

JOINT SELECT COMMITTEE ON PALLIATIVE CARE IN WESTERN AUSTRALIA



**TRANSCRIPT OF EVIDENCE
TAKEN AT PERTH
FRIDAY, 31 JULY 2020**

SESSION ONE

Members

**Mr Chris Tallentire, MLA (Chair)
Hon Nick Goiran, MLC (Deputy Chair)
Mr Zak Kirkup, MLA
Mr Shane Love, MLA
Hon Kyle McGinn, MLC
Hon Alison Xamon, MLC**

Hearing commenced at 10.08 am**Ms LANA GLOGOWSKI****CEO, Palliative Care WA, sworn and examined:****Dr ELISSA CAMPBELL****President, Palliative Care WA, sworn and examined:****Dr MARGHERITA NICOLETTI****Consultant in Palliative Care, Rockingham Hospital, sworn and examined:**

The CHAIR: Good morning. My name is Chris Tallentire and I am the chair of the committee. The deputy chair is Hon Nick Goiran. Kyle McGinn, Zak Kirkup, Alison Xamon and Shane Love. In a moment, we will give the nod to the broadcast people so that this can be broadcast. Before I do, just to say that if you have any confidential notes or anything, keep those flat on the desk so that they do not show up on the camera.

If you can each say your name, please, and your position, the capacity in which you are here.

Ms Glogowski: My name is Lana Glogowski; I am the CEO of Palliative Care WA.

Dr Campbell: Elissa Campbell; I am the president of Palliative Care WA.

Dr Nicoletti: I am Margherita Nicoletti and I am a board member of Palliative Care WA.

The CHAIR: Thank you. The next thing is I need each of you to take either the oath or affirmation, please.

[Witnesses took the affirmation.]

The CHAIR: Thank you. I need to give the nod officially that the broadcast begin. The broadcast is underway. You have signed a document entitled "Information for Witnesses". Have you read and understood this document?

The Witnesses: Yes.

The CHAIR: Thank you. The proceedings are being recorded by Hansard. Please note that the broadcast will also be available for viewing online after this hearing. Please advise the committee if you object to the broadcast being made available in this way. You are happy with the broadcast proceeding? Thank you. A transcript of your evidence will be provided to you. To assist the committee and Hansard, please quote the full title of any document you refer to during the course of this hearing for the record. Please be aware of the microphones and try to talk into them. Ensure you do not cover them with papers or make noise near them. Please try to speak in turn, as well. I remind you that your transcript will be made public. If for some reason you wish to make a confidential statement during today's proceedings, you should request that the evidence be taken in a private session. If the committee grants your request, any public and media in attendance will be excluded from the hearing. Until such time as the transcript of your public evidence is finalised, it should not be made public. I advise you that publication or disclosure of the uncorrected transcript of evidence may constitute a contempt of Parliament and may mean that the material published or disclosed is not subject to parliamentary privilege.

Would you like to make an opening statement, perhaps, and then we have a whole series of questions to talk you through and tease out some of the things raised in your submission. Thank you very much for the comprehensive submission as well. Over to you for an opening statement.

Ms Glogowski: Great. With your support, what we would like to do is to speak to some key points from our submission. I would like to start talking about the importance of advance care planning being integral to palliative care. Dr Nicoletti is going to talk about diversity in our community and considerations around that in terms of both advance care planning and palliative care. Dr Campbell is going to talk about the critical importance of choice and the models of care that we currently have available. Dr Campbell will also talk about voluntary assisted dying. Then I am going to conclude by talking about communication both with the sector and with the WA community. We will make these comments brief so that that will allow plenty of time for you to ask us questions.

The CHAIR: Excellent, thank you.

Ms Glogowski: Okay. I would like to start out by talking about the critical importance of advance care planning as part of palliative care. I make reference to the 2017 report and the fact that your report was broken into three main components—advance care planning, palliative care and voluntary assisted dying. What I regularly find, particularly in my communications with WA Health, is a notion that advance care planning is separate to palliative care, which I find quite concerning. From our perspective, advance care planning is critical to palliative care and is a really important first step in terms of engaging people in the provision of quality palliative care.

One concern that I would like to raise with the panel is that we are just in receipt of a tender opportunity around the palliative care hotline, which was a recommendation of the 2017 panel. That document again separates advance care planning from palliative care. I am really concerned about that as a reflection of a theme that seems to be coming through our communication with WA Health. From our perspective and our experience of piloting the hotline for the last four months, is that often when people ring us they are in a very distressed state because they have just been told that their loved one needs to consider entry to a palliative care service, and so the first part of that conversation is, “Okay, what services are you currently receiving? What are your values or what are your loved one’s values and priorities? What do they want to achieve? What do they want to receive as part of their palliative care journey? Do they want to receive palliative care at home? Do they want to be admitted to hospital? Do they want to access palliative care via hospice? Do they want an emphasis on treatment so that they can live for as long as they possibly can? Do they want minimal treatments? Do they want palliative care—a recognition of the need for pain management and symptom control—but do they not want treatments that extend their life for a long period of time?” They are the sorts of conversations we are having on the hotline. That is advance care planning. That is a conversation about what your values and priorities are moving forward. I would really encourage the committee to consider the critical importance of advance care planning as an integral part of palliative care.

I just draw your attention to our submission and a quote on page 23, where we highlighted the fact that —

The Joint Select Committee on End of Life Choices identified three streams of work: advance care planning; palliative care and voluntary assisted dying. It is important to recognise that these streams are not discrete, there is much overlap and they can’t be seen in isolation.

Just further emphasising that fact, if I could talk about very briefly the workshops that we deliver in the WA community on advance care planning. Member Kirkup would be able to provide testament to the value and the engagement that we get in the community around advance care planning and then our opportunity to talk about palliative care. Again, that reinforces advance care planning as

the critical entry pathway to people's understanding about palliative care. Then further, if I could talk on the community consultations that we ran very quickly to inform our submission to this committee. I can report very honestly that across almost all of those consultations the emphasis was, by the people we were consulting, on advance care planning. For them, they recognise that their community members wanted to be a part of these discussions. They wanted information on advance care planning. I think for them COVID-19 has really highlighted all of our mortality. I think for them that was a really key factor in saying—you know, I gave them next to no notice and they all came together really promptly and really engaged at a significant level for hours, I have got to say. They were really clearly reporting, "Yes, our community wants to find out about advance care planning and in that context we can more understand about what palliative care is." I will now hand over to Dr Nicoletti.

[10.20 am]

Dr Nicoletti: We are a diverse community and in palliative care, one size does not fit all. We have heard from that diverse community. We have done workshops with Aboriginal people, local culturally and ethnically diverse people, people with disabilities and people with diseases that do not often fit into the mainstream palliative care model here in WA like motor neurone disease. What we have heard loud and clear is that one size does not fit all, that the palliative care sector needs to be made more aware, maybe trained in or certainly informed about cultural differences, about becoming more culturally competent in providing care at end of life for these vulnerable groups of people, and vulnerable groups of people that have a high mortality. I guess what I am saying is that in palliative care more training needs to be done to cover the care providers in cultural safety.

Dr Campbell: I wanted to talk about choice and the models of care. It is well-recognised that early palliative care from the time of diagnosis or at least early in the course of a terminal illness is very important both in improving quality of life for that person with a life-limiting illness, but also economically. There was a KPMG report that was published in May 2020 called "Investing to Save" that was commissioned by Palliative Care Australia—I am not sure if the panel is familiar with that report.

The CHAIR: We have seen it, yes.

Dr Campbell: Excellent. We need to educate health professionals and also the broader community of the benefits of early palliative care. But alongside that, there needs to be access to palliative care services for those people early in the disease trajectory. I know from reading other submissions to the committee, such as one from the Health Consumers' Council that described a woman with metastatic cancer who had been discharged by Silver Chain hospice. Then when her disease progressed, she was—the word they used was "rejected" by Silver Chain. I know that the motor neurone disease WA submission mentioned a number of people who recognised the benefit of palliative care early in the course of their illness but are not able to access palliative care services, again, often because they get discharged when their symptoms become stable.

