dying. Every day nurses provide care and counsel to people facing the end of their life. We are witness to the struggles that come with dying, the difficulty of comprehending one's own mortality and, hopefully, a sense of peace that can be achieved before death. We hear their stories and we are privy to their fears and reflections that some choose not to share with family out of concern that this will be a burden to loved ones.

Nurses provide pain relief, track medications and coordinate care. Nursing care extends to those facing the loss of the loved one as we educate family and friends about the stages of dying. For those who have passed we continue to provide care as we wash their body and brush their hair. Often we speak to the souls of the dead as we say our own farewells. There is not a nurse who has not privately shed a tear for a life ended. This is the essence of nursing, and nothing is more important.

Being able to provide the right nursing care for people at the end of their life is time sensitive. It simply cannot wait, and we must have the right laws, policies, framework and, most importantly, the right funding that supports nurses to do their vital work in caring for our community.

We ask the committee to carefully consider the ANMFs submission. Education, symptom management and the expansion of existing services are key to meeting the needs of the community and a sustainable health service which supports end of life choices in the ACT.

THE CHAIR: Thank you, Mr Daniel.

MRS DUNNE: Thank you for your submission and your time today. As key providers of services in this space, what do you see as the top three or top five—whatever you choose—significant barriers or problems that need to be addressed in a public policy sense to improve the delivery of services for people who are facing death, whether that is imminent or in the long-term prospect of a new diagnosis?

Mr Daniel: It is access to the right service for people with a new diagnosis or someone who is close to the end of their life—the right service for that individual, whether that be in their own home, in a nursing home, wherever they choose to be. Along with that come some of the other things we mentioned in our submission around things like symptom management. That may be simply looking at trying to help manage pain relief so that people at the end of their life that might be experiencing pain do not bounce around between home or a nursing home or a hospice and a hospital and so on. That needs to be really effectively managed. Symptom management is one of the key things we really need to address to make sure people's wishes in where and how they want to die are met.

Ms Corradini: I can talk about people being in a setting where they are comfortable. I had one patient who was being managed in the community by the palliative care nurses and when she was admitted she deteriorated rather quickly. She had an advance care directive in order; she was not for resuscitation and she also was not for any medical emergencies, which is when we call a code on someone and the team rush up to see them. But she also was not necessarily for comfort measures at that time, and that caused a bit of confusion as she was deteriorating quite rapidly.

This happened after business hours, when we do not have access to the pal care nurses on call. There is a social worker around for the family and there is just a doctor that will cover our ward for that period of time. They have contact to the consultant, but not at that time. She deteriorated very rapidly to the point where she actually passed away. She rolled over to the nurse and said, "Can I go now?" And the nurse who was on that night shift just said, "You can rest now." The patient actually passed in a two-bedded room because we did not expect it to happen so suddenly, so there was a patient next to her.

The next day I came in to shift and the palliative care nurse called and asked how this patient was going and I had to explain that the patient passed away. The palliative care nurse said, "I am really sad to hear this because this lady actually wanted to pass away at home." That story stuck with me for a while just because in her last hours she was suffering. It was for a very short period but to the point where we could not get on top of her pain in that time.

MRS DUNNE: Could I drill down into that a little bit. We have to be careful about individual stories, but they form the case study as well. Was it that you could not manage this person's pain because the right people were not there at the right time? Is that what you were saying?

Ms Corradini: It was a combination. Because she had a chronic condition it was not expected that she would deteriorate so quickly, and it was also about having very quick access to talk to the palliative care nurses who were in the hospital and did not know this patient. So they did not see her that day either; she was just managed in the community.

MRS DUNNE: So in this case there was not the right communication. So the people who had been seeing this person were community nurses and, therefore, they do not have a communication channel through the hospital?

Ms Corradini: They do, but she came in that day and she just deteriorated so rapidly. She came in after hours and at that time we were quite a high turnover ward. Our ward has changed a bit, but it is quite busy, it is an acute setting and there are things happening. She just deteriorated unexpectedly so we were not prepared for this to happen so quickly. You have to prepare medications; it is not quick. We were trying to organise a syringe driver, which is pain relief that is delivered over a period of time, but by the time we get that machine and get it prepared it does take time.

Palliation scares me still and I have been a nurse for eight years now. When I get people who are deteriorating rapidly it is quite scary because you are also dealing with the family. It affects you as well because you want to make this person as comfortable as possible and some days you just feel that you cannot get on top of it.

Mr Daniel: That really highlights the point of wanting to make sure people can be palliated and live out their life where they choose so that you do not have this sort pressure as a nurse to try and meet all these needs that suddenly land on you. Certainly in a ward scenario, whatever is going on in that ward the nurses will try and make sure there can be one-to-one nursing for that one palliative care patient because it is so important and so time sensitive to get that care right. Other nurses will pick up the load for that nurse to ensure that one-to-one nursing can occur. It does not always occur because you will have the pressures of the ward. That is that point about the right place. A hospital setting has so many pressures on it. Palliative care, dying, end of life choices is an oddity but a difficult place to happen in a hospital for the best care to occur.

MRS DUNNE: Sometimes it is too medicalised, as it were.

Mr Daniel: Yes, and wards are busy. And that also relies on a patient being able to get out of an ED environment, and that can also be a challenge because of pressures on beds.

Ms Pell: Sometimes in the advance care directives it is not always clear exactly what the patient wants. If they are in a hospital setting and they have had that discussion with the social worker, with the doctors, with the family and they have decided they want certain measures, sometimes it is just comfort measures and other times they want CPR and all the medical interventions possible. If they go to another setting, say home or a hospice or wherever, you cannot predict, when someone is dying, when they are going to die or how they are going to die. In an ideal world it would be lovely for everybody to have the choice to die in the manner and the place they choose. Unfortunately, most of the time that does not happen.

