



**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, 12 JULY 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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Amended 20 May 2013

The committee met at 9 am.

GREENWOOD, MS SUZANNE, Chief Executive Officer, Catholic Health Australia

ETCHELLS, MS JANE, Manager, Clare Holland House

THE ACTING CHAIR (Mrs Dunne): Good morning, and welcome to this inquiry by the Select Committee on End of Life Choices in the ACT into matters referred to the select committee by the Legislative Assembly on 30 November 2017. The proceedings are public; they are being recorded by Hansard for transcription purposes, and will be webstreamed and broadcast live.

Can I remind witnesses of the protections and obligations entailed in parliamentary privilege, and draw your attention to the pink privilege sheet which is on the table before you.

On behalf of the committee, I acknowledge that we meet on the land of the Ngunnawal people, the traditional custodians, and respect their continuing culture and the unique contribution they make to this area. I would also like to extend an apology from the committee chair, Ms Cody, who is ill and cannot be here today.

I welcome our first witnesses for this morning's hearing, from Catholic Health Australia. Could you confirm that you have read and understood the privilege statement?

Ms Greenwood: Yes, I have; thank you.

THE ACTING CHAIR: Does Catholic Health Australia have an opening statement?

Ms Greenwood: A brief one. Joining me here today is Jane Etchells, the manager of Clare Holland House, which is a specialist palliative care service in the ACT, which I am sure needs no introduction.

Thank you very much for the opportunity to talk to you today. We applaud you all for considering the issue of end of life choices, because choice is something that is very important to us all. I apologise for the massive submission that we lodged with you. As you can imagine, this has been such a topic of discussion all around Australia that we were able to bring together a lot of the questions we have been asked elsewhere; therefore we have brought that into the submission itself.

This morning I want to give a brief introduction about who Catholic Health Australia is, and our members. Essentially, Catholic Health Australia is the peak body that sits over the Catholic hospitals and Catholic aged-care facilities across Australia. There are 80 hospitals; 23 are public and the rest of them are private, and 17 of the hospitals are located in rural, regional and remote Australia, which is something that is very important to us. We also have 25,000 aged-care beds across our sector, and over 36,000 home care, community care packages for people whom we are caring for at home.

Here in the ACT, obviously, we have Calvary John James Hospital, the Calvary Public Hospital at Bruce and the new Calvary Bruce Private Hospital. We also have our specialist palliative care service at Clare Holland House at Barton, and we also provide aged care in Aranda, Braddon, Bruce, Campbell, Deakin, Garran, Manuka, Page and Yarralumla.

For Catholic Health Australia members, we have always valued the delivery of person-centred care that is founded in respect for human dignity and life; so we really do welcome the opportunity to speak to you today. We do so from a position, obviously, that it is the medical profession's duty of care to preserve and protect life.

We feel that there is probably not choice open to every person in the ACT to receive good palliative care. The aspect that we are really wanting to talk to everyone about today is the need to improve availability of palliative care, awareness of palliative care and understanding of palliative care.

Some individuals will say, "Don't refer me to Clare Holland House; they're going to kill me there. That's where you go to die." Of course, that is not what palliative care is all about. It is very much about holistic care, caring for the whole person and bringing together a very multidisciplinary team to consider the spiritual needs as well as the physical and emotional needs, and other very specific issues like pain relief.

We strongly believe that the provision of good palliative care should be available to all. That is mainly what I wanted to say, as an opening comment. We are happy to take any and all questions this morning.

THE ACTING CHAIR: Ms Greenwood, I want to start where you concluded, and that is the availability of palliative care. I am not sure who is most qualified to answer this. Maybe Ms Etchells is qualified to answer this. Because this is an inquiry into end of life issues in the ACT, where do you see the gaps in palliative care in the ACT?

Ms Etchells: I am happy to answer that. I would think that the biggest gaps remain in the community and in residential aged care for supporting patients at end of life. I believe that we offer a specialist palliative care service but, in terms of primary palliative care in the community, I think that is lacking. People who choose or wish to die at home do not have access to enough care in their home to be able to stay in their home and so often will end up having to go into a residential aged care facility end of life or go to hospital or to a hospice, depending.

If people are dying naturally without a huge symptom burden but their family needs daily care assisting them with washing, looking after them in bed—someone is confined to bed, they do not have a big symptom burden but the family need to wash them in bed, toilet them in bed, provide them with meals in the home—we do not have the care packages to go into the home and provide a level of care that will allow someone to stay comfortably at home 24 hours a day.

Our service will go in, provide an hour or two each day and a consultancy service and look after the symptom burden, provide them with some support, some psychological support. We can provide OT, physio, pastoral care, social work in the home. But we are not there 24 hours a day and people at end of life really do need a great deal of

hands-on care to stay at home. We do not have specific palliative care packages that will look after people in the last, I would think, two to three weeks of life in the home. I think that is one area where we could really improve in the ACT.

In residential aged care, we provide a consultancy service into all the residential aged care facilities in Canberra, and that is done now with nurse practitioners, which has been a great improvement because they can at least do some diagnostics and prescribe treatments for patients. It stops the delay from when a patient has a symptom to when the GP can actually visit the patient in the facility, which can sometimes be hours but sometimes can be days, especially when we have got GPs who are working part time and may not be able to get there. That has been a significant improvement.

But what they do not have in residential aged care is some physiotherapy access, easy access to physio or OT. Some of them have some access to pastoral care support but probably not at the level that people need when they are reaching the end of life, when they are really exploring their existential distresses.

I think the other thing that is missing from residential aged care is any bereavement support for families once people have passed. The families who come to Clare Holland House will get that support but families who are cared for outside of that aspect do not get that bereavement support. A lot of people think, "People are old, we were expecting them to die, and therefore the bereavement will not be as great," but our experience is that people grieve regardless of how old the person is when they die.

I think those are the areas that I would see are missing greatly.

Ms Greenwood: I would also like to comment. I think too there is a gap or a disconnect between our hospital care and—

THE ACTING CHAIR: I was about to ask that question. You anticipated my question.

Ms Greenwood: Thank you, because very much nobody wants to die in hospital. We might have 80 hospitals in our group but we realise that people do not want to die in hospital; they want to be with their loved ones, and that is why the community palliative care is something that we are terrific supporters of. A lot of our end of our life care services all around the country have really expanded their in-home care support. But the statistic is that you present to hospital seven times in your last year of life and nobody wants to be going through that kind of a journey at their end of life.

There is clearly also a gap around training those in the hospital context to recognise when somebody is at end of life, to recognise when some care options may actually be futile or even distressing for the individual, and some good training and support to help those already working within the hospitals to identify when somebody would benefit from receiving palliative care and having a community service taking care of them in their own home.

But again it is about training the clinicians and others as well, even in the palliative care space. I think the AIHW statistic is that Canberra has four specialist palliative care physicians, which is distressingly low.

Ms Etchells: That is right.

THE ACTING CHAIR: I want to expand a little, before I hand over to Ms Cheyne, on the issue of in-hospital palliative care. There is some palliative care provided at the Canberra Hospital but there is no palliative care ward. Could you tell us what in-hospital palliative care is provided at Calvary?

Ms Etchells: Similar to Canberra Hospital. At Calvary Hospital there is a consultancy service that sees patients who are deemed palliative. If a treating team decides that there are no future care options for that patient, that they are reaching end of life and that they require palliative care, then they call the consultancy team at Calvary who will go and see the patient and provide advice for management of symptoms or care that is needed. If the patient requires transfer to Clare Holland House then we will make a referral to Clare Holland House for that to occur. It happens the same across both hospitals.

THE ACTING CHAIR: It is a similar model? There is no palliative care ward?

Ms Etchells: No, there is not a palliative care ward at Calvary.

THE ACTING CHAIR: What are the merits and demerits of that sort of approach?

Ms Etchells: Of not having—

THE ACTING CHAIR: A consultancy team rather than having a dedicated ward?

Ms Etchells: I am not really sure that there is enough need for a dedicated ward at both Calvary and TCH for palliative care patients. I think we have got to understand that palliative care is a very broad topic. The philosophy is that patients should be referred to palliative care early. Not everybody that is a palliative care patient actually requires to be in a ward or in a bed. I think when people require a specialist palliative care service and they do need to be in a bed then they are referred to, at this point, Clare Holland House. It could be a ward in a hospital but at this point in Canberra it is Clare Holland House.

Other people will stay within their specialty and be discharged home as a palliative patient to the care of their general practitioner to manage. Not everybody requires specialist palliative care. A lot of people require primary palliative care, and I think that is where we need to provide more education in terms of not just the hospitals but in terms of the GPs recognising when they have got someone with a chronic illness who is reaching the end of their life, they start to have those discussions early on and they start to plan for what is going to happen. Does the person want to go back to hospital or is there another or a better way of managing their disease process?

That is what happens with our nurse practitioners in residential aged care. They have a case conference with the family, with the patient, with the patient's GP and they go, "Okay, this is the likely scenario for this disease. If your disease burden takes over do you want to go back to hospital? If you go back to hospital this is what is going to happen. You will have multiple tests and multiple possible indignities, all the risks of

being in a hospital—infection, pressure injuries and all the other risks that go along with being in an emergency department for a period of time and then moved around a ward—or we could keep you in the residential aged care facility and offer you this treatment, manage your symptoms, look after you, you stay with the care workers who know you, you are with your family, and that is the choice that you can make.”

Most patients will chose to stay in the residential aged care facility unless they, obviously, have a fall and break their hip or something. Then, obviously, they will need to go in and have that fixed. But the majority of those patients who are guided through that and have those conversations with their GP and the people who are closest to them choose to stay at home. I think we need to be doing that for people who are not in a residential aged care facility but are reaching end of life, whether it be a young person with a chronic cancer or whether it be an older person who is dying of a non-cancerous diagnosis like COPD or heart failure.

THE ACTING CHAIR: How satisfactory is the flow of patients between either the community or the hospital and Clare Holland House? Is there an unmet need at Clare Holland House? We have heard different things as to whether there is unmet demand.

Ms Etchells: Clare Holland House prioritises patients from the community. They are the people probably who have the greatest need to have another set of nursing staff or medical staff looking after them. We would always prioritise people from the community and it would be very rare that if a person was needing to come in from the community we would not be able to take those patients in. We use the palliative care outcomes collaborative data, and that says we get 90 per cent of patients into Clare Holland House within 24 hours of referral. I think the evidence is quite strong that beds are available.

From the hospitals, again we prioritise those by need. For example, today we have one person on the waiting list who will come over today. They went on the waiting list yesterday. And we have got three people being admitted today: two from Calvary one from TCH. One of the patients from Calvary has waited two days for the bed but the doctors have been saying they are not quite ready to come anyway. It is really not a huge issue.

My feeling—and I do not want to be disrespectful to TCH—is that TCH probably does not have enough medical consultants to look after the patients who are in their team. Often they do not get to see their patients and make their referrals until the end of the week. Sometimes we might get three or four referrals on a Friday afternoon, at which time it is very difficult for us to necessarily take those people in to Clare Holland House because we do not have medical staff on 24 hours a day; we have medical staff on Monday to Friday, 8 till 5.30, and then on call after hours.

We can get doctors but they are on call, and obviously it is a significant cost burden to bring someone in on call. So we try not to do that. And we do not have a multi-disciplinary team on staff 24 hours a day either. If someone comes over from another hospital and requires some counselling from a social worker or a lot of pastoral care and they come in after hours, we cannot give them the best service at that time.

We try to flow our patients as best we can but we do admit that if there is someone from the community we will get them in on the weekend, whatever. If they need a bed on the weekend we bring them in. The on-call doctor comes in and admits them.

If we know that there is a patient at Canberra Hospital we might say, “We cannot take them in on Saturday but we will bring them in on Sunday when the doctor is doing the rounds.” We flow it that way. My personal opinion is there is not a huge issue with patients getting beds in Clare Holland House.

MS CHEYNE: I want to follow up on some of Mrs Dunne’s line of questioning. In your view there is not an issue from the Clare Holland side of things; if you have to take people in, you will take them in, even if the circumstances are not perfect. I guess that is what I am hearing?

Ms Etchells: Yes.

MS CHEYNE: In terms of not having exactly the staff that you would prefer to have on at the time, while it is okay for you, would it be better if TCH were doing their referrals in a different way? Instead of having it occur on a Friday, would it help your staffing and planning—

Ms Etchells: Yes, obviously it would. I do not work at TCH but my feeling is—

MS CHEYNE: No, but you are getting the pressure from it.

Ms Etchells: Yes. My feeling is that if they had more medical staff and their rounds were done more frequently, earlier in the week, they would be making referrals earlier in the week and we could plan better into Clare Holland House.

MS CHEYNE: In your view, as manager of Clare Holland House, not as someone who works at TCH, would that give patients a better outcome as well?

Ms Etchells: Yes.