From my own experience, I do not work in palliative care; I work as a geriatrician. A lot of my work is with people with dementia and it is really difficult to access palliative care services for them. It is not because the palliative care services are being lazy or mean, it is because they are not resourced to have that many patients on the books. If they do take on one patient, then that is another one that they cannot take on. It is really finding that balance. I know for the staff working in those services, often there is a moral dilemma associated with discharging patients. They do not want to discharge patients; they just have to because they have to choose which patients they are going to take on. Part of the issue is that traditionally palliative care was designed for people with cancer and people who were fairly well and independent up until the last few days or weeks of life when they

became very unwell, and that was when they had a high level of symptoms and needed the palliative care services. With modern cancer treatments, often the journey does not look like that anymore. People can live for many years with cancer with the newer treatments that are available, and for diseases other than cancer such as motor neurone disease, dementia and chronic heart and lung diseases, the traditional model of palliative care where there is an intense amount of care provided in the last days or weeks before death, it just does not suit the needs of the person anymore. What we do need is different models of palliative care that suit the needs of people. For example, different palliative care services have different key performance indicators that they have to meet that might not necessarily fit in with the needs of people. They might need to get a visit every week, for example, to meet those KPIs, but the person with the palliative care needs might not need a visit every week; they might just need a telehealth consult once a month or something. Our models need to be updated to match that need. Then also with choice, it is all well and good to do advance care planning and make people aware of palliative care and the benefits early in the disease process, but if someone says, "I want to receive palliative care at home, I want to stay at home and I want to die at home" there also needs to be the services to support that. Often the default is having to go to an emergency department because the services are not there. People usually want to die close to home. It is extremely important for Aboriginal people to die in country, but even, say, in the Perth metro region, we do not have any inpatient palliative care units south of Murdoch. There is a huge gap. We do not have a palliative care specialist in the Peel region, for example. For people south of the river in the metro area, and very much people in the outer metropolitan areas, there are huge gaps there as well in accessing palliative care. We have been very pleased to see the work done with the WA Country Health Service and the new models that are being set up there to improve access for people in rural and remote WA and we wonder if some of those models could also be helpful for people in the outer metropolitan areas like Waroona, Two Rocks or Gidgegannup.

Finally, navigating the palliative care system is extremely complex; we see that time and again in our consultations and in the submissions as well. We wonder if there could be a role for a care navigator, similar to what is proposed for voluntary assisted dying or, for example, what exists within WA Health for cancer streams where there is a specialist nurse who helps patients navigate between their different appointments with different specialities and the different services they can access. Having that one-stop shop for palliative care would be very helpfully. I know that I, as a health professional with a high level of health literacy, find it very difficult to navigate all of these things. I can only imagine how difficult it is for someone who is very unwell or is caring for a loved one who is very unwell. I think a care navigator service would be really useful in helping to access palliative care services.

Hon ALISON XAMON: Just out of interest, where would you see the care navigation model ideally situated within the overall system? Would you want to see it in the Department of Health or would it be best managed by community-managed services? How would you see that?

Dr Campbell: I do not think it is so important where it is managed as the qualifications of the people that are managing it and their knowledge of what is available.

Hon ALISON XAMON: Thank you.

Hon KYLE McGINN: There are two spots I want to touch on. Firstly, Aboriginal people and dying on country. I have a conflicting view with that based upon some research I did during the VAD legislation. Some evidence that came to me was that there is a high number of people that do not want to die on country because of cultural reasons that happen, in particular the 12-month smoking ceremonies et cetera, which surprised me because, logically, I would have thought that dying on country was important. But it seemed out in the goldfields region that it was more important to

have a process that was off country, and then the same issues arise too because all the family come in for the palliative care and see that person die in that room, which then, again, becomes another cultural issue. When you talk about the importance of dying on country, have you got figures that that is more likely than people coming to a palliative care unit?

Ms Glogowski: If I could respond to that. As part of our consultations, we communicated with some Aboriginal communities in the Pilbara and the Kimberley—slightly different perhaps to the goldfields scenario. But I think in that consultation that dilemma was recognised that in some instances there is a reluctance to come to metro because they want their family and their extended family around them, but then also there is the dilemma about dying in their community and the fact that they then cannot inhabit that place for a period of time. I think what was recognised is that it is an incredibly complex area and that there are different approaches for different communities. Maybe slightly more urbanised Aboriginal families may have a slightly different approach than very traditional families.

[10.30 am]

I think the message that came through to me loud and clear via our consultation—and I think it was reinforced by Dr Nicoletti—is that we need to be talking with Aboriginal communities and we need to be building on their knowledge of their own communities. We had the pleasure of being able to connect with some staff with the Derby Aboriginal Health Service, who from my understanding have a very comprehensive model for supporting their community with palliative care. What was really surprising was that we were then talking to other Aboriginal communities who had no notion that this team was doing the work it was doing. What that alerted to us was that there is a real need for expertise sharing, particularly within Aboriginal communities, about how they are managing some of these dilemmas.

Hon KYLE McGINN: I am not referring to coming to the metro area, either; I am referring to simply coming off the lands and coming to the closest regional hub. In that respect it would be Kalgoorlie instead of Tjuntjuntjara or Ngaanyatjarra lands. My experience was that there was a higher rate, particularly in the goldfields, that wanted to be in the palliative care unit, and your comment just threw me a little bit, that is all. I suppose the other point is in respect of palliative care beds being filled up with people who potentially do not need to be in palliative care. There was a comment around palliative care beds being filled with people who potentially do not need to be in palliative care yet; they could be at home on lesser services, but because those services are not there, that then takes away places from the palliative care unit. Is that what you were alluding to?

Dr Campbell: I think I was probably more talking about the community palliative care services, such as Silver Chain, in the Perth metro area, that they are limited in their funding to how many patients they can take on, rather than the inpatient beds. But what does happen is that people cannot access community palliative care or the inpatient palliative care beds, and they end up in an emergency department in an acute hospital bed, which not only is very expensive, it is also not what many people want at the end of their life; they do not want to spend their last days in acute hospital beds in emergency departments.

Dr Nicoletti: Unless that acute hospital bed is south. I am just going to say, as my bugbear, that people from the Rockingham region in the south do not go to a hospice bed because it is too far to travel, so they stay in acute hospitals if it is inappropriate to be at home.

Mr Z.R.F. KIRKUP: Where is that in the context of Mandurah?

Dr Nicoletti: It includes Mandurah.

Mr Z.R.F. KIRKUP: I think Peel Health Campus has five palliative care beds.

Dr Nicoletti: There is no palliative care service. They have nominal palliative care beds, but there is no palliative care service.

Mr Z.R.F. KIRKUP: What does that mean, sorry?

Dr Nicoletti: That is something I have tried to work out for the last six years.

Dr Campbell: It is a bed that is labelled “palliative care”, usually for people who are dying, but there is no palliative care specialist doctor and there is no palliative care multidisciplinary team of nurses and allied health professionals to care for that person.

Mr Z.R.F. KIRKUP: So effectively it is just a nicer room?

Dr Nicoletti: Correct. It has a crocheted doona on the wall.

Hon ALISON XAMON: And it is just giving pain relief, presumably.

Dr Nicoletti: The generalist staff will look after that patient, yes.

Mr Z.R.F. KIRKUP: In an area like Mandurah, which is obviously particularly old—how old is up for contention—there is a population demand there. For that size population, what would be the service level you would expect to see, for the Mandurah or Peel region, for example? I realise we get lumped in quite a lot with Rockingham, but obviously they are two very separate areas and, as you know, Mandurah is still some time away from Rockingham.

Dr Nicoletti: I have not done a needs analysis, but I confess that I work at Rockingham Hospital and I see outpatients from the Peel area. Before Silver Chain took on Peel Palliative Care, I worked with Peel Palliative Care. There is a huge need in that area, because not everybody can die at home; it is not appropriate that everybody die at home. Even people who do die at home sometimes need to have some of their time spent in an acute hospital to have their symptoms sorted so that they can be more comfortable at home. As to the number of beds, I do not know, but there is a huge need for inpatient beds; I want to say 20, but I am picking that figure out of my head, for the area between Rockingham and Bunbury, and that Peel area is the appropriate place for it. I do not know why north was written in your submission and south was missed out.

Mr Z.R.F. KIRKUP: You and I both.

Dr Nicoletti: It is my understanding that there is a bigger need and actually less beds per capita south of the river than there is north of the river.

Hon NICK GOIRAN: Mr Chairman, I could say something with regard to why north was chosen, but that would mean revealing committee deliberations, which I cannot do, but for the public record it is a statement of facts that the minutes of the meeting of that particular committee remain locked.