We do the very best we can with pain and symptom management and with the resources we have, but people change their minds. That is what makes us all individuals. And people die as individuals. There is no set "Okay, this person has a brain tumour so they are going to die in this manner." It does not happen. That person will die as an individual. They need this symptom pain management. They may deteriorate very, very, quickly or they may linger for days, weeks, months. It is individual.

With the advance care directive sometimes people have very good intentions in the hospital and they say, "Yes, I want this," or "I want that," but then when they get home they decide they do not want that anymore. They may have wanted CPR; now they just want comfort measures. Or they may have said, "I want comfort measures, but now I want CPR. I want the whole shebang. I want to have the ambulance come and I want to do the whole thing like they do in the movies." But it does not happen that way. Families change their mind; patients change their mind.

As nurses, all we can do is go with the medical condition of the patient at that time and, as I said, do our very best for them, listen to the family, support the family and make sure that we can address the pain and symptom management the best that we can. And, hopefully, for the most part, we give them a lovely, nice, comfortable death. But, as I said, everybody is individual.

MRS DUNNE: Could I just go back to the point that Mr Daniel made about being in the right place and perhaps draw on your experiences, Ms Pell. We say that most people want to die at home but less than 20 per cent do. What are the barriers to that? Is it the nature of their illness or is it that we do not have the right resources to address the illness?

Ms Pell: It is a combination of things. Sometimes it is a family issue: however well the nurses may manage pain and symptoms, the family may say, "Yes, we can deal with it." Some families do brilliantly. But as their loved one becomes progressively worse, or someone who was mobile is now immobile, all of a sudden they may have to give subcut injections.

THE CHAIR: Sorry?

Ms Pell: A type of injection to the patient for pain relief. They may not be prepared to do that. The patient may not be swallowing, so they may need those injections, but the family may find they just cannot deal with that. So it is for a whole combination of issues, sometimes resources, sometimes carer stress. You can manage them as best you can, but unfortunately some people do end up back in hospital, in the ED, perhaps because they have had a fall, and they go through the whole process again. Or some people end up in the hospice because the family just cannot cope, though they have done the best they can.

MRS DUNNE: How do you minimise the infrastructure issues? What proportion would you say, of the people who want to die at home but do not die at home, do not do so because of infrastructure issues? Some of the other things, about the willingness or capacity of family carers, are outside the scope of public policy.

Ms Pell: Right.

MRS DUNNE: But inside the scope of public policy, with issues of resources, for instance, what proportion of those people would be prohibited from doing what they want to do because of reasonable infrastructure that does not exist?

Ms Pell: Probably less than half. I do not know the exact figures, but I would say less than half.

MS CHEYNE: Not to put too fine a point on it, where do we need the investment?

Mr Daniel: I think in the workforce. There is a lot of opportunity to meet the challenges of end of life. The right number of nurses working in the community and in services outside the hospital setting will go a long way towards meeting some of the challenges. That should include nurse practitioners, who can bring all sorts of expertise and skill, and timely care; who can make decisions around medications and so on; who have specialist knowledge that people can tap into there; and who can collaborate with other specialists, perhaps surgeons who might be able to offer a palliative approach. They can be very central to the coordination of care and keeping people out of hospitals.

It will be particularly important for nurse practitioners and nurses with advanced skills to be working this area. With the increasing number of aged people getting home care packages, which is a good thing in certain regards, that will keep them at home longer. But it may well be that they will end up in a nursing home or in hospital at a much more acute stage or chronic stage because they have been able to be in the home much longer, whereas once they might have gone to a nursing home earlier or gone into hospital for an acute illness. That is a possible emerging problem coming our way: addressing that issue.

That is compounded by the fact that a lot of nursing homes, in particular, are not equipped and do not have the nursing staff to provide palliative care in situ. If a nursing home is my home, I want to stay there, and there are not enough nurses in that facility to provide the care that I need to stay in my home. That needs to be addressed. I understand that there are issues around the federal nature of funding in that space, but at the end of the day the ACT pays the cost of the person ending up in hospital when the care cannot be provided.

MS LE COUTEUR: I am interested in how dementia and other conditions of impaired mental abilities interact with both palliative care and any possible decision about voluntary medically assisted suicide. Do you have any comments on that? It is not just physically that people deteriorate.

Mr Daniel: Absolutely. We are not here to provide the absolute answer on that, though it would be nice.

MRS DUNNE: Our work would be done.

Mr Daniel: We can provide insights into what we see around that. It is particularly complex where any person has a cognitive decline, whether it is dementia or someone experiencing a mental illness. These are really difficult issues that, as nurses, we have seen in the workplace. I myself nursed someone who was being palliated on an acute care ward, and there were all sorts of questions swirling around about whether this person had capacity, because of a possible mental illness, with that condition at that particular time, of wanting to refuse treatment. That was no quick fix. It is difficult. I just wanted to give you that example to say that nurses are grappling with those issues on a daily basis. They are not uncommon. We are looking for the answers and we want to be part of that discussion.

Ms Corradini: Sometimes as well—

MS LE COUTEUR: How do you think the answers can come? The problem is not going to go away.

Mr Daniel: No.

MS LE COUTEUR: If there is no legal change to the potential for voluntary assisted dying—

Mr Daniel: Yes, sure.

MS LE COUTEUR: Even if we take that totally off the table, just from a palliative care point of view and choices that people may want to make about their treatment, how do you do it?

Mr Daniel: Again, if I can draw on that one example to provide what I believe would have been the fix in that situation, it is quicker access to specialist services. At that point, it probably went on for a week, not knowing whether this person had the capacity to decline medical and nursing interventions. We needed a psychiatric review, and that took too long. We need specialist services that might come along with that, such as social workers to talk with families about their understanding of the situation. We need arrangements so that those things that needed to happen, and eventually did happen, occur in a much more timely manner.