MS CHEYNE: Picking up on what Mrs Dunne said, we have heard that sometimes people have been refused. These hearings have been going on for a while, so other committee members can correct me if I am wrong. Was there a case where there ended up being a call to one of the clergy?

THE ACTING CHAIR: There was a case where the family came in and gave evidence that the family’s priest made a call, and after that the family member got into Clare Holland House. But there was a long period while the family asked for their family member to go into Clare Holland House and it was not happening. They were in the Canberra Hospital at the time.

Ms Etchells: I cannot comment on that case because I do not know about it. Obviously, we have admission criteria for Clare Holland House, and the admission criteria for Clare Holland House may not accord with the wish of the patients who want to come into Clare Holland House. Clare Holland House has a great reputation and, seriously, if I was needing care, I would go there.

The fact is that we have 19 beds and we are under the restrictions of activity-based funding. We cannot have people come to Clare Holland House and stay for months and months. We have to use our admission criteria to say, “This person has a high symptom burden and they need to come over because they need our expertise,” or “This person is reaching the last two to three weeks of their life and they can’t be managed at home, so they need to come to Clare Holland House.”

There will be some people who the consultancy teams will see in the hospitals, or we might see in the outpatient clinic, and we say, “You’re still eating and drinking, you’re still mobilising. Technically, we can provide you with your care elsewhere, not within Clare Holland House.” The family are disappointed by that because they clearly want to be in Clare Holland House; that is the place where they are going to be most comfortable and get the best care. If the ACT wants us to do that, that means we are going to need to open more beds and consider how those beds are going to be funded, because under an activity-based funding model it will not work.

MS CHEYNE: Speaking of criteria, I do not know how to say this delicately, but—

Ms Etchells: Don’t be delicate.

MS CHEYNE: is it a criterion that if you get a call from a priest, you just make it happen?

Ms Etchells: No.

MS CHEYNE: That was the impression we were perhaps left with; that the priest had quite a lot of power and just made it happen.

Ms Etchells: No.

Ms Greenwood: I would be very surprised if, when the person was at Canberra Hospital, the priest had any sway over what their clinical processes were.

MS CHEYNE: So it might just have been timing?

Ms Greenwood: Yes. Something that we have always really struggled with in this space is the fact that you are dealing with people who are at a point in their life where they are extremely vulnerable, extremely distressed, and all of their normal support networks around them—their carers—are all extremely distressed and extremely vulnerable. With what the family may have been seeing in that situation, where they interpreted it as being delays in Canberra Hospital referring them on, it may have actually been Canberra Hospital assessing the clinical needs of the person at that point in time as not, as you say, meeting the criteria for entry into Clare Holland House. It may have just been a coincidence—you do call a priest when it is the end days—so it had probably just naturally reached a point where it was appropriate for the clinicians at the hospital to transfer to Clare Holland.

MS CHEYNE: Mrs Dunne was talking before about the gaps and what is missing. I know you focused on what is missing in the home palliative care. Just to help us get a sense of how much is missing in terms of what dollars would need to be committed to

that to fund it adequately, do you have a sense of how much it costs per person to be in the home and how many people we really should be having in the home to—

Ms Etchells: No, I do not. I could take that on notice, if you would like me to.

MS CHEYNE: Yes, that would be extremely helpful. Something else we have also heard about is the people who require palliative care and who are not necessarily older. What I am thinking about is those with brain tumours and similar things. How do we provide adequate care there? You were talking before about Clare Holland being the place you go to right at the end of your life. But those with brain tumours cannot be in a nursing home, and a hospital often is not the best place either. In terms of long-term care, that surely can be a huge pressure on you as well because they are there for months.

Ms Etchells: You are right. There is a group of patients who have a high level of disability, along with their terminal illness: people with a brain tumour, people who have motor neurone disease and who are young people who have quite a high level of disability and cannot manage at home, or cannot be managed at home. They perhaps have young families and a wife or spouse who is working. Those patients do miss out. Mostly they will stay at Clare Holland House; those patients will long-stay at Clare Holland House. I am not sure that that is a great place for people to be, because they are obviously seeing a lot of people dying as they spend months in Clare Holland House, and they are forming relationships with different families and then losing those relationships because the family members die.

That is something that health systems have grappled with for a long time, as to how to manage those people. Ideally, you would have some sort of residential care set-up for younger people. That would be the ideal model: that they have a home which has 24-hour care that those patients can come and go to, or those residents can come and go to. As they deteriorate, they can be cared for, and, if necessary, moved to an acute unit if required. It is a sad place to be if you are a young person, and it is a sad place for your children to be visiting you as well, if you are a young person and you have a young family that come in to visit for a long period of time.

Ms Greenwood: Ms Cheyne, another thing that you are really touching on here is the fact that often it is a multidisciplinary team that needs to come together to care for someone, particularly in that situation. You need neurologists working with the palliative care people; in other situations it might be that you need a cardiac care specialist. The mere fact that we are all ageing, with more comorbidities, means that our needs at end of life are more complex.

We would say that there is another gap at the front end, with the training of the clinicians, and around how you connect the dots between those different disciplines to make sure that there is a truly effective multidisciplinary team that is able to come together around an individual who needs care.

MS LE COUTEUR: Can I confirm what I think I have heard: that the average stay in Clare Holland House is only three days?

Ms Etchells: No, that is not true.

MS LE COUTEUR: In that case, what is true?

Ms Etchells: Right now, in the last financial year, the average length of stay was 11.7 days. But it can be anything from hours, obviously, to over 12 months. We have had patients who have stayed for over 12 months, although not in the past year. In the past year probably our longest-stay patients have been there for five months.

MS LE COUTEUR: Okay; that is quite different then. You were talking about activity-based funding, which really gave—

Ms Etchells: With an activity-based funding model, the pressure is on to—

MS LE COUTEUR: It made me feel it must be for very short periods of time.

Ms Etchells: Yes, the pressure is very much on keeping the length of stay as short as possible. The expectation is that you have a good throughput, because that is what makes money for the health system. Therefore the pressure is on us to make sure that we are constantly talking to people about what we will do if you stabilise. If you are in here, you have come in with acute symptoms and those symptoms stabilise, where will the next place be? Unless someone has clearly reached the end of life, being stable in Clare Holland House is not what the government want. They want us to have throughput.

MS LE COUTEUR: You said that things had improved considerably insofar as palliative care in aged care was concerned. I am particularly reflecting on the fact that my father spent a lot of time visiting ED at Calvary. He would go back, go back and go back. That was a couple of years ago. Can you give us a bit more information about what has changed to make aged care better? My observation was that it was pretty horrible.

Ms Etchells: I am not saying it is perfect; I am just saying it is better. We have introduced a new model of care in aged care whereby the nurse practitioners go into the facility and, instead of waiting for a referral to come to us, they have been having the discussion with the facilities, to say, “You bring to us patients who you think might die in the next 12 months.”

We have been case conferencing and discussing those patients and putting a plan in place at that point for what will happen for those patients. At the same time we are educating the staff around how you find someone and what you think about when you are thinking about who is going to die in the next 12 months, and raising their capacity to look after people in residential aged care. That is, very briefly, the model that we have put in place.

Ms Greenwood: We also have some terrific examples across the country. One that pops into mind is Catholic Homes in WA, which has a residential aged-care facility that has a six-bed dedicated palliative care ward within the aged-care facility. It means that, for a couple that enter aged care together and initially are able to go into low care, maybe one of their needs escalates, and they are still able to stay where they are and receive high care. If things escalate further and they need palliative care, they are able

to stay in what is their home, that residential aged-care facility. So there are new models emerging. Certainly, even the community care is a new model, with respect to how that interacts with the hospitals.

THE ACTING CHAIR: If members have any other questions for Catholic Health, we can put them on notice. Ms Etchells, you did take some issues on notice about the cost.

Ms Etchells: The cost, yes.

THE ACTING CHAIR: The secretary will provide you with a copy of the proof transcript, when it becomes available. If there are any issues that arise out of that, you can raise them through the committee secretary. We thank you for your contributions and for your appearance here today. Thank you very much.

RAMSAY, MR GORDON, Attorney-General, Minister for Regulatory Services,
Minister for the Arts and Community Events and Minister for Veterans and Seniors
GARRISSON, MR PETER, Solicitor-General for the ACT
HARVEY, MS TAMSYN, Executive Director, Legislation, Policy and Programs,
JACS

THE ACTING CHAIR: I welcome the Attorney-General to these hearings of the committee's inquiry into end of life choices in the ACT. These matters were referred to us by the Assembly in November 2017. I am sure that the Attorney-General understands the privilege statement, as does Mr Garrisson. Attorney, do you wish to make an introductory statement?

Mr Ramsay: Thank you for the opportunity to speak to the select committee today. As you can see, I am joined by Peter Garrisson, Solicitor General for the ACT, and Tamsyn Harvey, who is the Executive Director of Legislation, Policy and Programs in the Justice and Community Safety Directorate. As I start, I want to acknowledge the traditional owners of the land that we are on and pay my respects to their elders, past, present and emerging.

I welcome the process of engagement with the community on what is clearly a very sensitive topic. I recognise that the issue of end of life decision-making affects diverse and strongly held views. I note the sometimes harrowing and deeply private stories that people have shared with the committee in their submissions and in their evidence and the analysis that has been provided by diverse agencies and groups who have shared their expertise and experience.

As Attorney-General and Minister for Veterans and Seniors, I have a range of interests and responsibilities in relation to the matters that the committee is exploring. Conscious of the limited time available in providing this opening address I simply want to take time to focus on and reinforce some of the key issues that have been raised in the written submission that I have provided to the committee on behalf of the ACT government. Chief among those is the threshold issue of the territory's legislative autonomy.

As the committee is well aware, the ACT cannot currently legislate for voluntary assisted dying due to the law-making restrictions that have been placed on the ACT Legislative Assembly by the commonwealth parliament. Section 122 of the Australian constitution enables the commonwealth parliament to override any territory law, which it did by enacting the Euthanasia Laws Act 1997. This legislation precludes the Legislative Assembly passing a voluntary assisted dying scheme such as one similar to Victoria's Voluntary Assisted Dying Act 2017.

The government is strongly of the view that, regardless of one's views on voluntary assisted dying, Canberrans should be afforded equality under the law to legislate on this issue if the community desires. And we have agitated this view with our commonwealth counterparts repeatedly over the years since the Euthanasia Laws Act was passed.

I do note, with some disappointment, the recent exposure of the deal that has been

struck between the Prime Minister and Senator David Leyonhjelm which linked the issue of lifting these restrictions with the revival of the Australian Building and Construction Commission. It would have been my hope that recognising the ACT's right to legislate for the interests of its citizens could be debated and successfully resolved on its own merits. It should not be a bargaining chip in a broader conversation but simply acknowledged as a matter in its own right.

The ACT government, nevertheless, welcomes the upcoming Senate debate on Restoring Territory Rights (Assisted Suicide Legislation) Bill and we encourage senators to give people in the ACT the right to decide if voluntary assisted dying laws should be introduced here.

I recognise and wish to reinforce the fact, that even with this threshold issue resolved, any consideration of whether or not to legislate for assisted dying would necessarily require thorough exploration of community views and robust consideration of what safeguards might need to be in place to support a scheme for assisted dying in the territory.

Any such safeguards would have to be closely mindful of the protections contained in the ACT Human Rights Act as a yardstick against which to compare various options. And I look forward to working through any recommendations that are made by the committee, once its deliberations are complete, along with community stakeholders and MLAs across all parties.

THE ACTING CHAIR: Could I take up essentially where you left off and go to the next part of your submission, which is about health directions. Has the government had any thinking about amendments to the medical treatment health directions legislation, which passed in 2006, in light of developments in other jurisdictions, particularly the advanced care planning legislation that has passed in Victoria?

Ms Le Couteur and I discovered, when we went to a seminar at the Canberra Hospital earlier this year, that in the next round of hospital accreditation there will be an increased demand for hospitals to provide more comprehensive end of life planning and medical directions. What is the government's thinking in relation to the medical treatment health directions legislation and where, if at all, it needs to be updated or amended?

Ms Harvey: That is something that we might actually need to take on notice because that is not a particular thing that we have been looking at in JACS in terms of the health directions. We have been involved in other pieces of work around elder abuse and guardianship and those areas but not particularly with the health directions legislation. I think it might be something we would need to take on notice and talk to our Health colleagues about.

MS CHEYNE: I want to talk about democratic freedom and more particularly our terms of reference about the impact of the federal legislation. Obviously you have touched on it in your submission and opening statement. How great an impact does it have on ACT citizens to exercise democratic freedoms in terms of all citizens being equal under the law compared to the states?

Mr Ramsay: I am aware that the Human Rights Commissioner has already mentioned before the committee that, in her view, the commonwealth act unreasonably restricts the rights of ACT citizens to participate in public life. I certainly support the comments by the Human Rights Commissioner on that.