Dr Campbell: Palliative Care Australia makes recommendations about the number of, I guess, palliative care beds and palliative care staff, and for palliative care specialist doctors it is two per 100 000 of population. WA is nowhere near that. It also gives recommendations on how many nurses and allied health professionals as well, to go along with that, so based on the population of Peel, we could make a calculation. For inpatient palliative care beds it is generally considered that you would need to have a minimum of 15 just to have the efficiencies required to run a service in terms of the staffing and the expertise.

The CHAIR: Are there any further questions on the opening statements?

Hon NICK GOIRAN: Mr Chairman, I am not sure the opening statements are finished.

Dr Campbell: I was going to very briefly speak about the interaction between voluntary assisted dying and palliative care. There are a few important points. Firstly, we want to ensure that no-one in Western Australia is opting to choose voluntary assisted dying because of a lack of access to

palliative care. Secondly, for people who do choose voluntary assisted dying, that they are still able to access palliative care. Also, I do not feel that a lot of work has been done yet in Western Australia on how we are going to support our palliative care services once voluntary assisted dying is implemented. We have seen from jurisdictions in Victoria and around the world the massive impact it has on palliative care services when voluntary assisted dying is introduced, and that is regardless of whether those individuals working in the services are for or against voluntary assisted dying; it has a huge impact on their day-to-day clinical work, but obviously there are a lot of moral dilemmas associated with that as well.

Ms Glogowski: The last few comments I would like to make focus on communication. As you will have seen from our submission, we consulted with a total of 167 people across the WA community in quite a tight time frame. What the consultations and particularly the survey reveal is that very few people within the sector have any idea about what is happening in terms of implementing the recommendations of the 2018 joint select committee. From our perspective, we really encourage WA Health to engage in much more transparent—no, that is unfair. I do not want to assert that they have not been transparent, but they are certainly not communicating their progress in a way that the sector understands, so for us that was a very clear outcome from our consultation processes.

The other thing I want to raise with the committee is Palliative Care WA's priority around communicating with the WA community about advance care planning and palliative care. I think the 2017 committee very clearly identified that most people in our community have very little understanding of advance care planning and even less understanding of palliative care, so we think it is really critical that we really up the ante around that public conversation. You may be aware that last year we had a media campaign called "You Only Die Once". We had a television advertisement with a couple of women in a car talking about her end of life.

[10.40 am]

That campaign cost us a total of about \$350 000, so relative to big public health campaigns it was a very small amount of money, but can I tell you that our evaluation of the campaign was very, very positive. We saw a 60 per cent increase in awareness before and after that campaign, so I am very happy to forward to the committee if you would like that summary evaluation. But for a small amount of money we were really effective in increasing awareness. If it was not for COVID-19, we would have had the second phase of that campaign about now. It has been put off until next year because we were concerned about mixing messages with COVID-19 and, you know, the need for us to be really sensitive and clear about the messages that we share. Can I just share with you that we have sector support for those campaigns, so sector agencies who are members of Palliative Care WA have contributed quite a significant amount of money from their own bank sheet to contribute to that campaign. So I think collectively as a sector we recognise the critical importance of raising awareness about advance care planning and then palliative care with our WA community, and then our WA community will be asking for palliative care and putting increasing pressure on services to deliver what they want. Thank you.

Hon NICK GOIRAN: One question that arises from the opening statement: you have been quite critical of the separation of advance care planning by the government with respect to palliative care, and I just want some extra clarification around that. Far be it for me to be a defendant for the government, but I have actually got a little bit of sympathy for the separation. My question is: would an advance care plan be of any use to someone not requiring palliative care?

Ms Glogowski: I am going to ask my clinical colleagues to answer as well, but certainly from my perspective advance care planning is about empowerment. It is about people having an understanding about what their chronic disease looks like, the choices they may have moving

forward. They may not require palliative care as part of their disease management, but from my perspective it is about feeling empowered, knowing what the choices are and being able to engage in an informed conversation with their treating team about what the options are and having those conversations with their family and friends and people that are important to them so that the pathway moving forward is clear, so that you do not get to that point where for whatever reason they get taken to emergency, they have had a major health crisis, and then there is a flurry of crisis decision-making that is not in anybody's interests and puts a huge stress on the emergency physician who is trying to deal with a very complex situation. So whether or not people require palliative care, for me advance care planning is about empowerment.

Dr Nicoletti: Advance care planning is integral to palliative care; you cannot take that out of palliative care. It is part of what we do in palliative care; however, I wonder if the confusion lies in the advance health directive compared to advance care planning. An advance health directive is a legal document. I agree everybody needs to have some advance care planning in their own life; they want to know and have an idea of that. I just wonder if the confusion comes when we are not actually talking about advance care planning but an advance health directive, which is not the complete domain of palliative care. Palliative care can use an advance health directive.

Hon NICK GOIRAN: If we agree on that, that an advance health directive is broader in its application and just palliative care —

Dr Nicoletti: Absolutely.

Hon NICK GOIRAN: — my question still remains: is an advance care plan limited in scope to palliative care?

Dr Campbell: No. Any adult can do advance care planning but I would deal with an analogy with pain management. Pain management is an extremely crucial part of palliative care, just as advance care planning is a crucial part of palliative care. It does not mean that all pain management is palliative care. There is pain management for surgery or a stubbed toe. Advance care planning is a very important part of palliative care, but it is not exclusive to palliative care.

Hon NICK GOIRAN: I think where this conversation started was the comment around the tendering process. There is a tendering process with regard to the palliative care hotline, which is entirely appropriate, and we look forward to the conclusion of that, and then there is a separate tendering process advance care planning.

Ms Glogowski: No, so if I could clarify. Palliative Care WA has entered into a negotiation process with WA Health around a raft of services that Palliative Care WA is going to provide WA Health and the broad WA community. That is not an open tender process; that is a negotiated process. As part of that we are continuing in the delivery of our very successful advance care planning workshops. We will also be delivering community education on palliative care and grief and loss that will look differently. But we are in the final stages of a negotiation process with WA Health, which will enable us to progress that work over five years. Palliative Care WA is very grateful that WA Health for that support of the very successful work that we are undertaking. The hotline recommendation is an open tender process, so Palliative Care WA will be tendering along with a raft of other service providers in WA. What I was attempting to share with the committee is my concern, and it has happened over a number of different processes. The hotline tender is just another one of those where I am seeing a real separation of the advance care planning work and the palliative care work. We are continuing to have the conversation with WA Health, but it is a concern to me that we are seeing that separation.

Hon NICK GOIRAN: Just to conclude on this, Mr Chairman. So if I understand the concern, are you saying, for example, with the tender for the hotline if you are picking up the phone and there is a person who is raising a concern with you about advance care planning, you want to have the capacity to be able to help that person?

Ms Glogowski: Absolutely.

Hon NICK GOIRAN: That is not unreasonable.

Ms Glogowski: No.

Hon NICK GOIRAN: That is fair, but I also think it is fair if the government are saying advance care planning is much broader than just palliative care.

Ms Glogowski: Right, yes, okay.

Hon NICK GOIRAN: I think trying to fit those two concepts together—I do not think they are mutually exclusive. I think there is overlap.

Dr Nicoletti: I guess they have actively excluded advance care planning; they have not mentioned it. They have actively said not advance health planning.

Hon NICK GOIRAN: In the tendering for —

Dr Nicoletti: Yes.

Hon NICK GOIRAN: Okay.

Dr Nicoletti: And that is the problem. I think it is probably an administrative—I do not know.

Hon NICK GOIRAN: Okay. I think that is an important point for us to be aware of.

Mr Z.R.F. KIRKUP: As part of the conversations that you have been having with Health, has any discussion come up about a palliative health care centre of excellence at all?

Ms Glogowski: No.

Mr Z.R.F. KIRKUP: There is one that has been proposed by a member of the government for Kalamunda, which is unusual in itself is a location, but I am keen to understand what that might even look like—if anyone is particularly aware of what a palliative care centre of excellence would achieve or do.

Ms Glogowski: Can I start out by making a comment. From my perspective it follows on from that whole notion of increasing awareness and understanding about advance care planning and palliative care, so a centre of excellence I think is about building a community of practice around advance care planning and palliative care. Certainly, my learned colleagues probably have some stories to share about some very skilled health practitioners who still have very little understanding of advance care planning and palliative care, so from my perspective that notion of a centre of excellence could do a significant amount in terms of raising the profile of this very important part of the human experience and build on that development of expertise.