Ms Pell: I have palliated people with dementia, and it has a number of issues of its own. We rely a great deal on the family, where we can, to get decisions about how we are going to proceed with palliation. As you know, numbers will increase as we go along, so it is becoming an increasing issue. We are not seeing very many at the moment, but most of them are in residential aged-care facilities.

MS LE COUTEUR: Yes.

MRS DUNNE: As I understand from one of the points that you made, Mr Daniel, there is often a transition out of residential aged care at the very end of life because there are not enough staff to deal with the issues that would present with that particular patient.

Mr Daniel: Yes. There are not enough of the right staff with the right skills.

MRS DUNNE: Thank you; that was very insightful.

THE CHAIR: Can I just ask a quick follow-up to that? The right staff with the right skills? Does that mean that, predominantly in residential aged-care facilities staff, there is not a high enough skill level? In hospitals you have staffing ratios; I believe there are no staffing ratios in aged care.

Mr Daniel: No, there are not. There are no mandated ratios.

MRS DUNNE: It is not necessarily about ratios but about the skills as well.

THE CHAIR: It is the skillset as well.

Mr Daniel: I was going to say that it is both things. It is the right number of staff, but it is also the right number of nurses who are lawfully able to give certain medications and provide certain care, who are educated to do that and have all the right qualifications, education and authority to provide that level of care. Our members tell me that there is a particular problem in nursing homes in just providing everyday medications in a lawful way, let alone the problems of dealing with restricted medications that you might require for pain management.

THE CHAIR: At end of life?

Mr Daniel: At any time, but particularly end of life, yes.

Ms Pell: I worked in aged care before I did palliative care, and a lot of the workers in aged care are from other cultures and non-English speaking backgrounds, so they have their own issues with how they culturally deal with end of life anyway. There needs to be a lot more education of the carers and the other nurses as part of their training, and perhaps palliative care training. That would mean that they would need to go off and do specialised courses. I think most residential aged-care facilities need someone on site who has palliative care knowledge. It is not just nurse practitioners, but perhaps they can be guided by the nurse practitioner and then relay and say, “This is what we should be doing for this resident now.”

MRS KIKKERT: Most of my questions were answered before, but I will just ask a very simple question. If assisted suicide is legalised here in Canberra, what would you see as a genuine concern for the patient, as well as for the nurse?

Mr Daniel: In terms of nurses, the policy position of the ACT branch is that it is looking for reform to support assisted dying. But we acknowledge that nurses come from different cultures and different backgrounds, have different belief systems and have different views on assisted dying. So, while we have our overarching policy position, if assisted dying legislation does bring about reform, we also need to make sure that those who have a conscientious objection to providing that care are protected and that those nurses who may or may not be part of that framework of assisted dying are protected, too, to participate in any lawful framework. For patients—

Ms Pell: Access in general to information so that they are making an informed decision, and canvassing a wide range of opinions: medical, social work, pastoral care, whatever. It is a bit of a minefield for a lot of nurses. A lot of nurses do have their own opinions, and others are still quite undecided and not sure what they would do when placed in that situation. As of this moment it has not happened, so it is hard to know what you would do. For nursing, you want to do the very best for your patient. You want to advocate for your patient, and if that is what it means to advocate—

Mr Daniel: One of the things that come up time and again—and I am sure you will have already heard this, or may hear it tomorrow—is concern from patients and family members. If, say, pain management is going to be increased—and that might include morphine or those sorts of drugs—you always get the question about whether this will actually end life. That is very much at the forefront of everyone's thinking. You get asked that time and again. There can be reluctance by nurses and medical staff to increase pain relief because they might be seen to be assisting that person to die. We really need to be very clear about how we can support current and existing palliative measures and not take anything away from that. In fact, we need to add to that knowledge and confidence about palliation versus assisted dying.

Ms Corradini: It is a hard one.

THE CHAIR: I have a very quick follow-on; I know we have reached our time limit. This morning one of the other witnesses described end of life as a specific period of time towards the end of life, usually within the last 12 months of life. You may agree or disagree with that. That is perfectly fine; I am happy to hear your points of view on that. One of the questions I asked that person was: is assisted dying an option that could assist with providing end of life care? I would be interested in your thoughts, granted that I understand there are personal opinions as well as professional opinions in that. I am happy for either of those to come through.

Mr Daniel: Taking it from our policy position statement, assisted dying should be made available to assist with dignity and the choices that people wish to make at the end of their life.

MRS DUNNE: How did you come to your policy decision? You are very conscious and very careful in your discussion paper to say that there are a diversity of views in the nursing profession.

Mr Daniel: Sure.

MRS DUNNE: How did you discern the position that you came to?

Mr Daniel: That overarching ANMF-wide policy position is developed at our conferences and so on, from all the state and territory branches.

MRS DUNNE: So this is not an ACT branch policy? It is a national policy?

Mr Daniel: It has been affirmed by the local branch.

MRS DUNNE: So it is a national policy which has been affirmed by the local branch?

Mr Daniel: Yes.

MRS DUNNE: So it is through a sort of policy debate on the floor?

Mr Daniel: Yes, on the floor.

MRS DUNNE: Okay.

Mr Daniel: Which is why we need to reflect that there are very many different views here.

MRS DUNNE: Yes.

THE CHAIR: Please feel free to add anything you would like to.

Ms Corradini: Sometimes I will have patients who are progressively passing and who have had a chronic illness for a while, and they will get to a point when they are still able to comprehend and talk to you, and they just say, "I don't want to do this anymore." They are just suffering for this period of time. I know it is in their final stages, and maybe they are having all these thoughts come to them. But if they had the conversation option prior to that suffering, I do not know what that would be, what that would change. Sometimes I walk out of the room after someone has passed and I just feel they were comfortable, but most of the time I will walk out and go, "That person should not have suffered like that. What would their opinion have been prior to this?" I do not know.

MS CHEYNE: We heard this morning from a palliative care specialist that there is no situation that cannot be managed with palliation. He was definitive.