I think one of the most fundamental rights that we have as a society is to be able to determine the ways in which we live, the ways in which our society operates. For the commonwealth to have chosen that there is one particular area that the states have rights to legislate in, as we have recently seen with the Victorian legislation, which I think demonstrated significant community input, community interest—I think there was a very strong move across Victoria as part of that, as well has been the case in other jurisdictions which have considered but not passed legislation—and for that right to be denied to the ACT citizens speaks of two classes of Australian citizens when it comes to democracy, two classes of jurisdictions, two classes of governments. I think it is not only one that, as Dr Watchirs has mentioned, infringes on human rights, it is one that infringes on the nature of our society and on the respect, the sovereignty of the Legislative Assembly and of the people of the ACT itself.

MS CHEYNE: And just for the record, attorney—this seems like an obvious question but I think it is worth noting—how many citizens in the ACT are impacted by this legislation?

Mr Ramsay: The reality is that every single citizen in the ACT is impacted by this. It is not only people who may or may not be directly affected by any legislation that is considered but all 400,000 citizens of the ACT are affected by this because our society is treated by the commonwealth parliament as a second-level jurisdiction, and that impacts on the way that all of us live.

MS CHEYNE: Why is participation so important?

Mr Ramsay: One of the things that I have regularly talked about is that a strong society is one when we all belong, when we are all valued and when we all have the opportunity to participate. That is actually one of the hallmarks of a strong civil society. It enables us to consider how it is that we choose to live out the values that are shared across the ACT population, how it is that we choose to guide ourselves in terms of all of the decisions that we make.

By the time that you have impacted onto a society that you can make most decisions, but when it comes to this particular decision that every state is able to do but the territories are not, that says to us, that says to every person who lives in the ACT, “We do not believe that you are capable of making that decision, we do not believe that you are competent to make that decision and we do not believe that the representation that you have in your elected Legislative Assembly is appropriate.” That is something that I think, by the commonwealth doing that, has a deep impact on the way that we live and the way that our society and our democracy operate.

MS CHEYNE: Does the ACT government get feedback from its citizens about how disenfranchised they feel or whether they do not actually really care?

Mr Ramsay: I have certainly had direct feedback and I know—

MS CHEYNE: In your role as attorney?

Mr Ramsay: In my role as attorney and in my role as an elected member as well, people speaking with me in a number of forums, either in more formal ways or less formal ways, as I am engaging with the community. Yes, this is one that is raised with me as something that is of concern to members of the public.

MS CHEYNE: I will give Ms Le Couteur a chance to ask questions this time. One of the most common arguments I think what we hear is that the two issues cannot be separated—and I think we hear it in the ACT but also from federal members as well—and that, if the commonwealth removes the restriction, that is essentially a green light to go ahead for voluntary assisted dying.

I appreciate in your opening statement you said they are separate issues but are you able to expand on that? If for example later next month the restriction did hypothetically get removed, is the ACT government planning to ram through legislation?

Mr Ramsay: Starting with the second part of your question and working backwards, the ACT government has not formed a view, has not actively considered the area around voluntary assisted dying. It is not a matter that the government has reached any particular view on and has not had active conversations about, primarily because we have no legislative authority to pass laws in that matter anyway.

MS CHEYNE: Because a committee exists?

Mr Ramsay: We value the work of this committee, looking right across its terms of reference, not only in terms of the legislative impediment there is through the commonwealth act at the moment but also the further considerations. I think that the recommendations of this committee, the deliberations of this committee, will be extremely helpful to government.

The government is not coming to these conversations and I am certainly not coming to this hearing this morning with any particular view on the substance of voluntary assisted dying. We are certainly aware that there are a number of areas that would have to be worked through very carefully.

If there was a mind to consider that matter—and I raised some of those areas in my opening statement—the primary area that from my perspective in this, to start with, is a matter of legislative sovereignty and autonomy, what is appropriate for a jurisdiction within Australia to be able to legislate and for that to be denied to the ACT is something that has direct impact on the rights of every single citizen, every single person here.

It is my view, and it is government's view, that, irrespective of how people may consider the issue of voluntary assisted dying, the ACT should have the right to be able to consider that, it should be able to legislate in that area, in the same way that we should be able to do so in any other area that states and territories can legislate. We do not always agree with what other jurisdictions do. We certainly do not automatically

follow any other particular jurisdiction.

It does not make sense for it to be argued, either by our federal counterparts or by others, that if the ACT were given the authority to legislate we would necessarily go in any particular direction. That is simply not the case.

MS LE COUTEUR: I have two related areas that I would like to talk about: elder abuse and capacity of people to make decisions. We have had a lot of evidence about trying to work out whether or not people have capacity to make decisions. In particular, there was quite a discussion about what was called supported decision-making, where someone had diminished capacity but it was not zero, and they were able to be supported to make decisions, including potentially end of life ones. Do you have any commentary on how this could work? Clearly, decision-making is a very relevant issue, with “voluntary” being part of the name.

Mr Ramsay: As an introductory matter—I am also happy to hand over to Mr Garrisson for some further observations on the way the law currently operates in the ACT around the area of decision-making—the initial observation is that the government does not have a particular view on this, because the government has not actively considered the area of voluntary assisted dying. In terms of supported decision-making more generally—

MS LE COUTEUR: We clearly have a need for this—

Mr Ramsay: That is right.

MS LE COUTEUR: This is possibly, you could say, the most extreme example.

Mr Ramsay: That is right.

MS LE COUTEUR: This already happens every day in Canberra.

Mr Ramsay: That is right. There is a lot of important work that happens in the area of elder abuse. I know that the Public Trustee and Guardian also appeared before the committee and offered some very helpful observations on the area as well.

One of the key areas that is being worked through in terms of elder abuse, and in some work that has happened from the law reform advisory committee, is how we can best support people with impaired decision-making capacity. There are a number of recommendations that have been made, both by the ACT and by the federal law reform bodies, in relation to whether it is operating in the best interests of someone; operating with the will and intent of someone. There is some broader policy and legal reform work that is happening, both within the ACT and more generally, about that. That is a very important conversation for us to have, while noting that elder abuse itself is a very diverse matter, and it does not necessarily relate to impaired decision-making.

MS LE COUTEUR: I was going to say that the two could be related but are not necessarily related.

Mr Ramsay: That is right.

MS LE COUTEUR: As a matter of personal observation, when people are young and healthy they may make some very clear statements, saying, “I would not wish to be alive if various things happen.” But 20 years later, it is not obvious that that would be their view anymore. They are potentially not in a position to formally change their views because their decision-making capacity has been impaired. I have observed that around many people. End of life is only one of the decisions they might be making. There are other decisions that they could well be making. Are we doing work around making it possible for people to still make decisions even when they are not as good as they were at decision-making? They may have changed their minds.

Ms Harvey: Certainly, the attorney mentioned the Law Reform Advisory Council work around guardianship. That talks about that assisted decision-making model. Importantly, it recognises that it is something that would need to be well thought through, particularly from a very practical way about how it would work. That is the kind of thinking. We are looking at that report and trying to look at what a model might look like.

You raised points about people making decisions at a particular point in time that may then be quite long ranging. We are not talking about voluntary assisted dying in the ACT, but I know that in the Victorian legislation, for example, there is that nexus between when the decision is made and when a person with a terminal illness is expected to pass away. That is the kind of nexus that they have drawn. Certainly, when we are doing this work, we are looking at a broad range of practice. Certainly, coming back to that supported decision-making, it is about who would support people and how that will happen. How will they record their wills, rights and preferences? That is one of the key recommendations.

In the elder abuse work, there is also some thinking about how you record enduring powers of attorney so that there is a more centrally accessible bank. There is that key issue about the point in time that a person might make a decision and the length of time until that decision might become active, if you like.

Mr Ramsay: In the national area at the moment, obviously, the work that is happening at the Council of Attorneys-General, and in a national working group sphere as well, has a key impact on this. There is work that is happening to see how we can have potentially a national register of powers of attorney so that, as people move from one jurisdiction to another, it is recognised. With some of that work, we are seeing how we might be able to develop a nationally consistent approach to reforming enduring powers of attorney; and how we may be able to develop a national plan in relation to elder abuse, which also impacts on the decision-making capacity that may be able to flow from that.

MS LE COUTEUR: Are we also looking at being part of the national aged-care directives? That seems to be one of the other problems.

Mr Ramsay: There is work that is happening. I cannot speak in the area of health policy or health matters. That is obviously a matter for the minister for health. But in terms of the areas of elder abuse and matters in relation to enduring powers of

attorney, in terms of the broader work on supported decision-making and guardianship, all of that is being considered across jurisdictions.

Mr Garrison: Talking about the voluntary end of life process, the starting point is the proposition that any medical treatment can only be administered with consent. That is the common law. There are circumstances where consent is either not able to be given, or cannot be given, and that brings in a range of legal principles around emergency action in certain circumstances, or indeed the question of futility of medical treatment. There is quite a developed body of law around that.

There are statutory exceptions to the common law. The current statutory framework of departures from those basic principles—that is, the capacity for someone else to consent on behalf of the patient or for the patient to identify ahead of time, so to speak, their consent—needs to be viewed in that broader context.

The statutory schemes are all different and they all have some different detail. They have different wording around issues of decision-making capacity. They use the same language but then have different definitions. You expressed earlier a concern about a person who changes their mind. If a person has given a health direction, the legislation actually builds in a number of clear safeguards to deal with that very eventuality.

First of all, the medical practitioner must be satisfied that the person has capacity, that the person understands and has been informed about the treatment and the options that have been given. The act also provides that if the medical practitioner is not certain then it should not be implemented. There is what one might call a range of common-sense tests built into a number of the legislative schemes that are in fact protective of the rights of the individual in relation to the medical treatment that is administered.

There is no doubt, of course, that the withdrawal of some medical treatment may result in the end of a person's life, but through natural causes. That can happen when someone ends up in palliative care, where there is an obligation to ease the person's condition and pain, and where, in essence, it has reached a point where further active medical treatment, for example, may be futile, in the sense that it detracts from the person's quality of life, it may impose pain and discomfort, and a range of things.

The law does not set the test; it is the medical opinion at the time about the condition of the person that is determinative of what care ultimately is going to be administered. There is, of course, always the safeguard for the medical practitioners, in the case of the territory being responsible for the administration of health care, to seek the views of the Supreme Court, where there is a difficult decision to be made about withdrawal of treatment for a particular individual. It is called the *parens patriae* jurisdiction of the court. It is exercised very rarely, not just in the ACT but elsewhere. It is very rarely introduced, and it tends to be in very difficult cases. Of course, you will all be familiar with a lot of cases in the United Kingdom involving treatment of young persons who are suffering from ailments.

The law is complex, in the sense that there are a number of different legislative exceptions to your basic common law principles. Each does operate separately, but

each piece of legislation actually has in-built safeguards for the individual. For example, under the Guardianship and Management of Property Act, there are certain things that a person appointed as a guardian cannot give consent to. There are some prohibited medical treatments that they cannot agree to.

It is not that legislation can never be fine-tuned, but, broadly speaking, the system seems to function effectively well to protect the rights of individuals. Of course, we are now in an environment where decision-making by individuals has to be governed, certainly by the public health system, and by other decision-makers. It has to be governed, of course, by the principles in the Human Rights Act. One has to have regard to those as relevant considerations when one is making decisions.

The ultimate call, of course, for a doctor is their duty to do no harm. I think sometimes the debate loses sight of the fact that doctors actually have their ethical standards by which they operate, and that is more or less your starting point. Although there is a lot of law, and it can become fairly complex, in the end it is a matter of clinical judgement and opinion by medical practitioners that will decide whether a person has capacity, for example.

Capacity is not a binary concept. You referred to assisted decision-making, for example. There is a bit of work that has been done in relation to that because you cannot simply wheel a doctor in to a patient and say, "Does this person have capacity or not?" The question will be, "Capacity to do what? Capacity to decide what? What sort of decision does the person have to make? What do they need to know? How can it best be communicated to them so that they may understand it better? What environment should it be conveyed to them in?" There are even things like, "What time of day," and the like, because people who are in a difficult health environment will have those sorts of factors that can operate on their capacity to comprehend matters that are being put to them.

The question of having decision-making capacity is complex, but, as I have said, it is not a binary decision. It depends entirely on the circumstances and what they are being asked to understand.

THE ACTING CHAIR: I am very mindful of the time. If members have other questions to put to the attorney, they can be put on notice. There was an issue that Ms Harvey said she would take on notice. That concludes the evidence from the attorney today. I thank the attorney and officials for attending today. As you know, the secretary will provide you with a proof *Hansard* in the coming days. If there are issues that you need to raise as a result of reviewing *Hansard*, you can take those up with the committee secretary. Thank you very much for your attendance today.