Hon ALISON XAMON: But you had not heard anything about that?

Ms Glogowski: No.

[10.50 am]

The CHAIR: We have a question on notice already indicated. That is the details of the analysis of the advertising campaign—that evaluation report. We will have that as a question on notice 1, if we can get that information from you.

Thank you very much for those excellent opening statements and the questions that came up. In fact, I am sure that we will be going back to some of those areas as we go through. I have got a list here of about 35 questions to get through in the next hour to tease out things for our report. Some of the things you have already covered comprehensively, but some of them we might just need to revisit a little bit.

Could I just kick off with a question about the relationship between Palliative Care WA, Palliative Care Australia, the Department of Health and other stakeholders—an overview of how that looks?

Dr Campbell: Palliative Care Australia is the federal peak body for palliative care. The various state and territory palliative care peak bodies, including Palliative Care WA, are members of Palliative Care Australia. It also has a few other members, including the Australia and New Zealand Society of Palliative Medicine, which is the doctors group, the Palliative Care Nurses Association and PaPCANZ, which is the paediatric palliative care group. We are members of Palliative Care Australia and we are the peak body for palliative care in WA. We are a non-government organisation, as is Palliative Care Australia. We have received some funding to date through project tenders with WA Health in delivering advance care planning workshops to the community and are currently in negotiations for a service agreement with WA Health, which I know they mentioned in their submission to you.

The CHAIR: That is the extent of that relationship? You would have other connections with WA Health as well?

Dr Campbell: I should declare that I am an employee of the North Metropolitan Health Service separate to my role at Palliative Care WA, which is a volunteer role. There is an end-of-life and palliative care advisory committee at WA Health and I sit on that committee ex officio as the president of Palliative Care WA. Some of our board members, such as Margherita, are also members of that committee as individuals.

The CHAIR: The next question, and you have touched on this, is about the implementation of the recommendations of the end-of-life choices report. If you would care to say a little bit more about that—you are recommending that the Department of Health be encouraged to more comprehensively communicate progress on recommendations. Have you got thoughts on how they should be doing that?

Ms Glogowski: It is not our role to advise the department on how they best communicate, but something as simple as a regular newsletter with an update of progress. I recognise that there are confidentially issues that will need to be considered as part of this. I think it is about the notion of sharing with the sector that, in fact, significant work is being done. When we consulted with some of the WACHS teams, I have to acknowledge that some of us were quite surprised at how much work they had actually done. That was fantastic to hear, but that was the first that we had heard of it. Without necessarily going into a huge amount of detail, I think some regular communication, just letting us know that progress is happening, perhaps, would have been reassuring for the sector that, in fact, these recommendations are being implemented. I know they have been working furiously and it is a big piece of work, but regular communication would be very helpful, I think.

Hon NICK GOIRAN: That form of regular communication, would it be of some assistance to the sector if there were actually some time lines associated with the progress of particular items?

Ms Glogowski: Absolutely.

Dr Campbell: Yes. Could I give an example of during the COVID-19 planning? The cancer and palliative care network at the health department did a huge amount of work which was very visible, I think. I had colleagues from outside of palliative care saying to me that the palliative care network

at the health department seemed to be doing a lot of work and putting out some very useful resources as part of COVID planning. Clearly, they have the ability to do it.

The CHAIR: Moving on to rural and regional palliative care, the WACHS model—how well has that been received by stakeholders in the sector? How are you finding it?

Dr Campbell: I have only heard good feedback to date. I think it is still early days. It is obviously a complex model to put into place. I guess that as that rolls out, as people are employed into the clinical positions, we will have a better idea of what it actually means for people living in rural and remote areas with palliative care needs.

The CHAIR: Your submission notes that access to chaplaincy, psychology and psychiatry in rural and regional areas and proposes a linkage with the mental health sector to improve this. To what extent is this issue being addressed by the WACHS model?

Dr Campbell: I would have to take that on notice. I am not aware.

The CHAIR: Okay. Sure.

Ms Glogowski: If I could add, from a very superficial level, we did consult with WACHS staff as part of our lead-in to the submission. Certainly, while there was an emphasis on access to palliative care specialist physicians, there was not any particular mention about allied health or other services. That is not to say that that is not coming, but that certainly was not clearly articulated to us. If I might just pick up on the mental health comment that you made, a board member with Palliative Care WA has worked quite extensively in the mental health arena and is suggesting that there are some really successful initiatives that the mental health approach has used in terms of communicating with the community, engaging with community, informing recipients of mental health services. There was a suggestion that the palliative care approach might do well to build on some of those successes and consider some of those approaches. We have undertaken to do that. Again, we are in the very early stages of doing some research on what approaches they have used. It is a strengths approach. It is saying, “Look, some other sectors are doing some really good work. Let’s look at their approaches and see if we can build on that.”

The CHAIR: Moving back to community palliative care services, your submission states that the community services remain overwhelmed despite the additional funding announced in 2019. Could you please give more details about this, including which community services reported this?

Dr Campbell: In the metropolitan area we have Silver Chain hospice and the Metropolitan Palliative Care Consultancy Service, which is based out of Bethesda Hospital. Outside of metro Perth there are a number of different providers. Certainly, Silver Chain and MPaCCS have both reported that they are having to discharge a number of patients because of overwhelming referrals and demand for those services. When we did our sector consultation and we asked everyone who was presenting and asking questions whether they had noticed any difference in the resources they had since the end-of-life choices report came out, none of them had noted any increase in resources. There is a high level of demand. They are needing to discharge patients. I worked for Silver Chain hospice in 2013. It was very uncommon back then to discharge patients. It is because the demand for palliative care is increasing and patients are becoming more complex in their needs as well. I know for those services there are high rates of staff burnout and staff retiring that cannot be replaced. The community palliative care services do need better resourcing, I believe.

The CHAIR: Can you say what proportion of community palliative care is provided by Silver Chain? Do you have a view on that?

[11.00 am]

Dr Campbell: In the Perth metropolitan region, all of it! So MPaCCS, which is the other service I mentioned, covers areas that Silver Chain hospice is not contracted to cover—so that is residential aged care facilities, group home for people with disabilities and prisons for the most part. But for anyone that is living at home or in a facility that does not have a 24-hour nursing cover, Silver Chain hospice would provide the community palliative care.

The CHAIR: Right. And MPaCCS—any other organisations involved in other circumstances, though?

Dr Campbell: No, not for specialist palliative care.

The CHAIR: Now, several submissions have noted that carer involvement is essential to the provision of palliative care in the community. You have noted in the submission that provision of respite for carers is an ongoing challenge. Could you please expand on this and suggest what the reasons for it being such a difficulty are? Is it primarily around funding or what are your thoughts?

Dr Nicoletti: Caring for someone who is chronically ill and dying takes time. It is exhausting. It is 24 hours. It is unrelenting. A method of in-home respite where the family member could be removed for a period of time just to have a good sleep or go get their hair done—those sorts of services do not exist and the patient gets burnt out. The patient gets sick. The relative gets sick and they end up in hospital.

Dr Campbell: So there are different types of respite. There is residential respite, which is, for example, where the unwell person goes to stay in a nursing home for a period—that is if they are over 65 and have access through the aged-care assessment process. There used to be respite available in inpatient palliative care units, but they do not really have the capacity to do that anymore, and then there is another type of respite called in-home respite, which is where a carer comes into the home to provide that family member with some relief. Again, the access to that is often through the aged-care assessment program, which is only available to over-65s. There used to be a program funded by the commonwealth for emergency carer respite; that is no longer available. So you used to be able to get someone in at very short notice; say, if the person's usual caregiver, you know, had to go into hospital or had some emergency, that is no longer available. It is partly due to changes in aged-care funding. It is due to the changes with NDIS that has made it much more difficult to access these types of services and due to the increased demands on inpatient palliative care units, as well, that they are no longer able to provide respite care.