MS LE COUTEUR: He was, yes.

MS CHEYNE: He said it is all just about making sure you are aware and know what is going on. For me, there must be times when people are unconscious and you are not quite sure exactly what pain they are experiencing. Do you have any comment on that?

Ms Corradini: We would like him to educate us.

MRS KIKKERT: He is a specialist palliative doctor.

Mr Daniel: I would invite that specialist, with the knowledge that that specialist has, to the broader medical nursing health community to assist, if that is the case. It is not happening. We see where it does not. It just does not happen in every case.

MRS KIKKERT: That was part of the discussion as well: that even GPs do not understand the medication out there that is available.

Mr Daniel: That is not to say that the knowledge cannot be improved. Absolutely it can: the timeliness and the knowledge. But even when it is timely, I have still seen people suffer.

MS CHEYNE: Just to be completely clear, are there points where you believe that palliative care just is not enough?

Mr Daniel: I personally do, yes.

MS CHEYNE: In all your experience. So that is a yes from everybody?

Ms Pell: Yes.

Ms Corradini: Yes.

Mr Daniel: Yes.

MS CHEYNE: Thank you.

MRS DUNNE: I was reflecting on the point you made, Ms Corradini, that, as you say, you wished it could be better in particular circumstances. I was going to ask Ms Pell, as a palliative care nurse, essentially the question that Ms Cheyne asked: can it always be better?

Ms Pell: Yes.

MRS DUNNE: I suppose the question is: can it be perfect? Can you always address the issues? The specialist we were talking to this morning quite confidently was saying that, with the right interventions, nothing is too difficult.

Ms Pell: In an ideal world, yes, of course.

MRS DUNNE: But in your practice—

Ms Pell: No. In practice, most of the time, yes, people do have comfortable deaths: everything goes well; the family are relieved that we have done all that we can. But every so often you do get someone who, for existential reasons or just because we cannot get on top of the pain, will not die in a wonderful, ideal way but it will be a struggle where it is stressful for absolutely everybody. For the others, it is not stressful.

MRS DUNNE: Given your experience, do you see that in decreasing proportions or continuing proportions?

Ms Pell: At the moment it seems to be about the same. As I said, every now and then we do get someone, and I think that will probably always remain, but it will not be as often. I think there are just some people for whom death is a difficult thing. They may have existential issues that they may not be able to get on top of. They may have served in the army or the AFP. They may have seen things or done things that have all come flooding back when they are dying and created a whole set of issues that, on top of pain, exacerbate absolutely everything else.

MRS DUNNE: There is a spiritual, psychological, social dimension?

Ms Pell: Yes. Absolutely. It exacerbates pain.

MRS DUNNE: Which may be much more exacerbating than the condition itself.

Ms Pell: Absolutely, yes.

THE CHAIR: Mr Daniel, with your indulgence, can we have a couple more minutes of your time?

Mr Daniel: Absolutely.

MS LE COUTEUR: Given your comments about reality being different from how it was described, is one the things that we really need more training for medical staff, in particular in palliative care, and more staff? I think it was you, Mr Daniel—it might have been Ms Corradini—who said we needed one-on-one staffing for palliative care patients. It seems a very high level of staffing. I assume it cannot usually be achieved.

Mr Daniel: That is right, and that is why I say that the nurses will actively work around reallocating patients so that one nurse can really provide that one-to-one support. You will be trying to provide cares; you will be trying to provide regular turns so that skin does not break down, toileting, mouth care—all those comfort measures that people should receive. Then you are also doing the syringe driver observation checks, finding the drug keys to go and fill up that pain device—and we all know what that is like to wait for—for pain medication and all those things.

You have got the family that comes through the door and are in distress and you want to spend time with them and you want to talk to them about what is going on for their family member, where you see things are at, at this point. They want to speak to the doctor, so you need to try and get hold of the team managing the care to come and talk to the family. It is heavily resource intensive.

Nurses do it because that is the essence of nursing. But the pressures can really be very difficult to manage. They provide, in some cases, the level of care that you believe this person deserves. That is while a person is moving into death. And then there are a whole range of things that need to go on after that. The level of staffing around that is often not up to what you need to provide the level of care. I am not sure if that answered it all.

MS LE COUTEUR: I guess the other thing iced over was level of training.

Mr Daniel: Sure.

MS LE COUTEUR: Was there a deficit in that regard?

Mr Daniel: Yes. You can get education—and I remember my days of you getting the education because you have got someone before you providing it—and you are providing that care. Then you may not have someone that is in palliation—you might be lucky, not necessarily—for a number of weeks or months. Because you are not using the skills and knowledge around whatever it is, the medication management and so on, you do need to keep this at the forefront of your mind.

More globally, I think, there is a real difficulty in having the conversations. How do you initiate a conversation with a patient, particularly where they might be at their part of the journey, as to having that conversation, sitting down at the right time and saying, “How are you travelling? What do you need? What are we not doing for you?” Those conversations can be difficult because there are time constraints or because you just need to get that person at the right time. I have seen it is difficult for nurses; I have seen it is very difficult for doctors to have those conversations, yes.

MRS DUNNE: And possibly a hospital setting is not the best place for that?

Mr Daniel: No.

Ms Corradini: No. Sometimes patients will come in without an advance care initiative. They will not necessarily have an NFR order or anything and when they start to become unwell, just unexpectedly, and are deteriorating quickly again—and we are doing everything we can—at that point the doctors will go in and talk to the patient. That is not really an ideal time because these patients are unwell and then they bring the family in and the family deal with that shock as well. Sometimes hospital settings are unpredictable. But I guess community could be as well. But that happens a lot.

MS CHEYNE: Just to go back a little to the point you were making about the people that you think could have had a better death or where you did everything in your power and it still perhaps was not enough to make it a comfortable death—I know this is your job—what impact does that have on nurses psychologically or on their wellbeing to watch that and to have made those decisions and to live with that?