CORLEY, MR BRIAN, Chief Executive Officer, Community Options Inc
SVINTRADZE, MS IA, Executive Director, Quality Management, Community Options Inc

THE ACTING CHAIR: Welcome to the hearings of the Select Committee into End of Life Choices inquiring into the matters referred to it by the Legislative Assembly in November 2017. We welcome representatives from Community Options to these hearings. There is a pink laminated sheet there that relates to privilege in relation to the conduct of these and other hearings of the Legislative Assembly. If witnesses could acknowledge that they have read and understood the privilege statement? If I could ask you: would one of you like to make an opening statement?

Mr Corley: Yes I would, thanks. Community Options is an ACT-based non-government, not-for-profit organisation and we have been providing services in the territory and in the surrounding region since 1990, incorporated in 1991. We provide a wide range of services and we work closely with the ACT health system, mainly providing post hospital support to people, direct in-home support services following surgery.

Your inquiry into end of life choices is broad and covers some very complex and difficult issues. Our submission particularly relates to your reference in relation to current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care. Among the suite of services we offer, we have a small palliative care project that has been funded by ACT Health since about 2012.

That project is quite small and employs one person, and the aim of that project is to work with individuals and families who have a terminal illness and who make a choice to, effectively, die at home. Our role in that is to provide basic in-home support services: personal care, respite care, sometimes domestic assistance. Our staff will help coordinate the provision of equipment, access in some cases to hospital beds, hoists and other equipment, shower chairs and things like that, and then we will provide direct in-home support staff to support families and individuals over that difficult period as someone is dying in their home.

In some cases we achieve that goal working with families and in some cases we support families and, ultimately, because the burden on the family or the individual is too great, they may return to hospital. But generally the aim is to allow people to exercise their choice to die at home.

Evidence and research have indicated that the vast majority of people in this country, if given that opportunity and facing those difficult decisions, would chose to die at home but the reality is that the vast majority of people do not. They pass away in hospital or hospices or nursing homes.

As I said, our project that we initially named a pilot in 2012 is quite small. I think our submission has included some data. We can provide some updated data about the number of people we assist. It is a unique service. We work closely with ACT Health services, Clare Holland House and other home-based palliative care services.

As I said, our role is not the clinical role. What families need often in those circumstances is a break, have someone to come in and assist with the personal care and assist and be there. Often families burn out at this time because they do not get enough sleep. One of the gaps that we have identified in this process, and other people in the sector have identified, is overnight respite care. Someone could come in and be in the house while the other family members might get some sleep for the night.

It has been a very successful small project. It has potential, we believe, to expand and service an increased number of people per year. The feedback—and we have done a formal evaluation and ACT Health has been involved in that—from families and individuals has been very positive in terms of supporting people to make those sorts of decisions.

We have done a lot of work with the hospitals to ensure that they are informed of our project and our service and they are aware that they can refer, but we still hear stories of people who would like to return home but for some reason that is not possible. I think, with a greater focus and some additional resourcing, the number of people who could exercise that choice would increase substantially.

THE ACTING CHAIR: Could you outline for the committee what the service does? You said you have one staff member.

Mr Corley: We have a registered nurse whose salary is effectively covered by the funding that ACT Health provides, and that person's role is to work with people who are referred to us, to look at what supports they need in the house. As I said, we do not do the clinical supports; we do practical in home. We then coordinate those services. We often link the family and the person with other services and we play what we call a case management, a coordinating role across a whole range of services and work cooperatively with them.

The primary services we deliver would be at that coordination, case management level and then we would access the person or the family into a range of in-home supports that are basically what the person or the family needs. Basically it is around personal care, that is, assistance with showering, toileting. It might include changing sheets, laundry services, respite for the family if they need a break from their role and that whole gambit.

THE ACTING CHAIR: What are the sources of funding for those services?

Mr Corley: Because the funding received from ACT Health covers just basically the salary of our staff member, we then access the direct in-home support services from existing funded services. If a person is aged over 65 we will seek to get services through the commonwealth home support program. If a person is aged under 65 then we will seek to access those services through ACT government, the community assistance program, the ACT government-funded program.

As an organisation, we are a funded commonwealth home support program provider. We can access those funds directly. One of the problems with the changes in terms of funded responsibilities and difficulties in this area is that the process now to access

aged care services is quite lengthy and often in these circumstances you need quick access to services, if someone is at that final end of life stage and they do not have time to go through the ACAT assessment or the RAS assessment and then wait for the package provider to come in and all that sort of stuff. We are also a provider of commonwealth home support program services. With the appropriate referral, we can put those services in almost immediately.

It is an intense program. As you can imagine, the staff involved are very experienced and we work closely with a range of agencies to access direct support staff who are experienced in this area because it can be also quite difficult for staff in these situations as well. I think as a small program it gives an example of what can be done to increase the range of end of life choices people can make, people who are suffering a terminal illness and who make that decision that they would like to stay at home for as long as possible.

As I said at the start, a lot of people would like to stay at home until the end. That does not always occur. Sometimes the situation is such that they need either to go to Clare Holland House or back to hospital but we will work with the family and the individual as long as it is appropriate and safe to support that person to stay at home as long as possible.

THE ACTING CHAIR: Do you see that there is unmet need and, if so, have you been able to quantify it?

Ms Svintradze: The project started in 2012, and that was in response to unmet needs. The need that was identified was that these people were coming out of hospital and being referred to us, and it was an increasing need. Over the course of six years as we were providing the services to ACT residents, we have been seeking feedback from all the referring organisations that are referring to Community Options for the services. These are the Canberra Hospital, Clare Holland House, both home-based palliative care team and their in-patient unit, and also the Calvary hospital. It is all the ACT Health services.

What we found in consultation with other stakeholders—and they are these providers—is that what a lot of people, who want to stay at home for their end of life choice, experience in the end is sometimes burnout in the last few days or last couple of weeks of their lives. The burnout we are talking about is the carer's burnout. The majority of people who are supporting this program have co-resident carers and they rely on them. While we are supporting them in this relationship to try to reduce the burden of the care on their carer, there is a limit to what we can do within the resources, what we have.

In consultation with Clare Holland House, the social workers and other stakeholders, the need that was identified recently over the past two years is the overnight respite. There is basically no overnight respite—in home we are talking about—that can be provided to these families who would basically avoid that hospitalisation or them going into Clare Holland House for the in-patient unit.

THE ACTING CHAIR: That would be someone who comes into the house who is not the residential carer so that the residential carer can have a sleep?

Mr Corley: Yes.

Ms Svintradze: That is right. And it is that that people can go to. But, in the end, because it becomes so many sleepless nights, they just cannot do it anymore and they end up going into hospital. That is not the choice of the person and that is not the choice of the family. It is just the only choice available to them, which is not the preferred choice.

MS LE COUTEUR: I was just wondering: would that person need to be a nurse or would it be just at a carer level that would be required in general?

Ms Svintradze: It is a carer level. As Brian identified, we are accessing the services through a community assisted support program: the in-home support or the commonwealth home support program. Neither of them has the capacity to support people overnight because it becomes an expensive service and because of the level of support needed. The CHSP, the commonwealth home support program, in the past few years, with the aged care reforms, is seen as an entry-level program, a low-level program. Overnight respite is simply not available there.

Mr Corley: And if the option was a commonwealth home care package at level 4, the wait list currently is nine months.

Ms Svintradze: Twelve-plus months, yes.

THE ACTING CHAIR: Is that 12 months to get someone to—

Mr Corley: To get a level 4 home care package.

Ms Svintradze: Yes.

THE ACTING CHAIR: But once you have got the package—

Ms Svintradze: Formally on assessment.

THE ACTING CHAIR: Once you have got the package, you could access—

Ms Svintradze: Access, yes.

THE ACTING CHAIR: There is not a nine-month wait for the—

Mr Corley: No, it is to get the package. Once you get the package, from the point of assessment now to getting a package, the level 4 packages—

Ms Svintradze: Twelve-plus months.

Mr Corley: Twelve months, yes.

THE ACTING CHAIR: I do not want to be too leading here but if in your experience—and I do not know whether you would collect statistics or whether this

would be more anecdotal—people say that they wish to die at home and they have a supportive family or a support network around them that is aimed at facilitating that but it breaks down because of the exhaustion of the carer, what impact does that have on the carer afterwards?

Mr Corley: We would have anecdotal feedback or particular carer comments. What tends to happen is that someone is diagnosed with a terminal illness, they go through their medical treatment, the point comes where the treatment is no longer an option or it is obvious now that they are in the final stage of that illness and the person makes a decision to leave hospital and go home, and you will generally find the family is supportive of that and families will rally together and support that.

But over the coming sometimes days, but sometimes weeks, that becomes an incredible drain on the family. Often family members will fly in from interstate to support mum, dad or brother, sister in that situation, but that is not sustainable. They have got family, they leave.

As a society, we are probably not as resilient as we might once have been to cope with death. Many years ago death in a family was a regular occurrence. People died at home much more regularly than they do now. What we find is that, while families say yes, we want to support mum, dad, brother, sister in the final stage of their life, it is very wearing and very tiring and families burn out. Often people return to hospital, not because their condition has changed but because the family now says, “We just cannot do this.”

THE ACTING CHAIR: It has become too hard?

Mr Corley: It has become too hard.

THE ACTING CHAIR: What sort of impact does that have, anecdotally, on the people left behind? One of the things that always strike me is that there are two lots of people to care for. There is the person who is terminally ill and there are the people who are left behind. Do people experience regret or a particular sort of mourning because they did not live up to the expectations or meet the needs of the person who has died?

Ms Svintradze: Yes.

Mr Corley: Yes.

Ms Svintradze: Obviously that would be a subject of research—and I am sure that something is done in that area as well—but what we see now in our client service delivery experience is cases where people are resistant to accept the service, where they have never had a service before, and with different cultural groups as well there is a sensitivity there. They accept the service, the person dies and then you see the wife or another carer in the family experiencing that guilt, “I have accepted the support. The husband did not want it and I have accepted it.”

We do the client surveys and one of the questions is, “What would you do without this service, or what impact would that have?” It is normally the carers who are

completing those surveys. What we do collect as part of our outcomes measures is this: almost everyone says, “I would not be able to survive. It would not be possible. I would not be able to care for my loved one if that was not possible.” We do try to collect that information and we do have that data. The evaluation report that we have attached to our submission does include that data and the comments as well that have been made.

MS CHEYNE: We heard before about gaps relating to people with brain tumours. Does Community Options provide support for families where there is a younger person with a brain tumour?

Mr Corley: Our service is non-diagnosis-specific. There is not one particular group. Obviously, the vast number of our clients, from our data, are people who have a cancer, terminal cancer.

Ms Svintradze: We do have it in the evaluation report. Brain tumours are one of the significant issues in the evaluation report that was attached. You can look at that.

Mr Corley: Motor neurone disease would be another significant—

Ms Svintradze: MND, yes.

MS CHEYNE: I want to briefly explore—it is something we have heard a few times, and we heard it again this morning—the support that is available for people at the end of their life. Some people’s end of life is actually quite prolonged, due to the type of illness that they have. I want to get a sense, perhaps anecdotally, of what Community Options provide, and what you hear back from those people in the home.

Mr Corley: Our service is intended to be targeted at people in the final few weeks of their life. Obviously, that cannot be predicted, so we will continue to work with those families and individuals. We have certainly had some clients who have defied the predictions and survived for many months, and in a couple of cases for years. What we will tend to do then is try to move them out of our palliative care project into another longer term service, with the option that they are then invited back in or can come back in for that more intense service as their situation deteriorates.

On the converse side, there are situations where our staff have done hours of work to organise and set up the system for someone to come home from hospital, they have arrived home and have died within the hour. It is difficult. Some would say, “Why would you bother doing that?” but for the family, the person desperately wanted to be home when they died, they got home for an hour, and the family thought that was a fantastic result. The number of hours involved in that particular case I am thinking of, in order to make that occur, was huge.

MS CHEYNE: In cases where someone has a longer illness, or is defying expectations and you move them back out into a longer term option, do we have sufficient services available for that? What we have been hearing, particularly about brain tumours in younger families—

Mr Corley: I think there is an issue. This interfaces with the broader reforms in these

areas—the national disability insurance scheme and the aged-care reforms. Certainly, anecdotally—and I might correct me—when the NDIS first started, people who might be diagnosed with a terminal illness seemed to be getting access much more easily. I understand that, as that scheme has now evolved, it is much harder for them to get access, and the NDIS is saying this is now a health-related issue.

That is a change, and, yes, in that situation, given that the state-based systems have shrunk significantly because the funding has transferred to the NDIS, that is a significant issue. As I said, we try to tap people into, if the person is aged over 65, the commonwealth home support program. If they are under 65, the ACT, through good management, has retained the community assistance support program, which is an ACT-based program. Some states handed all of their money to the NDIS. The ACT has kept a small amount—only a couple of million dollars—and we will try to tap people into those services. Again, even that program is really targeted short term. There are issues about people who cannot get into the NDIS or into aged-care services quickly, and how they access services in that period.