Ms Glogowski: If I could just add, the new carers' gateway service, which is the federally funded service that replaced the respite service that Dr Campbell has referred to—the new carer gateway service has a much reduced capacity to provide respite. In fact, they very clearly state that it is not emergency respite; it is only planned respite. So, picking up on what Dr Nicoletti said, I think it is really important to recognise that for someone perhaps in the last 12 months of life, the burden on the carer is enormous. So we are talking about physical care; we are talking about the emotional burden and the fact that often the carer is supporting other family members who are also being really challenged about the fact that their loved one is in the last 12 months of life. So I think we really do have a really significant issue in our community where we are not recognising that in fact the carer is the middle and the beginning and often the end of the delivery of quality palliative care; that if we do not support the carer, then the implication of that is the person is often admitted to hospital. Often that may be in direct conflict with their advance care plan where they have said, "I want to die at home. I want to have my cat in the bedroom and I want to have the dog at the foot of my bed. I want to have my loved ones around me in the home that I have lived in for the last 40 years." So I think we really undervalue our carers. We do not recognise their needs and it absolutely, as you say, Dr Nicoletti, often the consequence of that is that we have carers who then become unwell themselves because the burden is so significant.

Hon NICK GOIRAN: Mr Chairman, just further to this point.

You mentioned there was a previous program for respite for inpatient setting? Just explain, how would that work?

Dr Campbell: So, for example, in the hospice, like Murdoch or Bethesda or Kalamunda, you could admit a person for a week or two to the hospice to provide some respite to their carer.

Hon NICK GOIRAN: Okay. All right. So they were at home —

Dr Campbell: They were normally living at home with a family member caring for them and we would admit them into the hospice for a week or two. They would receive, you know, care in the hospice as well, but then it allowed their family member who provides the care a bit of a break.

Hon NICK GOIRAN: Okay. So it was using the hospice as a respite for what was otherwise community-provided care.

Dr Campbell: Yes.

Hon NICK GOIRAN: That is no longer available. If you wanted to get into the hospice, you would have to qualify in the ordinary way.

Dr Nicoletti: You would have to be quite sick.

Hon NICK GOIRAN: Yes.

Dr Nicoletti: Yes. It was always agreed in hospices that people booking for respite that if there was an urgent pain symptom or actively dying person, they would take priority for that bed. There were not two beds earmarked “respite”, and so sometimes those patients had to be put off—the respite patients—because the other patients take priority, and they took so much priority that there is no longer any respite.

Hon NICK GOIRAN: So at the moment the only reason that does not happen is because of the funding model?

Dr Nicoletti: Triaging —

Hon ALISON XAMON: Shortage of beds.

Dr Nicoletti: Well, yes. It is the shortage of hospice beds and triaging—who comes in—and respite is right down the bottom.

Hon NICK GOIRAN: Okay. So a person could apply to a hospice for respite and there would be no funding barrier to that happening; it is just a question of demand exceeding?

Dr Nicoletti: That is right.

Hon KYLE McGINN: So what was the original funding for, then, that was taken away?

Hon NICK GOIRAN: No, I do not think there was any.

Dr Campbell: There was no funding taken away. It is just that the demand for the beds has increased whilst the number of beds has not increased. So in the last 10 years since I started working in palliative care, the population of Western Australia has got older and older; there is more and more people with chronic and life-limiting illnesses; and there is more and more demand for those inpatient palliative care beds for people who are having severe symptoms that need managing or for people who are in those last days/weeks of life who go there for the end-of-life care.

Hon NICK GOIRAN: So the problem then appears to be that the funding model does not factor in a component for respite.

Dr Nicoletti: Not as a respite in an inpatient palliative care unit. It is about number of beds. If there were twice as many beds in the state, I suspect the hospices would open up to respite again.

Hon NICK GOIRAN: Sure, but no government of either persuasion is going to provide double the amount of beds without a rationale for it, and what I am saying as it sounds like part of the rationale for an increase in funding in terms of the bed count would be to allow a proportion for respite.

Dr Nicoletti: Some planned respite. Yes.

Dr Campbell: Yes.

Hon NICK GOIRAN: Yes, okay.

Mr R.S. LOVE: I think you have mentioned, and other people have mentioned, that the NDIS has been put forward as an avenue of funding for people who are palliative but then they fall through the cracks—they cannot actually get through the application. So, has that left the introduction of the NDIS and is that the trigger point that has left under-65s in a very precarious situation? Is there a need for a special palliative fund, in your view, for those under-65s not only to provide, I suppose, for the carers, but also to provide some level of support to those people who obviously cannot earn an income or do anything to support themselves? Is that a big hole that has been identified in your submissions?

Dr Campbell: In short, yes. People under 65 with palliative care needs who also had needs for either care in the home or residential care—it has always been an issue in getting access to that. We have a lot of people under 65 who are dying in the next few months who then have to go into a nursing home with much older people and it is not an appropriate environment, so there is always been an issue. But since the introduction of NDIS, it has become much, much worse. The previous process was that you would apply to Disability Services; we would very quickly get a response from disabilities within a day or two to say, “This person is not eligible for our services” and then we could refer them on to the aged-care assessment teams, who would then assess them.

[11.10 am]

Although the person was under 65 and aged-care services are not ideal for an under-65, at least there were some services, but now, with NDIS, it is a very lengthy assessment process—months before we can even get that reply saying, “No, this person is not appropriate for NDIS” and then explore other avenues. So it has made it worse, and we are hearing that from all across the sector.

Dr Nicoletti: I agree.

The CHAIR: Staying with carers, with the training of carers—this is something you raised in your submission, and their ability to deliver clinical support in the home and also to provide practical advice and support. Are either of those needs being addressed by the additional funding that was announced last year?

Dr Campbell: Not that I am aware of, and that is something that has come up recurrently in our consultations, and Carers WA is a member of Palliative Care WA, which has also identified that as a large need. Often when someone is a carer, they do not have the ability to come into hospital or wherever and learn about things, they need some resources that they can access in the home to teach them about the practicalities of caring. But also if they are going to be, for example, administering medication like strong pain killers, they want education around that to make sure they are doing it safely.

The CHAIR: Next question relates to compassionate communities, and we have all got a document here outlining it. You are enthusiastic about the uptake across WA. Could you outline the approach and how it could contribute to the delivery of the palliative care service across the state?

Ms Glogowski: So, “compassionate communities” is an overarching term for a lot of different approaches, but it is basically about activating community to support people in the last stage of their lives. For example, some of the compassionate communities activities that we are involved in, we are supporting the development of a group called Last Words, so volunteers who work with people who are in palliative care to record their life story. For many people this is a really powerful approach, a very powerful thing to do in the last stage of their life. Many of us want to leave a legacy. Some people do not have the skill or wherewithal to do that for themselves, so what we are doing is supporting a group of volunteers. These are unpaid, often professional writers who are prepared to spend many hours with people within palliative care service and/or their home to record their life story. We are also aware and working with other compassionate community groups who are activating volunteers to do home visiting, so people who will go into a person’s home who is receiving palliative care and spend time with them, take their dogs for walks, do a whole raft of things to support that person in their last stage of life. Other compassionate communities initiatives are much more neighbourhood based, so that is the notion of activating a support network of people around a person to mow their lawns, to walk their dogs, to come in and vacuum clean the floors and do a weekly shop, and all of that sort of stuff. In many ways the work that compassionate communities is doing now is what communities might have done in a previous generation. So, that notion of community, recognising that someone is dying and everybody says, “Well, I’ll do this,” and “I’ll do that”, and “I’ll do something else.” It is recognising that for many people a sense of community is less strong in the 2000s, so the notion of compassionate communities is to try and address that, activate volunteerism around a person who is dying to provide a whole range of supports.

The CHAIR: Have you got any thoughts on how it could be rolled out more widely across the state, and does it need funding to do that?

Ms Glogowski: Look, it needs some funding, of course, but funding is not what this is about. It is about awareness; it is about encouraging people’s sense that, actually, you can play an important part in the last stage of life of somebody. We certainly at Palliative Care WA are building a network of compassionate communities initiatives across WA. We would like to have compassionate communities symposiums. We would like to engage with the media in having a conversation about compassionate communities. It is recognising the importance of the last stage of life of us and getting it on the agenda really, not seeing this is something that we do not want to talk about and that we do not want to hear about. It is about, okay, let us have a conversation about this. People do die and let us debate that and activate that willingness within community to do what we can.

Dr Nicoletti: But some funding is needed to get it up and going.

Ms Glogowski: Yes, yes.

The CHAIR: To manage, to organise, sure.

Dr Campbell: You do need a small amount of staffing to manage the volunteers, whether that is a half-day or one day a week, depending on the size of the compassionate communities program.