Ms Corradini: It is hard. When someone passes or is in the stage of passing it still scares me because the family will ask you questions and you are trying to answer the best you can. It is still quite daunting when I am looking after someone. Yes, it is. And sometimes I will leave my shift and I will still think of that patient and how they passed. It does affect you.

MRS DUNNE: Do you, in the nursing profession, have access to the capacity to debrief someone?

Ms Pell: In my workplace we do, yes. It seems to work better amongst us, where I particularly work, because if we do have someone who has not had the best passing you do tend to stand back and then go through it in your mind. Then you think, “Goodness, what could I have done differently there and what can I take away from this?” We discuss it amongst ourselves.

Where I work, we do not always have the same patient every day but the care is continuing. Perhaps the people who have looked after that person, say, for the last two days or three days will particularly get together and we will all go, “What do we do there? And if that ever happens again let’s do it this way.” And that is all you can do, really. We do have access to someone professional. Where I work, we tend to do it well amongst ourselves.

MRS DUNNE: Debrief amongst yourselves?

Mr Daniel: I am not sure about Claudia but my experience in the acute setting is it is not done well for nurses.

MRS DUNNE: That was the thing; the acute setting is different.

Mr Daniel: Yes, it is.

MS CHEYNE: It is done well over here, but over there—

Mr Daniel: It is not done well in the acute setting, where it is not palliation focused and so on.

Ms Pell: Yes, because we do it all the time.

MS CHEYNE: Whereas you guys are thrown into it.

Mr Daniel: Yes. And we debrief.

MRS DUNNE: And in the acute setting it is supposed to make them all better.

Mr Daniel: That is right. And we use nurses' humour to try and get through. But I still carry the 18-month baby girl that I cared for that had intractable seizures, that was going to die of aspiration pneumonia. I still remember her. I still remember a gentleman in his early 60s, locally, in what he saw—and I believe too—was the prime of his life. He just did not come to terms with that. And I still remember those vividly.

MS CHEYNE: We could do support better in the acute setting?

Mr Daniel: I believe so, yes.

Ms Corradini: Yes.

MS CHEYNE: With resources or money or people or—

MRS DUNNE: A combination?

MS CHEYNE: What do you need that you are not getting right now?

Mr Daniel: I think health services provide health services to a community. I do not know that they provide it so well to their own staff.

THE CHAIR: Thank you so much. I did have one further quick question, if it could be answered very, very quickly. I note we discussed this earlier. I have actually written this one down too. I note we discussed what an earlier witness described as no suffering that palliative care could not ease. We have already had that discussion. I was just wondering: how often are doctors around for the death, for the final moments? That is not a criticism; it is more a question to figure out. Is a majority of it a nurse-related moment? Are doctors there are well? I do not know the answer.

Ms Corradini: Most of the time it will be the nursing staff. We will contact a doctor. I do not know why it just happens to be after business hours, when there is one doctor. It just happens that way—or overnight, when there are only a very few staff on as well. There are not many doctors around at all, but we can call them to come in.

Mr Daniel: I would say it is most often in the acute setting when there is a med call and someone dies.

Ms Corradini: Yes, as well.

Mr Daniel: Because the medical staff are required to be there, yes.

Ms Pell: And I have held lots of hands as patients have died—I, nursing staff and/or family. I have got one hand; the family member has got the other hand.

THE CHAIR: Thank you so much for giving us a bit of extra time.

MRS DUNNE: It was so insightful.

THE CHAIR: I do not think there were any questions taken on notice. I would like to thank you for appearing today. When available, a proof transcript will be forwarded to you to provide an opportunity to check the transcript and suggest any corrections that may be required. On behalf of the committee, I would just like to echo again our thanks for chatting with us today and for all the information you have provided us. It really has been insightful.

Ms Pell: Thank you for the opportunity.

Mr Daniel: Thank you.

GRIDLEY, MS HEATHER, Manager, Public Interest, Australian Psychological Society

THE CHAIR: I welcome Ms Gridley from the Australian Psychological Society by phone. Ms Gridley, can I just confirm that you have read and understood the privilege implications of the statement.

Ms Gridley: Yes, I have.

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

Ms Gridley: Thank you, yes. I am speaking to the submission that we have made to the inquiry, which I think the committee members already have.

THE CHAIR: Yes, thank you.

Ms Gridley: I would like to respectfully acknowledge the traditional custodians of the land on which we are all meeting today, the different lands, and to pay my respects to their elders, past and present and emerging. I particularly acknowledge that for many Aboriginal and Torres Strait Islander people their need to return to country is very important at the end of their lives.

The APS is the leading organisation for psychologists in Australia, with more than 22,000 members. Psychology is the largest of all the non-medical health professions in Australia. We are very pleased to be involved in this inquiry. As with all our submissions, psychologists with key expertise in end of life contributed to this submission, but unfortunately they were not available to speak directly in today's hearing, so I got the short straw. I apologise for not being able to be there in person and also for having a cold; I hope you can hear me okay.

THE CHAIR: Yes, thank you.

Ms Gridley: I will not say too much, because most of what I am saying is in our submission. I will make a couple of points to emphasise that we do think that psychologists have some important knowledge and skills to contribute towards addressing some of the personal and ethical challenges surrounding end of life trajectories, not just around legalising voluntary assisted dying but also on broader issues like comprehensive palliative care systems and advance care planning protocols.

We think psychologists can and should be involved in end of life issues in a number of ways: facilitating conversations and addressing the stigma around death and dying; contributing to policy development and best practice for the care of the terminally ill; involvement in the process of support and decision-making for family members as well as the patient, including around assisted dying, should that become legal; the assessment of psychological disorders and mental competence; and the treatment and management of distress associated with end of life. They are all issues that psychologists can be involved in.

Our submission is focused on the context around end of life care and choices from a psychological perspective. We have highlighted the importance of ensuring that people approaching the end of their lives are supported by practitioners and broader systems to access appropriate information and care.