MS LE COUTEUR: You were saying there was a year's wait to get a level 4 package. What do families do in that year?

Mr Corley: Often the process is that someone will have their assessment for a home care package, and they might be assessed at a level 3 or 4 but those are not available, so they may be offered a level 1 or 2 package, which is substantially less. The family can make a decision to accept that and make do with a much lower level of service. Of course, there is a twin-pronged issue here, because the service provider has to be satisfied that they can deliver a safe and adequate level of service. You have a situation where a person is assessed as needing this amount of service, but they are only offered this amount. You have to make a decision about whether that is safe, in the first instance. So they will accept a lower level package and get fewer services, potentially—even with that, there is an extensive wait; there is a process for that to occur—or they can seek to access service through the commonwealth home support program, which is the old HACC program, effectively.

Again, the guidelines around that program are low level and entry. If someone needs what would be equivalent to a level 4 or higher, it is up to the goodwill of the CHSP service provider to say, “Yes, we will provide that higher level of service.” That provider then runs the risk of the commonwealth saying, “You’re providing too much service.” They look at the data. We now have to report actual hours of service delivered to each individual, and the commonwealth are actively looking, under the CHSP program, at all of these people who are getting higher levels of service under that program, because they want them moved into home care packages.

MS LE COUTEUR: Do families have the option, if they are able to, to supplement the commonwealth provision, with private provision of care?

Mr Corley: Many families are now having to pay for additional services privately, yes.

MS LE COUTEUR: Would they have to get a separate organisation or themselves to coordinate that? You were talking about providing the lower level care if you thought

it was safe. If you have been funded for only a lower level of care and you think it is not safe, what does the family do?

Mr Corley: In any service provision industry, there is an issue. In the modern environment, the decision about allocation of resources has been taken away from the service provider. In the old world, the service provider met with the family. The service provider would say, “What do we need to provide an appropriate and safe level of service to this family? How many hours a week?” The service provider would look at its resources and say, “Yes, I can do that,” or “I can do this component. Can we get another service provider to do that component?”

Under the new environment, whether it be in disability or in aged care, an external assessor, an allocator, will say, “We’ve assessed this person, and we’ve assessed their support level at, say, home care package level 1.” The service provider may go in there and say, “I disagree with that assessment. The one or two hours a week of service that a level 1 package allows is not enough for this family.”

The service provider, at that point, can say, “I can’t do it.” The service provider has to manage its risk as well as the family’s risk in terms of poor outcomes. All that the service can say is, “We can do the level 1, but we now need to find some other resources.” Those resources can come from other providers. The commonwealth kind of turns a blind eye to commonwealth home support package funds being used to top up home care packages—I know it is a complex system—or, in many cases, the family will use their own private resources to buy additional services. Obviously, not all families have that capacity.

MS LE COUTEUR: Obviously, not everyone is able to do that.

THE ACTING CHAIR: I am mindful of the time. Just to conclude, how many clients would you have at the moment in this program?

Mr Corley: From 1 January 2018 to the end of June, we have had 128 clients come through this service. In a full-year period, the previous—

Ms Svintradze: 278, I think it was, in the last financial year.

Mr Corley: In the previous 12 months, yes.

THE ACTING CHAIR: Would you know this: what proportion of people wishing to access home-based palliative care would that represent in the ACT?

Ms Svintradze: Home based? If you look at the referral sources, it is in the evaluation report, about the data. With the most recent one, 47 people were referred from the home-based palliative care team. The way it works is that even if they were not referred, all of them get services for care, like at Clare Holland House. That is how it works. It complements clinical services that are provided through the home-based palliative care team, primarily. A lot of times it is Clare Holland House or the home-based palliative care team referring to us. Sometimes there are other referrals that come from hospital, and the referral is made to Clare Holland House at the same time. Sometimes we refer people. We get the referral from the hospital and we refer

people. That is where it goes hand in hand—

THE ACTING CHAIR: So one client may have more than one referral? You cannot measure it just by referrals?

Ms Svintradze: Yes.

Mr Corley: Yes.

Ms Svintradze: All of these people that we have supported have received services from Clare Holland House as well. That is how it works. We provide non-clinical support for people. They provide the clinical symptom management. That is how it complements the health system.

THE ACTING CHAIR: If members have any other questions, we will have to put them on notice. I thank you for your attendance here today and also for your submission to the inquiry and for the work that you do. The secretary will provide you, in the next few days, with a copy of the proof *Hansard*. If there are any issues that come up from your review of *Hansard*, you can take those up with the committee secretary. Thank you for your attendance today.

CHAPMAN, DR MICHAEL

THE ACTING CHAIR: The next witness is Dr Michael Chapman, who has already appeared in a previous guise but now appears, with his submission, in a private capacity. Thank you, Dr Chapman, for your appearance. I again draw your attention to the pink privilege statement. Have you had a chance to read that and to acknowledge it?

Dr Chapman: I have, yes.

THE ACTING CHAIR: Would you like to make an opening statement?

Dr Chapman: I was not sure whether or not the committee would want me to make an opening statement, given that it is likely to bear a lot of resemblance to—

THE ACTING CHAIR: Could you make a brief one?

Dr Chapman: Of course. I am a geriatrician and a palliative medicine specialist by trade and also a clinical academic. I am the Director of Palliative Care at Canberra Hospital and Chair of the ACT Palliative Care Clinical Network. I am not representing either of those organisations in any capacity today. I can speak for myself, and obviously have, and do still, represent the Australian and New Zealand Society of Palliative Medicine. I would like to think, though, that given my positions and my experience, I do have a lot of information and understanding about how palliative care is practised here in the ACT, and hopefully, therefore, have a lot to bring to the committee.

As we have discussed previously, the Australia and New Zealand Society of Palliative Medicine does have a position statement on the topic of assisted dying and suggests that this is not part of palliative care practice, a position which I support. More specifically, within our context, it creates an opportunity, in discussing this, to recognise that in fact there are lots of factors affecting the end of life choices of people in the ACT. A particular issue is the resourcing available for palliative care.

Palliative care, broadly, as the committee is well aware, is care focused on what is most important to those with a life-limiting illness. It needs ongoing development of flexible and responsive multidisciplinary resources, with the necessary expertise and communication skills, to provide holistic care, including in symptom management and care for the emotional and psychological needs at a given point in time, as well as the capacity to proactively consider and plan for future needs for those individuals, to try to minimise any negative impact of scenarios before they occur.

Given the increasing complexity of health needs for our community and within our ageing population, specialist palliative care services will remain an integral part of meeting the palliative care needs of our community. However, they are not the be-all and end-all of palliative care provision. As the committee is well aware, there are numerous other aspects to palliative care—social care provision, volunteer services and family carers—that all act to provide the palliative care that we seek and need.

Achieving great palliative care will require us to consider palliative care as more than a health issue. In fact a whole of health, whole of social services and whole of community response is required to be able to meet the needs of our community. Unfortunately, we know that there are deficiencies in these areas, all of which do require attention and focus.

As recommended to the committee on a previous occasion, I would echo ANZSPM's suggestion that there are probably seven key areas of focus that are required to meet recognised gaps within the ACT at the moment. Those would be, in no specific order, the need to focus on community awareness, and community awareness around death literacy, understanding of death and dying, and death and dying as a natural process, to address misconceptions and fears, and facilitate better awareness of the choices available and engagement in conversation around those choices. That is a clear need.

Improving death literacy and normalising natural dying are urgently required. It is something that I think that we as a community really need to take on. Shortages in the specialist palliative care work force need to be remedied, as we have discussed. Early integration of palliative care clinical services in all healthcare settings needs to be an area of focus. That includes, but is not limited to, aged care, acute care and in the community.

Palliative care programs need expansion so that access is equitable, regardless of location, time or the person who is seeking access. Minimum competencies in end of life care and communication skills for tertiary education and vocational training for all healthcare professionals in the ACT should be a mandated focus, and should require updating to ensure currency.

Investment in carer support is another thing that we really need to take on, to make sure that we are both enabling and supporting the carers who are providing care, as well as providing them respite for when they are not able to provide the care that they have been providing. Ongoing attention to policy and legislative frameworks around ensuring that advance care planning is valued and has appropriate legal standing is another important thing to focus on.

To summarise, I would suggest that a pressing priority to provide optimal end of life choices in the ACT requires people to have real access to quality palliative care, which is currently not always the case for many and not always the case when they need it. People often receive too little, too late, or no services at all.

I would suggest that this is not an issue unique to the ACT. My personal opinion is that confronting both improving our community's approach and recognising the need to recognise dying as a natural process within the complexity of our changing focus in health care and our changing culture is a whole-world issue. Certainly, in all jurisdictions in Australia, many healthcare services and many institutions are facing the same problems.

It is also important to recognise that this is not an issue that has been ignored in the ACT, or that there have not been steps to try to meet it. Obviously, there have been a lot of attempts at and attention towards improving palliative care services and

improving care for the dying in the ACT. Our conversation today around focusing on end of life choices avails us an opportunity to think about that more, and think about what extra could be done beyond what has already happened. It is an opportunity for us to grow as a community, and to be able to offer the best support and care options for those with palliative needs in the ACT.

THE ACTING CHAIR: In relation to meeting the gaps that you have identified and creating a holistic approach, what level of investment would you see is needed in the ACT in terms of personnel and resources? It was put to the committee earlier today that the AIHW figures indicate that there are four palliative care specialists in the ACT. Is that enough? If not, in addition to how many palliative care specialists you think we need, what other parts of the workforce are missing?

Dr Chapman: Thanks for the question. There are a number of different parts to the answer. On the particular issue around the palliative medicine specialist workforce, unfortunately, I think that that is insufficient. With respect to four specialists, four FTEs, that is certainly my understanding of what is available on the ground and I think that is insufficient.

We can be relatively confident about that based on at least peak body standards. Palliative Care Australia's national strategy and guidelines around workforce provision suggest, at least in terms of palliative medicine specialists, palliative care doctors, that there should be two per 100,000 head of population.

THE ACTING CHAIR: So we have half the number that we need, roughly.

Dr Chapman: Arguably, we have less than that because—

THE ACTING CHAIR: Because of the region, yes.

Dr Chapman: we also service surrounding New South Wales. I think we can be very confident that we are under-resourced in that category. The guidelines that we have on other healthcare providers, specialist healthcare providers who provide palliative care, are less robust than the guidelines around palliative medicine specialists. My personal belief would be that the number of trained palliative care specialist nurses that we have, rather than just nurses who work in a palliative care setting, but also trained palliative care specialist nurses, is insufficient. Our access to allied health support of a variety of different types including, but not limited to, psychologists, social work, physiotherapy and occupational therapists, all of whom have a very particular skill set and interest in palliative care and can be specialists in that area themselves, is unfortunately limited and is very context-dependent, as in, there are services available in one place that are not available in another.

In addition, in regard to specialist support, access to bereavement care, or the resources available to provide bereavement care, which is considered an absolutely cardinal part of palliative care provision, are very much lacking within the public system in the ACT. So there are numerous clear, professional-role-focused insufficiencies.

I would go further, though, and say, as I think we talked about last time, that while we

are under-resourced, there is an opportunity and a need for us to think further about how those resources are deployed and how resources are accessed within our community. I think that the problem of palliative care provision is such a big problem and it needs further resourcing, but I am not sure that it can be met adequately just by further resourcing. There is more that we need to think through and do for that.

It is something that we, as a palliative care clinical network, are very much engaged with at the moment, thinking about how we work more as an integrated territory-wide service, how we try to allow people a single point of entry into the service to make sure that they are seeing the right people at the right time and in the right place. All of that work needs to happen in concert with additional resourcing, to make sure that people really get the specialist palliative care that they need.

That is just the specialist part. The non-specialist palliative care is an even more complicated area, in some ways. You might argue, with some validity, that there are more non-specialist clinicians who can provide palliative care in the ACT. But given issues to do with the way that their roles are defined, the way that their roles are remunerated, if they are private providers or if they are self-funded providers, and given the training and ongoing support that they have, they may not necessarily feel that non-specialist palliative care is part of their role, even if the healthcare service would see that that should be what they are providing.

Again, my personal view is that while specialist palliative care is not the only body that should be interested in that problem, specialist palliative care has a role to play in helping other clinicians to provide non-specialist palliative care, to help them realise that it is everybody's business to do this care and to be involved in the education, integration and leadership that actualises those services.

THE ACTING CHAIR: Is there a dollar figure?

Dr Chapman: I am sure there would be. I would have no idea of what that might be, unfortunately. I would love to take that on notice. I do not know who I would ask to find that out, but I would love to take that on notice.