Hon NICK GOIRAN: I am glad that we are discussing this. It is a very important item, as the witnesses have identified. It is an area where some very useful improvements can be made at modest investments. Now, we heard yesterday in some of our hearings about a pilot program that is being funded by the commonwealth in the Albany–great southern area. Over the years, in a different capacity, I have heard much about the compassionate communities model in the Busselton area. We were not able to get from the witnesses yesterday clarity on this and we do have Busselton hospice coming in later today. Are you able to share with us, to the extent that you are aware, how long has the compassionate communities model been operating in Busselton; is it operating

anywhere else other than Busselton; and to what extent has that been funded by the state or federally, or is that just something that the local community has developed? I know there is a lot of questions there.

Ms Glogowski: I am not privy to the absolute funding details, but I understand the great southern initiative and the Busselton one—they are a three-year pilot—are now coming to the end of their pilot status, so an evaluation, I understand, is imminent. We have not had a lot of direct involvement in those particular initiatives, so from our perspective we have contacted lots of compassionate community models. For those two federally funded pilots, we were interested to look at the evaluation to see what we could learn from that and, with those learnings, to support other initiatives. In terms of how long compassionate communities has been around, that label, that title, has been out there for with quite some time. But, in fact, for example, there is a group in Margaret River called Margaret River Angels that has been operating, I think, for at least a decade, they perhaps initially did not see themselves as a compassionate communities initiative; it was community-driven, “Okay, we are aware of a few people in our community who are dying, what can we do to support them?”

Hon NICK GOIRAN: They were doing it without the label.

Ms Glogowski: They were doing it without the label, absolutely. Now we are seeing them as a compassionate communities initiative. I think what that does is reinforce the fact that compassionate communities can look quite different in different communities, so it is very much a community development approach. That is why I was suggesting that the emphasis, while we need some facilitation and some support, it has to come from the community; they have to own it, because you cannot fly in and impose it on a community, because it will just not get legs. It has to be owned by the community and then we can support, empower, train, facilitate and share, but it is very much community based.

Hon ALISON XAMON: Hence, the need to awareness-raise.

Ms Glogowski: Absolutely.

[11.20 am]

Hon ALISON XAMON: Hence the need to raise awareness.

Ms Glogowski: Absolutely, because then people go, “Oh yes, we can do that. Yeah, I’d love to do that”.

Hon ALISON XAMON: “I’ll walk the dogs.”

Ms Glogowski: Yes!

Dr Campbell: That is another thing where it builds upon, say, the Margaret River Angels model, is linking the people with need to the people that have the capacity to volunteer, because you might have a community group, say a sporting group, who have some capacity to volunteer, but they do not actually know anyone or they are not aware of anyone who has those needs to fulfil.

Hon ALISON XAMON: Or have the capacity to coordinate it.

Dr Campbell: Exactly; someone to link in the person whose dog needs walking with the person who is willing to walk their dog. That is where compassionate communities can really come to the fore.

Mr R.S. LOVE: Are you aware of any of these types of situations which exist in the metropolitan area? Because I can see it working in country areas. In my own electorate I know Toodyay Locals Care already do that sort of thing. With the COVID thing, there is a group kicked off in Northampton and it does occur to me that in most of the towns there is some sort of a group that has got up

around COVID, but probably that could be the beginnings of an approach like this. Are you aware of it actually working in the metropolitan area?

Ms Glogowski: Also, the Lasting Words group, the group that I was talking about people helping others to write their life story, that is a metropolitan-based service. We do not have that in any regional or rural locations at the moment. Look, I think to be fair there are probably a raft of metro initiatives that we just have not connected with yet. Again, I go back to the fact that people—I think you have said it yourself, people are actually doing this work but not seeing it under a “compassionate communities” banner.

Hon NICK GOIRAN: It would be routinely happening, I would dare say, in the metropolitan area in a number of churches. I would think it would be standard practice, but again done without the label.

Dr Campbell: Going back to the dog walking, there is a group called Pets of Older Persons who connect older people —

Dr Nicoletti: POOPS.

Dr Campbell: Yes, POOPS. That is metropolitan based.

The CHAIR: You touched on the issue of navigators and made the reference to the voluntary assisted dying navigators. The Department of Health’s report “WA End-of-Life and Palliative Care Strategy 2018–2028: Implementation Plan One 2020–2022” has this including some funding. Are you aware of progress of this navigator model at all?

The Witnesses: No.

Ms Glogowski: Could I comment that my understanding is they see the development of the hotline as in part providing some navigation support to people who were in that service.

Dr Nicoletti: It is more general than what we were talking about which was more specific.

Dr Campbell: We were discussing more of a case management–type model.

Hon NICK GOIRAN: We did have a discussion I think with a witness yesterday along the lines of, you know, if it is good enough to have a VAD navigator, surely it is good enough to have a palliative care one.

Ms Glogowski: Absolutely, yes.

The CHAIR: Your submission notes that telehealth has a great role to play. Are there any lessons to be learnt from the COVID-19 experience to date and its use of the telehealth approach?

Dr Nicoletti: Well, yes, I suppose. With COVID, a lot of outpatient clinics became telehealth instantly. Not every palliative care visit can be a telehealth, but I think a lot of them could be, particularly after you first get to know the patient. So yes, I think telehealth. It is not just for people who are outer-metropolitan or rural; it should be done for all people. I think we perhaps in this day and age are over doing the personal home visit or the personal outpatient visit.

The CHAIR: Next one is in relation to in-home services, you note that there is a need for more rapid access to formal in-home care, including respite care in order to support carers and assist people with palliative care needs to stay at home and that it is a common reason for otherwise avoidable hospitalisation for people with palliative care needs. As part of the funding announced in 2019, \$2 million has been allocated to the provision of a domiciliary home care service in rural and regional WA. Do you think there is a need for this to also be funded in the metro area?

Dr Campbell: Yes.

The CHAIR: Great. Are you aware of any allocation in the funding announcements for respite care? We have touched on that.

Dr Campbell: No, I am not aware of any.

The CHAIR: The submission mentions lessons to be learnt from COVID experience referred to in your submission about the expedited assessment for in-home care services. Could you expand on those lessons?

Dr Campbell: I think there are some members of the sector who feel that specialist palliative care services should be able to refer directly for access to, for example, aged-care services rather than having to go through another body being an aged-care assessment team or a regional assessment service, which are both commonwealth funded programs. That would then be more efficient in being able to access the required services. It goes back to historically before we had this commonwealth program there was a program called home and community care, which was much easier to access.

Hon NICK GOIRAN: Just in regard to that provision of funding in rural and regional Western Australia, the \$2 million for the domiciliary home care services, can you just explain to us what type of respite care does that mean?

Dr Campbell: I am not aware of the details of that funding.

Hon NICK GOIRAN: But it is a form of respite care? Taking the conversation from where we were earlier about the needs for that to happen, this would be one form of that?

Dr Campbell: Potentially.

Dr Nicoletti: I am going to guess it is in-home respite, but I do not know.

Hon NICK GOIRAN: It is really a question for the Department of Health.

The Witnesses: Yes.

Mr R.S. LOVE: This is the money that we have referred to before, I think, that was no longer available because of the NDIS change, which has now been put into regional areas.

Dr Campbell: No. That was always commonwealth.

Mr R.S. LOVE: Yes, but this is to make up for that gap in regional areas. Is that not the case?

Dr Campbell: I do not know.

Hon NICK GOIRAN: The Department of Health.

Mr R.S. LOVE: We will ask the Department of Health.

The CHAIR: Just looking at residential aged care. Your submission states that residential aged-care facilities are important providers of palliative care. Other submissions have noted there is limited palliative care training and medical cover in residential aged-care facilities. The AMA WA has submitted that because of these limitations, residential aged-care facilities are wrongly considered to be palliative care services. Do you have any comments about that?

Ms Glogowski: Can I just start out by making a comment that is a bit jarring for many people in the palliative care sector I think, where residential aged-care services indicate that they provide palliative care. But I think the reality is, and certainly my understanding—I am not an expert in this space—of communicating with residential aged-care providers is that when you scratch the service they actually have little understanding about the provision of quality palliative care. Certainly, we have heard some—you know we have a royal commission into aged care which is delving into this into much more detail—many aged-care providers' default position is to send their residents to

hospital. Again, that is in contravention of their advance care plan, where people say, “I wish to die at home”. If they are resident in aged care, then the aged-care facility is their home.