The major fear around end of life is not so much of death itself but the prospect of suffering, of not being in control and, often, of being a burden to others. There is quite a discrepancy between people's generally expressed preferences for end of life care and choices around dying at home, and dying and living in place, and what tends to happen, where the majority of us will die in hospital or residential care eventually.

This is a great opportunity to change and improve how we do things: in general, improving training to create a better health workforce; having better infrastructure; and having more appropriate policies and protocols in place to maximise the real choices and sense of control available to the seriously and terminally ill. I do not think anyone would disagree with that, but we also think that if all of those things were in place, we may have less need to think about assisted dying. At the same time, if assisted dying were to become legal, it would need those supports in place to avoid any abuses and to work well. So it is very much part of the picture.

We also note that the ACT is the only jurisdiction, to our knowledge, where the specialist palliative care services are only provided by a Catholic hospital. That is a concern in terms of the independence available in terms of people having their wishes met, particularly if voluntary assisted dying were to become legal.

The APS itself does not either endorse or oppose voluntary assisted dying. We just endorse best practice approaches in general to end of life care, ensuring that patients fully understand their alternatives and the ramifications of any decisions they make around accessing those services if they were to become legal. We certainly think that, if they were to become legal, psychologists ought to be involved in some of the process around assessment, decision-making, supporting families and such.

We think that probably the main areas that psychologists could be involved in are capacity assessment, therapeutic interventions and also providing clinical supervision for the service providers, especially for something where the process is quite new and many people—nurses, doctors and others in the workforce—have not yet been well prepared to accommodate this. There could be a great deal of stress on the workers themselves that psychologists may be able to assist with, although the psychologists also would need more training than they currently get.

We have identified a number of risks in our submission around competence and decision-making capacity, particularly in relation to mental illness and whether that automatically disqualifies somebody from being able to make decisions about the end of their lives. We have talked about coercion, not being a burden to others, but also coercion to stay alive when you may have had enough. We have talked about conscientious objection. We have talked about, as I mentioned, the impact on practitioners themselves in working with people who are approaching end of life. We have talked about the importance of equity in health care, where often the most vulnerable people in society are the ones who are least likely to be able to access adequate health care and might be more likely to make the request for assisted dying services. Perhaps that is likely to be well supported in those decisions. And we have talked about the importance of a properly trained palliative care workforce that perhaps is broader than the specialist workforce but also the importance of all health professionals having some understanding of palliative care and what it involves. That is probably all that I need to say now. I am happy to take questions from the committee.

MS CHEYNE: I suspect that my line of questioning is going to be where Ms Le Couteur's line of questioning is, but I will let her speak for herself. It is regarding mental incompetence and decision-making capacity. I want to thank you for providing quite a different perspective from what we have heard in other submissions or what we have read in other submissions and heard today, particularly around coercion to stay alive and equally about presumptions about someone with a mental illness or a disease like dementia that is not necessarily cancer but is going to cause someone to die and eventually affect their mental capacity.

I was just wondering, particularly for the *Hansard* record, if you could expand on how you have come to these conclusions and what we could be doing in the ACT to make sure that if we did legislate for assisted dying we provided the best scheme possible with respect to the issues that you have raised.

Ms Gridley: Mental illness is a bit of a two-edged sword, really. Obviously, on the one hand we do not want somebody to be expressing a wish to die and having that able to be acted on when in fact they might be temporarily depressed or understandably depressed by the situation of their illness and that might be reversed with good treatment options, proper support and proper access to care. While on the one hand mental health needs to be taken seriously and addressed, we do not think that it should rule somebody out: a person who is experiencing mental illness is not necessarily assumed to be irrational or unable to express their views. We know that a lot of the kinds of illness that lead to death, particularly forms of cancer and so forth, are extremely distressing, and it is a very normal reaction for somebody to be depressed, but they might still have a realistic understanding of what the trajectory is and they may have a clear view that they do not want that to continue or have some limits to that. Their depression should not, in itself, rule them out.

That means that each case needs to be assessed on its merits and there should not be a one size fits all rule applied that you are depressed and therefore you are not competent. We think that that is an inappropriate assumption. However, we do think there should be good assessment available so that people's depression is not the overriding reason they want to die when it could be treated and alleviated.

MS CHEYNE: Would you advocate for any scheme requiring a psychological assessment when someone does seek to access the scheme?

Ms Gridley: No, we do not. We have not said that we favour that, because it is a bit like throwing roadblocks in the way of somebody whose situation might be quite urgent, whose presentation might be perfectly rational and calm, and who may not require a mental health assessment. Obviously, we want to be sure that anybody who makes a request like this is competent to make it, but that should be indicated by the GP's assessment, or the treating doctor should be able to make some decision about whether that person is in a position, cognitively and otherwise, at least initially—to refer them for further assessment or to take their wishes on face value and proceed with their instruction.

MS LE COUTEUR: Another thing that you said in your introductory remarks was that in some overseas countries you think there is a higher proportion of people who are economically disadvantaged who are accessing voluntary assisted dying. Did I hear you correctly?

Ms Gridley: I do not know that we have evidence of that. That was just a guess that it would follow that if people have not got access to good health care that might be the reason they are distressed—they are not getting good palliative care. They may be expressing a wish to die when good palliative care would offset that. We certainly know that access to good care is affected by region.

This is just a personal comment and not so much a professional one, but I always wondered, when the legislation became legal for a period in the Northern Territory about 20 years ago, whether it was a coincidence that that is an area that has very high rural and remote populations and very proportionally high Aboriginal populations. I understand a number of Aboriginal groups were very wary about the notion of assisted dying because their lives had already been deemed to be less worthwhile than others in other circumstances. I think disability groups can be the same—there is a fear that their lives, which have already been perhaps not treated as equal with others might be, in this case, the first ones to be considered worthy of pushing towards dying. I do not have any evidence for that but I wondered about it at the time, and that is about all I can say about that.