MS CHEYNE: I appreciate that you are here in an individual capacity and not on behalf of TCH. If you are unable to answer this question in the capacity you are appearing in today, I appreciate it, but perhaps there is a way you could talk about it as an individual or in more general terms.

I think we raised with you last time that we had some evidence about referrals to Clare Holland House, how that happens and the timeliness of that. We had some clarity around that from Clare Holland House this morning, but I think that it was you or someone else who also pointed out that they do not necessarily have medical specialists on over weekends. They advised us this morning that their understanding of how TCH works is that the rounds are usually made on the Friday, which does then impact their ability to take new patients into their facility.

Is that the way it works and is there a reason it has to work like that, with it all happening on the Friday? That seems to be a suboptimal outcome at least from the Clare Holland House perspective. I was just wondering: if it has to happen like that,

are there reasons that we do not know of, or could that be changed, or is it just a matter of staffing?

Dr Chapman: That is a very good question. I think I can speak to that not representing the hospital but just from my own personal observation. Part of, I guess, the complexity of us trying to come to terms with how things are at the moment is that we, as a palliative care community, obviously are conscious of a lot of these issues, and things are constantly changing to try to improve care.

There was historically a run of issues where my availability, my work hours, meant that I was available to do a ward round only on a Friday because I was only 0.6 and there were a couple of days a week I could not be working. The latter part of the week was the day that I did ward rounds, and I am the person who says whether or not a person is appropriate to go to Clare Holland House. That was something that was happening.

Subsequent to that, we tried to change our approach at Canberra Hospital. We are earlier identifying patients who are very likely to be appropriate to go to Clare Holland House, prior to them being accepted, and transmitting that to Clare Holland House as soon as possible to make sure that it is not something that is happening in a rush on the last day of the week.

Thankfully, with some previous funding from the government, my hours have been increased. I am 0.8 now. I am there more days of the week. I see patients at Canberra Hospital every day that I am there. It is certainly not that it all happens on one day of the week. I think that certainly there was a genuine concern that that did seem to be happening a lot. I do not think it is as much of an issue now, is my personal impression.

MS CHEYNE: By “now”, do you mean in the past few weeks, few months, few years?

Dr Chapman: Six months or more would be my impression. From my perspective of working at Canberra Hospital rather than representing them, we continue to work with Clare Holland House and the other providers to make sure that we are changing and improving our services to give people the best care and the most continuous care that we can provide.

There are obviously limits to that. At Canberra Hospital, even though my hours have been increased as a palliative care specialist, I am only a single provider. That means I am not necessarily there all the time. I have a role that is bigger than just my clinical role, and I cannot be at work every day.

Additionally, there is no-one who can make those decisions after hours or at weekends, at least at Canberra Hospital. For instance, if a person on a Saturday came into Canberra Hospital and needed to be determined whether or not they could go to Clare Holland House, that needs to be done over the phone with the person who is on call. And while we do our absolute best to bring that about, that makes it more complicated and decreases the chance that the person will be transferred over the weekend because they are not a person who is necessarily known to the system.

Likewise, as I said—and I am sure Clare Holland have talked about it this morning—they always have access to a doctor over the weekend, though that doctor also has other duties as well. There is a limit to how much work they can do over the weekend and how many people they can practically admit over the weekend even if the beds are available.

MS LE COUTEUR: At the end of your submission you talk about several areas where action is needed. The first one you have is advanced care planning, advanced care directives and enduring powers of attorney. I am just wondering how much you think that is waiting on broader legislative changes, which we asked the Attorney-General about earlier today, or how much within the existing legal framework it is a matter of education for the medical professionals, the community et cetera.

Dr Chapman: It is a really good question. I think that both are required. My personal view is that, even with a completely crystalline understanding of exactly the legislative framework around advanced care planning and advanced care directives, if it were absolutely uniform across states and territories, they still would be underutilised without clinicians and community members being more cognisant and more empowered to actually engage in the conversations.

I think that those things are required but probably the most important thing is more around their use and particularly around, from my perspective, supporting clinicians to recognise that discussions that involve advanced care planning, discussions that involve finding out what is most important to a person and how that should affect their clinical choices, are actually a routine part of clinical practice and should be something that we are all aspiring to achieve and something that we are working towards completing with our patient.

MS LE COUTEUR: In your experience, are the advanced care directives actually referenced and adhered to by clinicians?

Dr Chapman: Yes. They are certainly adhered to when they are known. Knowing that they are in existence is more complicated. Again I am sure the committee has heard from others about this. The system, even within ACT Health's computer system, the system for flagging them, while it is robust and improving, is still miss-able. People still can miss that there is a document there that is available. It requires that document to be known to ACT Health to begin with. And that is just the ACT Health framework.

Obviously, broader than that, it is even more complicated and uncertain and it really requires a sense of empowerment of the patient and the family to have the document available for clinicians for it to be recognised that it is there and that it, therefore, has power and legitimacy.

MS LE COUTEUR: And probably a better national system because even if I have got it all organised with ACT Health and I go to New South Wales something might happen?

Dr Chapman: Absolutely, yes. It would be clearly beneficial for that to happen but,

unless the conversations happen and the documents are delivered, a national system will not actually improve care. There is still that upstream issue that needs genuine focus. I think from a healthcare perspective that starts as early as we start training health carers to be in that role that this is actually part of routine practice. This is best care, helping people understand what their choices are, and how that might impact on their lives from here is actually our job. Unless we are engaging with that, we are not doing our job properly.

THE ACTING CHAIR: I asked this question of Clare Holland House this morning as well. Both the Canberra Hospital and Calvary have a palliative care clinical team but not a palliative care ward. What are the merits and demerits of not having a palliative care ward as such?

Dr Chapman: The merits and demerits? And is that specifically at Canberra Hospital?

THE ACTING CHAIR: It is specifically at Canberra Hospital, in your case, yes. Also mindful that you are here in your own capacity and not representing ACT Health, if there are places you feel you cannot go, I understand.

Dr Chapman: I could certainly talk about my own perceptions of those things. From my perspective, the merit of not having a palliative care ward at Canberra Hospital, for instance, is that if there is not a palliative care ward then it remains everybody's business to provide palliative care. And that is a merit. We do need to continue to encourage people. One of the challenges of specialist palliative care provision is that the more that you do, potentially the less others do. And there are clear tensions around that. I think that there is a merit there.

There is also a merit in the sense that any hypothetical palliative care ward at Canberra Hospital would need to be very carefully avoiding duplicating services that were already in existence, for instance at Clare Holland House. Not having one avoids the possibility of duplication, and that is a merit as well.

Having said that, I think that there are lots of reasons why having a ward would be a really good idea, from my own personal perspective. I think that there are clearly palliative care needs in Canberra Hospital, from my own position, that are unmet and unable to be met within the current structures that are available to us and the resources available to us.

Canberra Hospital is an acute hospital. With the evolving understanding of palliative care being more than just care for people who are close to dying, that in fact there are some people who have palliative needs and who also have acute needs, those will never be able to be adequately met in a subacute or hospice-type environment because their needs are too acute for that environment.

There is a population where the only way to meet their needs at the moment, even if they are palliative acute needs, is for those people to be admitted under people who are not specialists in that area of practice. That is a clear unmet need.

There are also patients who are in Canberra Hospital and who have specialist

palliative care needs but who do not want to go to Clare Holland House, for a variety of different reasons. Therefore Clare Holland House or, for instance an expansion of that kind of service, again will not be able to meet their needs because that is not their choice. If this conversation is at least largely in part around end of life choices, there are territorians whose choices are not being met by not having that service.

Further on that, unfortunately, again my personal impression is that the current services and palliative care services in Canberra Hospital are stretched, they are under pressure and some kind of additional resourcing for those services is quite sorely needed. A palliative care ward would be one way of doing that but, if that is not the way that it is going to be enacted, another way certainly needs to be enacted, because there is a very genuine need.

MS CHEYNE: What other way?

Dr Chapman: The other way would be more consultation services, more funding to do more of what we are doing at the moment. And that obviously could focus more on some of these other matters. Some colleagues and I were at the national health roundtable recently. One of the things that was clear from the data available to us was that it seemed that in Canberra Hospital a focus on the experiences of people who were dying acutely, dying in the emergency department and ICU in Canberra Hospital, was probably quite urgently required. The data may suggest that it may be more required in the ACT than perhaps in other contexts.

At the moment, within the resourcing available to the palliative care consult team, we cannot respond to that potential need and explore that as sufficiently as we would like. We do not have the capacity to fully engage in trying to meet those needs for people who are just coming into ED or in ICU and who may have very significant palliative need.

There would be a number of discrete areas in addition to providing better and more robust care for the people who are already traditionally being seen by palliative care services in Canberra Hospital. There are a number of additional areas that could require focus with more resourcing.

THE ACTING CHAIR: Thank you for your time today, your submission and your attendance at this committee. I am mindful of the time. We will have to conclude there. If there are other questions that members have, I am sure that they will put them on notice. You took on notice the dollar figure.

Dr Chapman: Thank you, yes. I look forward to answering.

THE ACTING CHAIR: The secretary of the committee will send you a copy of the draft proof *Hansard*, and, if there are issues that arise from your review of that, you can take those up with the committee secretary in the first instance. Thank you very much.

Dr Chapman: Thank you for the opportunity.

THE ACTING CHAIR: The committee will suspend for 10 minutes. We are running

behind time but I think probably we need to have a comfort stop, stretch our legs.

Short suspension.

MOORE, MR MICHAEL AM

THE ACTING CHAIR: Welcome back to this hearing of the committee's inquiry into end of life issues. I welcome Mr Michael Moore. Welcome back to the Assembly. I understand that you have read and understood the privilege statement?

Mr Moore: I have.

THE ACTING CHAIR: Mr Moore, would you like to make an opening statement?

Mr Moore: I am appearing as a private citizen in this case. I am a former member of the Legislative Assembly and a former chair of a similar committee that looked at these issues.

Because the committee has received so many submissions covering so many of the terms of reference, the thing that I was really keen to ask you to think about was the principles upon which your decisions and your approach would be based, particularly with regard to the end of life care, but more broadly on the issues you have in front of you.

The reasoning behind that was twofold. Firstly, looking at the Victorian advisory panel and how they went about setting out the principles—and I have put those in my submission—I thought that was a really clever way to keep in mind the range of issues that need to be dealt with, and clearly they are extraordinarily complex.

The second one was particularly around the issue of freedom, and how people perceive their choices. The fundamental one here is your end of life choices, but choices generally. I went through a transition in my own political career in 1997 when I read a philosophy by Philip Pettit that talked about the way many people feel about freedom being that it is about interference: that we do not want anybody interfering with our decisions. So whichever way it goes, we do not want anybody interfering in our end of life choices. We do not want anybody to interfere in our ability to sell our product, and so forth.

Pettit, I think, opened up a whole new area of philosophy when he argued that actually it is not about interference. Freedom is actually about domination, and it is a domination of one view or control over another. It is that thinking that at the time allowed me to say that actually it is important for us to allow people to do their own thing to a point, but it is also a responsibility for us to ensure that somebody is neither dominating nor dominated.

I think that that style of understanding changes the way we think about politics and what we think about such issues as end of life choices. Who makes the decision is the dominating theory that actually interferes with our lives. Is it one that is based on religion or is it one that is based on non-religion? It does not matter, provided we actually say, "Can we play a role that is appropriate for individual freedom?" That also means that governments and legislative assemblies, in making decisions, do not just have a role to say, "It's our role to stay out of it," and for those who advocate non-interference to say, "Just keep out of my industry and out of my business."

They have a role in good guardianship, in good governance, to interfere where appropriate, where they see domination and ensure non-domination. The thinking in my submission, and in helping to understand how the broad issues here should be considered, is a part of that.

To really bring it home, the notion that the federal parliament can take a dominant perspective over the people of the ACT because they know better about our ability to make end of life choices is clearly inconsistent with that style of philosophy. A parliament that hands all of the power to the people of the ACT and says, “Except that we don’t trust you on a particular issue, a moral issue, because we’ve got better moral judgement than you,” is, to me, an anathema, and always has been.

That is the issue that I wanted to raise specifically with the committee, which I do not think others have particularly raised.

MS CHEYNE: In terms of the hypocrisy of the federal parliament that you have described in your submission—not my words—and the democratic freedoms or rights, as they should be, of ACT residents, as well as your own experience and what the community has expressed to you, are you able to elaborate on whether you think that the community, in their right mind, can separate the two issues of democratic rights and being able to legislate versus just going ahead with voluntary assisted dying, and what your experience has been from what you have heard in the community over your very long career and your advocacy of this?

Mr Moore: One of the best examples came from Gary Humphries as a senator, when he crossed the floor on an issue which I believe he personally did not believe in, because it was a prerogative of the ACT to take that action. I think that it was very well received by the people of the ACT. I only know that information anecdotally. I do not think anybody has ever done an assessment like that.