Hon NICK GOIRAN: Expect if it is an emergency.

Ms Glogowski: Absolutely, but I think, unfortunately, the residential aged-care sector do not see themselves as part of the palliative care sector. They do not seem to recognise that they are part of dying and death, that most of their residents will die in their facility, but they are not seeing that as a priority part of their service delivery model.

Dr Nicoletti: My heart is broken many times where a person from residential aged care comes into ED with a care plan that has been written with the care facility saying, “I don’t want any active treatment, I want to die in this facility and I do not want to go to hospital” and they end up in ED—not in my ED, but the ED of the hospital I work for.

[11.30 am]

But when you try to work that out, the nursing home has got limited registered nurses, perhaps no registered nurse on at the time. This patient is distressed. What else are they going to do? The family are often distressed because the patient has come to hospital. So it is wrong; it is absolutely wrong and it should not happen. They end up in hospital, they are distressed, so they need to be admitted so that we can make them more comfortable. The next day, when we are ready to send them back to the nursing home, the family say “We do not want them to go back to the nursing home because they do not have the care you have here.” So, I am all for people dying in nursing homes, but we cannot make people suffer as they die. If we do not support nursing homes not just to upskill but to have registered nurses at the very least on every shift, enough for the residents that they have, we cannot—it is a problem. It is a problem, and people’s expressed wishes are defied at the end of life.

Hon NICK GOIRAN: Is this not the point of having MPaCCS, though?

Dr Nicoletti: They are a consultative service that work nine to five, Monday to Friday. They are not there on Sunday afternoon or Monday afternoon, and they will not see people urgently. It is not part of their brief; they are not funded for that, or staffed. They cannot see people as an urgent thing.

Hon NICK GOIRAN: So is one solution to this that MPaCCS needs to be available seven days a week, 24 hours a day?

Dr Nicoletti: And make them more than a consultative service, then, because it is crisis situations.

Hon NICK GOIRAN: But would it be more than a consultative service? We are just saying that they continue to consult but they are able to be consulted at all hours.

Dr Nicoletti: And react immediately to a crisis, which is not the model that they have at the moment.

Hon NICK GOIRAN: No, they are trying to equip and —

Dr Nicoletti: Yes.

Hon NICK GOIRAN: But I think that is your point as well—that the aged care providers are not currently equipped.

Dr Nicoletti: No.

Hon NICK GOIRAN: They say that they are doing palliative care, but actually they are not.

Dr Nicoletti: They are not; exactly.

Hon NICK GOIRAN: So do we not need to have more MPaCCS training and equipping of these people?

Dr Nicoletti: Or perhaps nursing homes need to be better staffed with more senior staff that do not panic.

Dr Campbell: To administer drugs such as morphine, which most people at the end of life require to help with their symptoms, does require a registered nurse, and a lot of aged-care facilities do not have registered nurses on duty 24 hours. There are some residential aged-care facilities that do it very well, and they do make good use of MPaCCS for upskilling and education and advice on what equipment to use; they do get Silver Chain hospice involved for those last few days of life so that the registered nurses from Silver Chain come into the facility and give the medications. There is another service funded by WA Health called “Residential Care Line”, which is led by a nurse practitioner; that also is not a 24-hour service but also can assist in these scenarios. But I do agree that a lot of aged-care residents with palliative care needs do end up in emergency departments, because it is all well and good to say, “We’ve done an advance care plan and this person doesn’t want to come into hospital”, but you cannot also leave them suffering, extremely short of breath or in pain in the middle of the night and wait for a doctor to come in the next morning. I have worked for MPaCCS previously. The consultative nature means that the clinical governance or care of the patient remains under the general practitioner, not the doctors who work for MPaCCS, so we can ask the GP if they are happy for us to prescribe medications, but you cannot just go in there and write up medications, change the med charts and things like that. Most GPs are happy for the palliative care specialists to do that for them, but some do not want it to happen.

Mr R.S. LOVE: So the MPaCCS is really there to help to train and enable the residential aged-care providers to provide better palliative care, because we heard that there is a very limited understanding.

Dr Campbell: That is a part of their role, and they also do a lot of case conferencing, so advance care planning, where they meet with the resident and/or their family members and perhaps the GP and the staff of the facility to make plans for the future of what is going to happen.

Mr R.S. LOVE: But the carriage of the plan ideally should be carried out by the aged-care facility, and they need to have the staff available to actually do them.

Dr Nicoletti: That is my point, yes.

Mr R.S. LOVE: It does seem to me that there is this definitional problem between palliative care and residential aged care, because I think, statistically, when a person gets over the age of 90, the question of whether you would be surprised if they died this year would have to be no, not really. To me, there is a definite grey area or a Venn diagram where there would be a lot of crossover here between the two, and maybe instead of thinking or wrongly considering that they are a palliative care service in the sense of being a palliative care service for persons recovering from some heroic surgery or a very acute situation, but people in long-term chronic decline are in those homes, and, sooner or later, there is going to be an expectation that their life will wind up very shortly, but for a number of those people, that might be when they are still considered to be quite healthy, that their life is not going to be very long. Is it the case that people in residential aged-care facilities are now going into those facilities themselves at a later stage of life —

Dr Campbell: Yes.

Mr R.S. LOVE: — than what was previously the case because they are being encouraged to stay at home, so do we need to change the whole concept of what an aged-care facility is to actually be an appropriately staffed palliative care facility?

Dr Campbell: Absolutely. People going into residential aged care do have much more complex healthcare needs as well as personal care needs now than they did previously, because people are,

as you said, encouraged to stay at home, and most people choose to stay at home for longer before going into residential aged care.

Hon NICK GOIRAN: The final question from me on this point is: do you happen to know if there are residential aged-care facilities in Western Australia that do have a registered nurse present at all times?

Dr Campbell: No; we will have to take that on notice. There are some facilities that have really good linkages with aged-care nurse practitioners and GPs whose real focus is on good palliative care for their residents.

Hon ALISON XAMON: Do you want to name who they are so I can know where I need to end up?

Mr R.S. LOVE: Your recommendation!

Dr Campbell: I know in the ACT there is a really good model for palliative care in residential care called the “Inspired” model, wherein a palliative care nurse practitioner helps the staff in the aged-care facility do palliative care needs rounds, where they go to the residents and see what their needs are from a palliative care perspective to put plans in place, and that was quite a successful trial in Canberra; then the ACT government funded more broadly for all aged-care facilities.

The CHAIR: Shall we take that as question on notice 2, that you will let us know if there are any?

Dr Campbell: Any nursing homes with 24-hour RNs?

Hon NICK GOIRAN: I do not know; I do not want to ask you to take a question on notice that is not really sort of in the scope of Palliative Care WA. Is that in your remit?

Dr Campbell: I can easily find it out, but it is not really our core business.

Hon NICK GOIRAN: Look, it is unfair of me.

The CHAIR: Okay, we will leave that. Is there any equivalent service to MPaCCS in regional areas?

Dr Campbell: Again, I think Albany has an arrangement with Hall and Prior, but I am not sure of the details of that. I do not want to be too critical. In other states, there is no equivalent to MPaCCS, so I think that, to give credit, at least we do have that, and this residential care line service that I mentioned as well, which is being expanded.

Dr Nicoletti: I was going to say, Elissa, in other states, the equivalent of Silver Chain would go into nursing homes.

Dr Campbell: Okay.

Dr Nicoletti: So we are filling a gap that may not exist in other states.

Hon ALISON XAMON: Thank you.

The CHAIR: Some submissions have noted that recipients of aged care services both in residential care and at home require transfer to hospital when their palliative care needs cannot be met, and that the transfer to hospital is not always timely or well managed. Have you got suggestions on how that could be improved? I know it comes back to what we were saying before.

Dr Campbell: I am not sure how to interpret it, if the timeliness is referring to the fact that it is happening too late in the disease course or whether some intervention could have happened earlier on to prevent them needing to be transferred to hospital at all. But I am not really sure. Is that from our submission?

Hon NICK GOIRAN: No, other submissions.

The CHAIR: Yes.

Dr Campbell: Okay.

The CHAIR: Okay, we will leave that. You mention in relation to advance care planning that many aged-care facilities do not share their ACP forms with health providers. Could you expand on that?