I think it is a reasonable fear. Certainly a number of Aboriginal women have been concerned when we talk about access to things like abortion, but their concern is more about the right to have a baby and not the right to terminate, because often they have been subjected to fertility restrictions and such and forced sterilisation. I suspect that there could be a parallel process at the other end of life as well. That is just an observation not necessarily based on any particular evidence.

MS LE COUTEUR: Certainly we have heard evidence from people concerned that some older people in particular will feel coerced and that the whole issue of elder abuse will only increase if there is voluntary assisted dying legislation.

Ms Gridley: Yes, it is a concern. I do not know that there is evidence of that because, clearly, if you have good safeguards that theoretically ought not to happen. I think the bigger risk is the notion of social coercion in the sense of generally people feeling like: “The option’s there. I am a burden. Perhaps I should,” rather than somebody directly telling them that you should shuffle off or whatever and that broader sense of ending it.

Again, generally speaking, there is pressure sometimes on women to access fertility treatment to the nth degree, whereas once upon a time they may have just accepted their infertility because there were not any other options available, and the same may happen at the end of life. But my understanding is that where voluntary assisted dying has been legalised in other countries there is not much evidence that that has happened. The evidence is perhaps more that people feel enormously relieved by having the option available but usually do not take it up. It is just speculation, really.

MRS KIKKERT: You state on page 4 that palliative care is not always available to all people who might benefit. Do you think this is the case because there is inadequate funding for palliative care and, if so, would you recommend that the ACT government puts more emphasis on ensuring there is enough funding for palliative care?

Ms Gridley: It is certainly our view that it should not be a trade-off; we should not rush to assisted dying and, therefore, wind down palliative care. But we also do not think palliative care is enough of a reason to offset the need for assisted dying if it were to become legal. They are not necessarily mutually exclusive. Although, again, we do not have a formal position on the issue of assisted dying, they should be complementary rather than in competition. When we say fully funded, we are talking about accessibility in terms of language and in terms of remoteness, which is perhaps less of an issue in the ACT, as you have a smaller territory to reach. But there are a lot of different ways in which we can talk about access.

One of the things that concern psychologists, of course, is access to any kind of services when people are cognitively impaired and having difficulty making their wishes felt, whatever their wishes might be—being able to express pain when you are suffering from some sort of syndrome that makes some sort of communication difficult. Our position is not that that makes you incompetent to make your decisions or needs felt but that you should be properly assisted. There are lots of ways psychologists and speech therapists and other health professionals could be of assistance there and they are often not used.

MRS KIKKERT: Your recommendation 3 is that if voluntary assisted dying is legalised in the ACT you would advocate for more psychological assistance in all areas.

Ms Gridley: Yes, and I guess it is always my job to say there should be more psychologists everywhere. We were certainly pleased to see in the federal budget more allocation of funds for mental health in aged care. Previously, people in residential aged care were not able to access Medicare-funded psychological services. This is a different issue, of course, but we certainly think they ought to be. I think that was technically because they are not deemed to be living in the community, and I think that is about to be addressed, or I hope so.

We certainly think that better access to not just decent counselling services but decent assessment of competence and such and also support for families is something that is really important regardless of whether assisted dying is legalised. But, certainly, if it were you would want those systems in place as well.

MRS KIKKERT: How many registered psychologists are in Canberra?

Ms Gridley: I do not know that I have it available immediately, but I can check. I know there are something like 30,000 in the country. It is the largest health workforce after nurses, I think. There are quite a few in the ACT. I did have it somewhere but I have not got my hand on it right now. There is a reasonable supply, but when you get down to who has the capacity to deal with particular issues like ageing or clinical neuropsychologists who can do cognitive assessments of a particular kind it narrows down a bit, of course.

THE CHAIR: In your opening statement you mentioned that a concern for you, if voluntary assisted dying was introduced into the ACT, was that there is currently only one hospice.

Ms Gridley: Specialist service, yes.

THE CHAIR: Can you expand on your concerns around that, please?

Ms Gridley: My understanding from people who work in the field is that obviously Catholic services have a strong position around assisted dying, and it is one of the reasons why in every positive way they have become involved in palliative care. That means that if something becomes legal but those people who are the most likely to need that service are receiving services from a hospice that does not believe in it then you have a problem. That is what we were alluding to.

THE CHAIR: You mentioned in recommendation 5 of your submission that the implementation of any voluntary assisted dying scheme needs to consider the existing and future capacity of the workforce to meet the needs of people approaching the end of their lives. Can you expand on a little bit as well, please?

Ms Gridley: I have spoken to people in Victoria, in the context of the debate that was happening there last year. They have been very concerned that even though they may in theory support the notion of dying with dignity and people having access, they do not believe the system is capable of delivering it because of the infrastructure around people’s choice of doctor or people having access to good counselling. They feel even now in the current system, particularly around palliative care but also around assessment and a number of other in-hospital access, waiting lists and everything, that those things that need to be addressed first.

If we have long waiting lists for people to have some of the treatment that would alleviate suffering or if we have long waiting lists around emergency care or even just to do with wound care, those are the things that would provide a lot of relief. If the system is not very responsive in that, they do not know how it will be able to deal with the sometimes very complex responses needed if somebody is requesting to die and to follow through a good process and make sure that is enacted properly. That is where that concern comes from—if you have not got a workforce and the infrastructure to support it, it could just become a quick and nasty option rather than a properly thought through system that attends to people’s needs in the way that they want.

MRS DUNNE: Thank you for your time this afternoon. Could I go to an overall thing about the tone of the submission from the Psychological Society?

Ms Gridley: Sure.

MRS DUNNE: There seems to be a bit of dissonance, I suppose, for want of a better word, because you are saying that as an organisation you do not have a view one way or the other, but then there are a number of recommendations that say, “If you do this, you should take into consideration X, Y and Z,” like the issues raised by Ms Cody.