If I can go back to 1997, when that legislation was passed, and the ACT was on the cusp of supporting voluntary active euthanasia, or not supporting it, it was actually impossible—and I can tell you, as it was my legislation, I was counting the votes—I to know what the outcome was going to be; it was that close, when the Andrews bill was introduced. At that point I sought leave to remove my legislation because, in discussion with the other members of the Assembly, we did not want the community to believe that we would somehow have the power to do it. It was very clear that the self-government act had been changed, and we did not have the power.

But what I moved on to do, and what I recommended in my submission, was that we really ought to test it. I think the way to test it is through a referendum. That should send a very clear message to the federal parliament that the general public of the ACT feel they should have the right.

Referenda are very interesting things, because they tend to fail rather than proceed. But it is such an interesting issue where people have fewer rights because they happen to live in a territory—this applies to the Northern Territory as well—than if they live in a state.

I think the issues, though, do need to be separated. Of course, it is an example—the voluntary act of euthanasia. I think that the two issues ought to be separated and there ought not to be a referendum on end of life choices at all. There should be a referendum on the right of the Legislative Assembly to make decisions equivalent to those of the states.

THE ACTING CHAIR: Do you mean a national referendum or an ACT referendum?

Mr Moore: No, an ACT referendum, because we do not have any ability to do a national referendum. I cannot see a national referendum being supported—

THE ACTING CHAIR: I reckon that one would go down fairly substantially.

Mr Moore: Yes.

THE ACTING CHAIR: But if you had a referendum where ACT residents expressed a view about their legislative rights, how would you then envisage that that would be incorporated with the Constitution, without a national referendum?

Mr Moore: It is only an ability to flag the inadequacies of the self-government act. It is saying to the federal government, “You have given the set of powers to territories, withdrawn some, and this is something that 80 per cent or 90 per cent of territorians consider anathema.” If the referendum failed and only 40 per cent supported it, you would say, “Actually, people don’t care.” I do not think that would happen. I think people do feel affronted by it. In the end, asking people specifically on that issue would be a worthwhile exercise.

MS LE COUTEUR: I am slightly confused. Do you think we should have two referendums: one about the right to legislate and the other about the substantive issue?

Mr Moore: The substantive issue is end of life choice—

MS LE COUTEUR: No, I appreciate that they are different. I first thought that we would have—

Mr Moore: No, I am not talking about a referendum on end of life choice at all. I think that that is a responsibility of members of the ACT Legislative Assembly.

MS LE COUTEUR: You do not think that would be it. I am sorry; I am confused about what—

Mr Moore: Of course, you can poll to get a sense of it. No, I am not recommending that. I am recommending a referendum actually on the fundamental democratic issue that ACT residents have fewer democratic rights than others.

MS CHEYNE: In light of what we expect to be debated in one month’s time, noting the realities and the constraints of time, is there anything else that you would recommend in place of a referendum?

Mr Moore: An opinion coming from the members of the Legislative Assembly, a motion by the Legislative Assembly, to say that we ought to have the same rights, that is then conveyed—

MS CHEYNE: We have a motion.

Mr Moore: Yes. That is conveyed as the—

MS CHEYNE: It was passed in November.

Mr Moore: Yes. How that is conveyed to members of the federal parliament is the issue, before they vote. I presume that was passed unanimously. I do not recall the outcome.

MS CHEYNE: It was passed unanimously, yes.

Mr Moore: A view like that, which is then passed on to our federal colleagues, you would think would have some power. But with this particular issue—and I remember it; it is always Kevin Andrews that people talk about, because he introduced the legislation, but Tony Burke was the person who was playing exactly the same role in the Labor Party—it was a combination of the two. There was certainly a religious element associated with it at the time. Times have changed. I think a lot of that thinking has changed. I am sure Kevin Andrews' thinking on this particular issue has not, because of what I hear him talk about. For some people, of course, it is not a particularly important issue.

The other thing that has changed is that the Victorian parliament has made the decision that it is going ahead. So it is not about the ACT breaking ice. I think there was a big element of that in the thinking of the federal parliament.

MS CHEYNE: In your view, Mr Moore, with the current restrictions, are we, and have we been now for 21 years, second-class citizens in relation to the rest of Australian citizens?

Mr Moore: I think it is just a broad principle of democracy. Why would the citizens of a territory, of both territories, have fewer rights than other citizens? An interesting aspect of this is that, as citizens, if we are very unhappy with the decisions being made by our legislators, under the Hare-Clark system, we can even specifically punish particular members for the way they play their role as legislators. In some ways it is a stronger democratic right. I would love to argue that every state and territory should have a Hare-Clark system, but I would probably not win that one either. But I think that the federal parliament might be prepared to reconsider this issue.

MS CHEYNE: Have you done any lobbying yourself, Mr Moore, of federal parliamentarians?

Mr Moore: I have talked to members of federal parliament for many years, and I have raised this issue a number of times. In my previous capacity, I spent a lot of time speaking to federal members of parliament. Actually, the issue came up quite regularly. But I have not specifically set out to run a lobbying campaign to win this. I

am retired.

MS LE COUTEUR: Fair enough.

THE ACTING CHAIR: That is a good point. In your submission you reflect in passing on the voluntary assisted dying regime in Victoria. You are quite well known for having been an advocate of voluntary assisted dying regimes. Would you like to reflect on what you see happening in Victoria and how that fits into your paradigm of what voluntary assisted dying euthanasia legislation might look like?

Mr Moore: Politics is the art of the possible and clearly there have been compromises made. They have found a way to ensure that people who are in great pain and suffering are able to make the choice themselves to have assistance to die. I think that there are some limitations on that particular legislation. I probably would have gone somewhat broader to take into account advanced directives that can then be reinforced at the time. I think there are some limitations around that.

By and large the important part of the legislation is that it does have protections in place. It was always my view, and the view of those people I worked with on these issues, that you do have to have proper protections in place. But in the end, in our society the ability to end your own life in a way that is a good death really lies in the hands of medical professionals because the wherewithal to take such action is in the hands of medical professionals, other than jumping off a building or something dramatic. I think that that is really why it is that such legislation would be necessary, because we do not have access to the sorts of drugs and the sorts of methods that we know are available to some people.

The other part of the Victorian legislation that I really liked was the very clear protection for a medical practitioner not to participate. I think that is a very fundamental and very important protection. I do not recall whether we had dealt with that in our legislation 20 years ago.

THE ACTING CHAIR: Could I go back to the first part of your comment. I just want some clarity. I may have misunderstood. You were saying that the solution for a good death is more in the hands of medical practitioners because they have better access to a better range of—

Mr Moore: Knowledge and medicine and those sorts of things, yes.

THE ACTING CHAIR: What you are saying is that the modality which is envisaged in the Victorian legislation, which is essentially a take-home pack, is less than optimal from your point of view?

Mr Moore: No. Different people should be able to choose different ways. If there is a medical practitioner who is prepared to assist then that is excellent to be there at the time. But to be able to do what you describe as a take-home pack—the language is fine—still requires prescription and access to all those drugs: methadone and so forth. Very few people know how to do an intravenous drug, although that can be pre-prepared. But the final decision and the final action being taken by the person themselves are, of course, optimal in my mind.

THE ACTING CHAIR: In Victoria, when the committee was visiting, we were informed that at this stage, although the provision is there, they do not actually have—and we have not been updated—an optimal modality. They do not know what the cocktail of drugs will be. One of the impediments seems to be that although the drugs are available it is not legal to prescribe them in Australia for the ending of life under the pharmaceutical benefit scheme. As someone experienced in public health, what is your response to that?

Mr Moore: That makes a very interesting dynamic, and I am not familiar with that. I am a bit surprised by it. I suppose most of the drugs, yes, have restrictions on how they are prescribed and what they are prescribed for. I would think that, in the end, if somebody were willing to test that, it would be something that would be tested in the High Court as to whether the federal government have that power in terms of the states and territories, which is interesting compared to just changing our self-government act.

You have taken me by surprise with this comment. I was not aware that that was the case. I imagine there are doctors who could prescribe specific medications for specific purposes and somebody then uses them for a different purpose as well. But the whole point of the legislation was to try to make it really clear that if somebody does want to make this choice, then they can do it for, as they perceive, a good death.

I do not think I can be helpful on that. I think they are outside my area, and it has taken me a bit by surprise. There is one thing, though. We did have this process in the Northern Territory for a relatively short time, and that issue certainly was not raised within the Northern Territory, from my recollection.

THE ACTING CHAIR: It came as a surprise I think to members to learn that the way the prescription is dealt with through the pharmaceutical benefit scheme is, to some extent, an impediment.

Mr Moore: It is, I think, approval by the TGA.

THE ACTING CHAIR: I think it is at the TGA level rather than the PBS, yes.

MS LE COUTEUR: I think it was at the TGA level, not the pharmaceutical benefits scheme level. They were the second-level problem.

Mr Moore: Yes, the Therapeutic Goods Administration. That is how you can prescribe, not necessarily how it is paid for, whereas the pharmaceutical benefit scheme is how it is paid for.

MS LE COUTEUR: Continuing on with Victoria, obviously they have not yet started the scheme but presumably they will. Given your experience as a legislator, do you think that we should be waiting until after their scheme is operational to legislate if a decision is made in the ACT so that we can learn from them?

Mr Moore: I think first and foremost is to get the federal parliament to change its—

MS LE COUTEUR: Yes, assuming that there is an outbreak of good sense in the federal parliament, which we can all hope for.

Mr Moore: No, I do not see any reason why you would wait to see the practice. You have got the legislation, you have got the process. It is there in place. There is no particular reason why you would wait, just as there was no particular reason why the Northern Territory would have waited or we would have waited for the Northern Territory legislation had the Andrews bill not been introduced.

Of course you can learn, and legislation can be modified if necessary. And there will be some learnings. I imagine legislation will be modified because that happens right across legislation, and it is a normal process.

MS CHEYNE: Going back to the conversations you have had over the years, as someone who has been an advocate for such a long time, when did it first come to your attention that it was such an important issue for people, and do you think that feeling in the territory has grown over time?

Mr Moore: The discussion came to me while I was a member of the Legislative Assembly, not while I was campaigning for my first Legislative Assembly. It came, I think, at the time of my second. I think, perhaps because I had been involved in some controversial issues, people thought I might be interested. There was some consistency with the stances that I had taken to seek change on illicit drugs and prostitution and things like that. And that may well have been the reason. I thought that the notion that somebody should be able to make their own choice was important.

It was not because I knew somebody. Often these things are motivated by watching somebody close who dies a poor death. That was not the motivation for me personally. It was really, for want of a better choice, academic and understanding and listening to people who talked and actually being aware of situations even though they were not close to me where people did not have this choice and did die in great pain and suffering.

The committee that I chaired allowed us the opportunity to go to visit a number of palliative care establishments and really motivated me to say palliative care is actually priority one and if we can get our palliative care perfect then nobody would make that choice. And that would be the ideal. It is a bit like we would love to see nobody using illicit drugs, and if we got our systems perfect maybe that would be the case. But when we cannot, then we need to make another choice.

One of the things that motivated me most was that, in Calvary in Adelaide, I went into the clinical decision-making, and one of the decisions they made while I was there was about somebody who was very close to end of life and was in great pain. They could not control his pain, and he agreed to have his spinal cord snipped because he was only going to live for another week or something along those lines. He wanted to live and not be in pain because his, I think, daughter or son or something was coming from overseas. Whilst his brain was still in full operation, he could make the decision. I thought, "Wow, what an interesting choice to have to make."

THE ACTING CHAIR: What a heroic choice.

Mr Moore: And a heroic choice really. The decision was most interesting to me because it was also said, “We actually cannot control his pain, except in this manner.” I can see somebody like that going, “No, I do not want to do it to stay alive. I would prefer to have assistance to die to get rid of the pain.” It is sort of a double-edged sword. I emphasise that what we are talking about are extraordinarily complex issues, and I can understand why somebody would make that choice. I can understand why somebody would seek to make a choice to end their own life.

Later, when my own mother died—she died in quite a bit of pain but that was part of her choice around what drugs she was prepared to take—I remember having the discussion with my siblings that it is actually what she wanted. She was an absolutely committed Catholic, my mother, and I knew that what she was doing was offering up the pain for the suffering souls in purgatory. It is a term she used very regularly. And that was that.

MS CHEYNE: That was her choice.

Mr Moore: That was her choice. That is actually what she wanted, and it was a choice that was really important for us to respect. End of life people make choices for different reasons. Our gut reaction says, “People will want to choose not to have pain.” And it is not always the case.

MS CHEYNE: As someone involved closely in the health field for such a long time, you mentioned before that you have seen circumstances or have heard people say to you that they could not manage the pain. Is that something that you have heard regularly? I think it has been a point of contention throughout hearings whether all pain can be managed or not.