[11.40 am]

Ms Glogowski: One of the issues that I am becoming aware of is that people are recognising the importance of advance care planning, but they have concerns with the advance health directive form that is currently in place, so what we are starting to see is a proliferation of individual forms. Agencies are developing up their own approach to advance care planning, which for me is a huge risk. I suppose people are responding to their customers' needs. They see that in some circumstances their customers' needs are different from other customers' needs, so they are customising their forms. What we are now at risk of is that we have a proliferation of different types of advance care planning approaches and forms, and so then that multiplies the risk of when these forms come into emergency or into a palliative care service, does the palliative care physician look at this form and go, "Does this have common law directive status? Does it have legislative status? Is this the most recent form available? Does this hold true?" You know, I think it again reinforces the work that we need to do in the advance care planning space to get consistency—to get consistency of understanding and consistency of forms—and then, hopefully, that will lead to greater comfort in sharing that documentation. I think, yes, there is a lot of work to be done in that space.

The CHAIR: Your submission notes that complicated entry criteria for palliative care services, as well as complex clinical language, makes exploring options difficult. You made this comment especially in relation to carers from a CALD background, but do you think this is an issue for patients and families and carers generally?

Dr Campbell: Yes. It is an issue for healthcare professionals as well—to know this hospice has these admitting criteria and this service has these criteria. Someone I might be able to refer to the palliative care service at Sir Charles Gairdner Hospital might not be eligible for Silver Chain hospice, and again that is because of their funding and resourcing that they just cannot take on everyone with palliative care needs.

The CHAIR: So what could be done to simplify the criteria or improve the way criteria are communicated?

Dr Campbell: I think increase the resourcing so that they are not so limited in who they can take on. Also, a navigator service could be helpful in that as well.

The CHAIR: Great. Now, coming back to advance care planning and goals of patient care, you mentioned that COVID-19 had a significant impact on the uptake of ACPs. Could you please expand on that, particularly: why did that occur and how significant was the impact?

Ms Glogowski: From our perspective, we have now recommenced going into community. During the March to recent period, we have been doing our community engagement online. We have now gone back to face-to-face delivery and we are noticing a big increase in uptake. People have come face to face with their mortality as a result of COVID-19, and I think that has enhanced people's awareness of advance care planning. In terms of goals of patient care, from our perspective we can see an incredible connection between advance care planning and goals of patient care. What we are now saying to community when we talk about advance care planning is that if and when you develop chronic disease or you have had a number of frequent admissions to hospital and you have a physician that says, "I think it's time that we had a goals of patient care discussion", this is advance care planning; this is a continuation of that discussion. What we are attempting to do is to empower people to give them that vocabulary, to give them some understanding of the terms that they will

be hearing in this discussion. Certainly Simon Towler and others have very clearly articulated that they can tell the difference between people who have engaged in advance care planning and those who have not. People who have engaged in advance care planning, who have explored their values and their priorities, have some death literacy, so that when they have the goals of patient care discussion in the hospital setting, they are going, “Ah, I’ve been here before. I’ve given some thought to this.” So they can engage more fully and perhaps more easily in the goals of patient care discussion because they have been empowered at a much earlier time, and perhaps at a much less stressful time. They have explored what they want and potentially what they do not want, so when the goals of patient care discussion happens, and that will potentially be more stressful because they are experiencing some clinical deterioration, they hopefully, and certainly Simon Towler talks to this fact, have an increased capacity to do that.

Mr Z.R.F. KIRKUP: Certainly it seems, when I have held a number of these forums in my district for example, in the level of comfort about the discussion of, I guess, end-of-life choices, you get the real sense of empowerment. I have had a number of people come into my office subsequent to talk about their advance health directive and things like that, and they do seem much more clear about the pathways that they want to hopefully proceed with at that point in time. The challenge seems to continually be, from my perspective, the access to those services and what that looks like. I agree with you: it is one thing to be quite literate of it, but it is another thing to actually say this is a feasible option, which is increasingly what I find. I find that there are a number of people, particularly in village circumstances for example—aged-care villages and the like—who would prefer to just die at home, and it is often in the absence of any support that could otherwise be offered to them.

Ms Glogowski: Yes.

The CHAIR: I think in this session we are probably going to have time for one question, but it is a very important one, and it is about the concept of decision-making—and you raised this in your submission—in relation to people with disabilities and people experiencing cognitive decline. Could you please explain further what supported decision-making involves in a palliative care context, especially for people with disabilities and those in cognitive decline?

Ms Glogowski: Perhaps I will start out and then I will invite my clinical colleagues to share their perspective. Certainly, in our consultations with the organisation People with Disabilities and Alzheimer’s WA, there was a recognition—I will probably deal with them separately. People with Disabilities were very clear to say that they often feel disempowered in the health system, and that unfortunately some health professionals will make assumptions about their capacity and actually will make assumptions about the decisions that they want to make. They will assume that because they are highly disabled, that perhaps in the event of COVID-19 and becoming infected, they would not necessarily want all treatments known to medical science. They certainly were sharing a sense of some alienation from the health system, so for them, the opportunity to engage in advance care planning was even more powerful because it was their opportunity to really clearly articulate what their wishes were. That also applied to our consultation with Alzheimer’s WA. I think it was Alzheimer’s WA where the whole notion of supported decision-making was much stronger, and a recognition that once a person was diagnosed with some form of cognitive decline, it did not mean that they did not have capacity to make some decisions about what they wanted for the last stage of their lives, a recognition that it is not just you have capacity and now you do not have capacity, and the opportunity for everybody—health professionals, their family, friends and their support services—to work with them in a joined up way to continually provide them with opportunities to make decisions about the things that they can make decisions about. It was very clearly shared that for people experiencing the beginning of cognitive decline, one of their greatest fears was to lose the capacity to make decisions about things that affected them.

The notion of supported decision-making, which Palliative Care WA wants to really work with Alzheimer's WA and other organisations to progress, is that notion of working with people to make decisions about the things that they can for as long as they can. We think, again, in that notion of empowerment, that is critically important.

[11.50 am]

Hon NICK GOIRAN: I know that we are running out of or over time, so I just ask the witnesses to take this question on notice if they would. In the end-of-life choices committee inquiry, Palliative Care WA sent a letter to the committee, which is on the public record, and it was dated 15 May 2018. You set out a number of what you referred to as “novel models” that should be considered. Unfortunately, that committee, for reasons best known to it, decided not to comment at all in respect to that particular issue. I think it would be of benefit to this committee if you could come back to us to indicate whether you still hold the view that those novel models are worthy of consideration or whether there has been any adaptation to that, noting that the letter is some two years old now. In that same context, I think it would benefit the committee if you would provide us with your view as to whether any of the first 13 findings and six recommendations found in the minority report, which was appended to that particular report, are worthy of inclusion by this committee in its inquiry.

The CHAIR: That is question on notice 2.

Dr Campbell: Can I just add to the discussion on supported decision-making?

The CHAIR: Sure.

Dr Campbell: I think supported decision-making is quite a new concept within clinical medicine that has arisen out of the United Nations declaration on the rights of people with disability. Traditionally, we have used a substitute decision-making model, which is what the Guardianship and Administration Act in WA supports. So I think that even amongst my colleagues in geriatric medicine, who are specialists in people with dementia, the awareness of supported decision-making is not great. Within the more general medical community, certainly it is not widespread or understood and there definitely is a tendency for us, as a medical profession, to go directly to the substitute decision-maker without even attempting to support a person with cognitive impairment in making decisions. We even see it with older people who do not have any cognitive impairment. If they are a little bit deaf, you often will see a doctor talking to a family member over the bed and leaving the person out of the conversation. I think that supported decision-making is very important, and certainly we look forward to working on that.

The CHAIR: We have 10 questions that we are not going to get to. Can we provide those to you as questions on notice as well?

Dr Campbell: Yes.

The CHAIR: That would be great. Ms Glogowski, Dr Campbell and Dr Nicoletti, thank you very much—excellent conversation and hearing and very valuable to us. A transcript of this hearing will be forwarded to you for correction. If you believe that any corrections should be made because of typographical or transcription errors, please indicate these corrections on the transcript. Errors of fact or substance must be corrected in a formal letter to the committee. When you receive your transcript of evidence, the committee will also advise you when to provide your answers to questions taken on notice. If you want to provide additional information or elaborate on particular points, you may provide supplementary evidence to the committee for consideration when you return your corrected transcript of evidence. Again, thank you so much.

Hearing concluded at 11.53 am