Ms Gridley: Yes.

MRS DUNNE: How does the association hold those two somewhat separate views?

Ms Gridley: The main reason that we do not have a view is that often when the APS reaches a position on something like marriage equality, for instance, we know that not all of our members might agree with the position that we reached, which was supportive of marriage equality, but we feel that there was not really a good psychological argument to the contrary, and that the majority of our members would support it. But on something like assisted dying, it is much more complex. There are good arguments in both directions, so we have not gone through the process of formally asking the membership or even asking the board what the position is. That usually takes quite a long time.

We have gone through a process of saying we do not have a position but, if it were to become legal, these are the things that we think would need to happen. I suppose there is a slight, implied leaning towards a compassionate view and the need for people to have good supports. But if they get to the point where they are saying, “Enough is enough,” maybe that needs to be listened to. It is not a strong enough position to say it; that is the view of the society. Normally, we try in these situations to consult the groups that are most affected. Again, in the case of marriage equality we worked with the LGBTI psychologist groups and community groups that felt that they were the most affected.

In this case it is very difficult to say who the most affected groups are because we could all be in this position. We did not feel there was a strong sense one way or another that it ought to be supported. We still feel that, as in Victoria, if it does become a reality—and taking account of generally reported community views of up to 75 per cent in favour of assisted dying, it may well be inevitable—with the right supports and services, it should be available, and we think we should be a part of that.

We are certainly not saying that psychologists should not be a part of some of those processes. We are not in the position, in the same way that doctors and nurses would be, obviously, of actually administering any procedures. Certainly, it is quite possible that psychologists would be involved in the assessment. I do not think it is likely that the APS or the registration board would forbid that, but I do not think it is likely they would make it compulsory either, beyond what we said around conscientious objection—that if somebody does have a conscientious objection to something that actually is legal, they should not put that objection in the way of the patient having their autonomy respected.

MRS DUNNE: Going to some of the specifics, many of your recommendations, even those that refer directly to voluntary assisted dying, like your recommendation 5, would also ring true for the expansion of existing services in this space, even if we did not go down the path of providing a mechanism for voluntary assisted dying. For instance, your recommendation 5 still stands—that there should be existing and future workforce capacity to meet the needs of people approaching the end of their lives.

Ms Gridley: Yes.

MRS DUNNE: Whether that is through conventional palliative care or expanded palliative care et cetera, those recommendations still stand, in a way, irrespective of which path a jurisdiction might go down.

Ms Gridley: That is correct, yes. We certainly are aware, in our own profession, that we do not think we are particularly well prepared for these issues. With an ageing population, it overlaps with ageing, although it is not the same issue, obviously. It has not always been a core part of psychology training to be aware of these issues beyond the general ethical principles around doing no harm, respecting people's autonomy and dignity and so forth. But there are not many places, with a couple of exceptions, where psychologists are directly prepared for work either with people approaching end of life or with people who are in their later years in general. I suspect we are not much different from most other professions in that regard.

MRS DUNNE: Can I go to the issue of coercion? I suppose there are two sorts of coercion. There is coercion to take a particular path to end your life, which could be considered elder abuse.

Ms Gridley: Yes.

MRS DUNNE: There is also potentially coercion to go the other way and say, "No, Mum, you really need to have this procedure," et cetera. Both of those things can be considered to be coercion but have different outcomes.

Ms Gridley: Yes.

MRS DUNNE: Does the society have a view about whether there should be penalties, I suppose, for want of a better word, or strictures against people who are found to be coercive in these circumstances?

Ms Gridley: I do not think it is something we have directly discussed. Probably what is more important is prevention—more than penalties—in a situation like that, because it can be very subtle. Where you have economic abuse and people fiddling with people's wills, that is really obvious, and it is probably criminal anyway. In these situations sometimes it is more emotional and more subtle. People are not always even aware that that is the way they are behaving—that they are giving messages to somebody that they ought to hurry up or whatever.

I can think of an example of somebody that I knew in the last 12 months who had been on a death trajectory for about 10 years, and at least one of the people closest to her really could not face the idea of her dying and pretty much pressured her to keep having treatment after treatment, and she probably had one too many before letting the illness take its course. The final treatment was quite destructive, and people were saying that she really hung on because of that person, when she probably would have let go. This, of course, was not about assisted dying; it was simply around the course of treatment.

One of the things that strikes me—and this is a personal view—is that it is quite hard to die these days. We do have so many procedures to keep us alive and so many ways of doing things that once were not available. Stopping and not having anything further is quite hard, let alone taking another step and seeking assistance with dying. One of the reasons that this has become an issue is because we have so many ways of keeping people alive that we did not have before, and we have become frightened of death and unaccustomed to talking about it and facing it. It is the same as I was talking about with things like infertility and other things.

An example that I often use is cosmetic surgery. You do not see too many people around these days with buckteeth or crooked noses because the assistance is available; therefore they will get help. Somebody will say, “Why isn’t your child wearing braces,” or “Why haven’t you had a nose job?” Suddenly the person who has not availed themselves of those things becomes the exception rather than the rule. Those are much more social sorts of pressures that are hard to legislate for, but they are still things that we need to be aware of in our considerations. I do not know if that actually answers your question.

MRS DUNNE: No, it does.

Ms Gridley: Prevention is, in this case, probably more important than penalties.

THE CHAIR: Thank you so much for your time today, Ms Gridley. I really appreciate you letting us phone you a little bit late. The information you have provided to us has been quite insightful. When available, a copy of the proof transcript of today’s hearing will be forwarded to you. It will provide an opportunity for you to check the transcript and suggest any corrections, should they be required.

I remind any witnesses that undertook to provide further information or took questions on notice during the hearing that we look forward to getting those back within two weeks from the date of the proof transcript being provided. I will now close the hearing.

The committee adjourned at 4.32 pm.