Mr Moore: Actually there is another factor that has just come into it with the peddling among pain management specialists and the cutting of the use of codeine and pretty well all the drugs that come out of the opium poppy. I think there is a serious issue around that, not just for end of life choices but generally, because there is certainly a strong movement to remove reasonably easy access to codeine. My concern is that it will go to another level. Of course it is addictive but there are also many people who use codeine on and off for long times and use it successfully.

I think palliative care is not perfect. I think it has improved brilliantly, and we have to keep working, as the previous speaker was saying, to get it but there are still people who, despite the best palliative care, suffer. And it is not just pain. It is pain, it is indignity, it is the broader issue. For me personally, when I hear people talking about indignity, I think, “So be it.” These people seem to be able to handle all this stuff. Some people cannot handle the notion of indignity. I do not think it is personally such a big issue but I do not think I am embarrassed by anything. That is probably part of it. But some people are. I think that is also part of the choices that people want to make.

But you do have to have safeguards in place, and those safeguards are incredibly critical, not the least of which is those who make the choice because it would be more convenient for their family. And that is real. And that is why the legislation is important. It is not just a free-for-all.

THE ACTING CHAIR: I am very mindful of the time. We have someone waiting on the phone. Thank you very much for your submission and your appearance and your thoughts today. The committee secretary will send you a copy of the draft proof *Hansard*, and you can take up, in the first instance with the committee secretary, any issues that arise.

Mr Moore: Thank you for the opportunity, and I appreciate your work.

Short suspension.

PHILLIPS, PROFESSOR JANE, President, Palliative Care Nurses Australia

THE ACTING CHAIR: I welcome Professor Phillips, who is with us via telephone. The proceedings are being recorded by Hansard, they are being webstreamed and are available on re-broadcast as well. You will have received a copy of the privilege statement, which outlines the privileges associated with giving evidence to a parliamentary committee. Did you have an opportunity to read that?

Prof Phillips: Yes, thank you.

THE ACTING CHAIR: Would you like to make an opening statement in relation to your submission?

Prof Phillips: Yes, I would. I am a professor of palliative nursing at the University of Technology in Sydney. I am actually speaking at this committee hearing as the President of Palliative Care Nurses Australia. It is a national member-based organisation for nurses working with people who are dying from a progressive life-limiting illness, and their families.

The vision of Palliative Care Nurses Australia is to promote excellence in palliative care nursing for our community through leadership, representational and professional support. I am happy to answer your questions with regard to your inquiry into end of life choices.

THE ACTING CHAIR: Thank you. Your submission clearly states that Palliative Care Nurses Australia does not believe that assisted suicide or some form of euthanasia is part of the palliative care continuum. Would you like to expand on why you take that position?

Prof Phillips: Palliative care—and I am sure you have heard this many times—is actually about maintaining comfort and dignity. It is not about extending or hastening the end of life, as described in the WHO definition of palliative care. That is a very important tenet of all palliative care practice.

THE ACTING CHAIR: From your association's point of view, do you believe that assisted dying of any sort should not be in the toolkit of palliative care providers?

Prof Phillips: It is not part of palliative care practice.

THE ACTING CHAIR: Yes. Looking at palliative care practice, which is where you have made your submission, what do you think is needed to optimise palliative care in Australia generally?

Prof Phillips: Australia is fortunate that we have a commonwealth government that has funded a national strategy. Palliative care in Australia is guided by a national strategy and this has been done since 2000. That is very important for providing strategic direction for each of the jurisdictions. It is the blueprint about the way in which palliative care ought to be operationalised and made available to ensure equity and equal access for all Australians.

However, having said that, there are many opportunities at a jurisdictional level for palliative care to be strengthened. The jurisdictions are the providers of direct health care. In every jurisdiction in Australia there are probably people who do not have access to palliative care or, for whatever reason, may elect not to access the service.

The really important point is to make sure that people have the support that they and their families require, to have their symptoms optimally managed. When I talk about symptoms, I do not just mean typical symptoms; I also mean psychosocial symptoms and any other forms of distress that they may experience. It is really about attending to a person's physical, social, psychological and spiritual domain.

MS CHEYNE: Thank you for appearing today, Professor Phillips. In your submission you note that palliative care nurses respectfully and compassionately acknowledge a person's desire to die and also acknowledge that for a small proportion of people pain can persist and not be alleviated. Where that circumstance occurs, and without the option of something like an assisted dying scheme, what other options are there?

Prof Phillips: The first thing is that what you would endeavour to do is to make sure that people have their symptoms optimally managed. In that statement we are mindful that there are a very small number of people for whom that is not possible. It is very difficult, and it is very challenging. It is challenging not only for the patients but also for the family, and it can often be quite distressing for them. What you would want to be doing is to be working with each patient and each family to make sure that everything that was feasibly possible had actually been attended to.

Sometimes there are opportunities to improve people's symptom management, but for whatever reason patients may not elect to follow or take up that option, or it may not be possible for them to do that. In thinking about the future, there are some great opportunities for us to be thinking about different ways in which we manage many of the symptoms that patients experience. When you came back to the question earlier, it was really about the way in which we invest in developing new knowledge, new medications and new procedures, and the way in which we can ensure that people are comfortable.

MS CHEYNE: Do you think, with the right investment, development of knowledge and expansion of expertise, that there could ever be a point where all pain could be managed?

Prof Phillips: I am an optimist. I would like to think that that were possible. But I think that pain is actually multifactorial and there are many underlying mechanisms that we do not necessarily fully understand. It is very complex. Often people have enormous distress, which may not necessarily be relieved by drugs.

MS CHEYNE: Just on that, Professor Phillips, we have heard this a lot. An earlier witness, in his submission, said that there seemed to be increased understanding or awareness in the community of death. But with that comes increased fears and horrors associated with it. How can we alleviate people's distress, including that of those around them, and, for lack of a better word or term, improve people's death literacy or

their familiarity with death, so that it does not become the horror that it seems to be for many?

Prof Phillips: You would have heard this many times before: death has become very institutionalised. Whereas once our grandparents would have grown up in an era where they were probably quite exposed to multiple deaths, with new technology and new developments, and our reliance on advanced treatments, many Australians will actually end up dying in an acute care setting. That is not necessarily an inappropriate place; it just depends on the circumstances. I do take your point that increasing death literacy is a really important idea.

Some of the things that happen are things like Death Over Dinner, which are events where people have an opportunity to gather and talk about death. The Compassionate Communities movement is another great example where people are trying to put death in the public domain and have the conversation. I guess it is like with many things: not everybody is ready to talk about death, even though it is inevitable for all of us. In some respects we live in quite a death-denying society. It is also, too, about the way in which death is portrayed in the media. It is often the only reference people have to what death actually looks like.

MS LE COUTEUR: This is a continuation of Ms Cheyne's question. She asked you whether you thought good palliative care could alleviate all pain. My question is: do you think that good palliative care could alleviate all desire for voluntary assisted dying or euthanasia so that, in effect, is what we are seeing in this discussion a reflection not of what we are not doing but what we could or should be doing with palliative care?

Prof Phillips: That is a difficult question in some respects because, in relation to some of the most public statements that have been made about voluntary assisted dying, not necessarily all those individuals have had the benefit of palliative care. I think that is the first thing to be mindful of.

The other thing is that once again people have a choice. They may not choose to actually have palliative care but I think that, where they have got an opportunity many patients, when they are referred and often when there is a lot of information and discussion in the community about topics like voluntary assisted dying, will often have the conversation with you when you first meet them.

Often that dissipates as you work with them and other members of their family and the healthcare team work to alleviate some of their fears and distress. But I think there will always be probably a small proportion of people where their fears may not be alleviated.

MS LE COUTEUR: I suspect you may be right.

Prof Phillips: Should we be changing the law for the minority?

MS LE COUTEUR: It may or may not be a minority but we have many laws which deal with only minorities of the population. That, in itself, is not a reason not to have a law dealing with it. You said that you thought that it would not be appropriate for

palliative care specialists to be actively involved in voluntary assisted dying. Do you think it could work, clinically, to have some other specialist come in as well at the end of life for that part of a person's choice, if they chose to make it?

Prof Phillips: I think that will probably be a decision for medicine to make but if that were decided then we really need to make sure that there is very good communication. And it may be very difficult for health professionals, if you have walked with a patient as well.

THE ACTING CHAIR: Are you aware of or familiar with the recommendations of the Productivity Commission in late March in relation to end of life care?

Prof Phillips: I heard that but I have not re-read that recently. Are you going to ask me a specific question?

THE ACTING CHAIR: The main recommendation is for state and territory governments to increase the availability of community-based palliative care so that people with a preference to die at home can have access and support to do so. That is their first and, in a sense, their major recommendation. Would the Palliative Care Nurses Association be broadly in agreement with that recommendation?

Prof Phillips: Totally. If we are going to be able to enable people to spend as many days as possible in their place of choice, which is usually home, you can only do that through strengthening community-based services. And that is a combination.

That is really the whole effect of reform in not only thinking about the way in which we have configured community nursing, specialist home-based palliative care services, but probably, equally importantly, how we have actually configured our home and community care services so that they are nimble enough to be able to respond and provide hands-on personal care to people who want to remain at home and who are often very fragile and have limited mobility.

Given that the average age of a patient referred to palliative care is 74, we are not talking about a young cohort. These people may be living alone and/or have a carer or a partner of a similar age, often with their own comorbidity and disabilities. We will never be able to perfect it. People survive and remain hopeful as long as possible.

You would need quite a substantial investment in home palliative care programs and the adjunct services. You have got to think about the way in which we fund and support GPs to be providing medical care to people at home. We have to think about the way we configure it and supporting our specialist palliative care community nurses.

Other specialist nurses are often required to be involved, be that all the therapists, be that the continence nurses, diabetes nurses, wound care nurses, some of our nurse practitioners, our specialist nurses working respiratory, cardiovascular, renal, diabetes and neurology, and the equipment that we make available to people that is readily available and easy to access but, most importantly, the type of support that we provide people to enable them to have personal hygiene, being kept clean and dry within their home on a daily basis. That is probably one of the biggest gaps and often why people

end up in the acute care sector, because their care needs exceed the available community responses and/or they have exhausted their family.

THE ACTING CHAIR: Has your association done any work that might quantify the unmet need or the cost of addressing unmet need?

Prof Phillips: Not necessarily, but I think one of the services that probably provide the most comprehensive home-based palliative care in Australia would have to be Silver Chain nursing service in WA, which is an integrated program that has operated since the mid-1980s. They would probably have the most comprehensive dataset. Given that 80 per cent of the Western Australian population live within the metropolitan area, that is a service that has got extensive in-reach into the community with an integrated primary healthcare program with GP support and also home-based community care and an equipment service.

THE ACTING CHAIR: We have heard evidence before. Would that be considered the acme of what home-based services should aspire to, the type of service provided by Silver Chain?

Prof Phillips: In WA, because I think the model of care in WA is slightly different to what is probably being offered elsewhere or paid for by jurisdictions elsewhere.

THE ACTING CHAIR: The other issue that has come across the committee's table quite a lot is the provision of palliative care in aged care facilities. The Productivity Commission does make recommendations about funding to facilitate that. But from your association's experience, what needs to be addressed in palliative care in aged care settings?

Prof Phillips: You could have a whole inquiry on that. There are many opportunities. I think, first and foremost, there needs to be a position shift so that, essentially, by the time you end up in a residential aged care facility you are effectively requiring flow-stream palliative care because you are going to have very advanced dementia and/or frailty and, highly likely, other comorbidity. They are, essentially, a main flow-stream hospital but we do not call them that. We do not fund them like that and we do not require them to meet the same standards.

I think there are many challenges and I think one of the biggest challenges was that in 1997 there was a repeal of the ratio of registered nurses to residents. What you will often see in residential aged care is very elderly people with multiple comorbidity—most of them with dementia, incredible fragility—largely being cared for by an unskilled workforce and a few registered nurses. Yet their care needs demand a skilled response. There are a number of factors but just increasing the ratio of registered nurses to residents is important.

I think the other thing in residential aged care is that we say to older people, “You are able to choose and maintain your own general practitioner,” but not all general practitioners have the capacity and/or the interest to be able to provide in-reach into residential aged care facilities. We do not have a model, other than perhaps some of the super organisations, where there are on-site GPs allocated to residential aged care facilities.

There is huge scope for aged palliative care nurse practitioners working in partnership with the resident's general practitioner and the geriatricians and the palliative care team to improve the delivery of palliative care in residential aged care.

There are multiple things that can be achieved, I think, by rethinking the way in which the workforce is configured with residents in residential aged care.

THE ACTING CHAIR: I am aware of the time. I thank you for your submission and your evidence here today. The committee secretary will send you a draft of *Hansard* when it becomes available. If there are issues that you wish to clarify, you can take those up with the committee secretary. I thank you again for your time. And that concludes our hearings today.

The committee adjourned at 12.17 pm.