

# **JOINT SELECT COMMITTEE ON END OF LIFE CHOICES**

**INQUIRY INTO THE NEED FOR LAWS IN WESTERN AUSTRALIA  
TO ALLOW CITIZENS TO MAKE INFORMED DECISIONS  
REGARDING THEIR OWN END OF LIFE CHOICES**



**TRANSCRIPT OF EVIDENCE  
TAKEN AT PERTH  
THURSDAY, 14 DECEMBER 2017**

**SESSION FOUR**

## **Members**

**Ms A. Sanderson, MLA (Chair)  
Hon Colin Holt, MLC (Deputy Chair)  
Hon Robin Chapple, MLC  
Hon Nick Goiran, MLC  
Mr J.E. McGrath, MLA  
Mr S.A. Millman, MLA  
Hon Dr Sally Talbot, MLC  
Mr R.R. Whitby, MLA**

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**Hearing commenced at 2.30 pm****Ms LANA GLOGOWSKI****Executive Officer, Palliative Care WA, examined:****Dr ELISSA MACKENZIE CAMPBELL****President, Palliative Care WA, examined:****Ms CAITLIN MAREE CALCUTT****Project Officer, Palliative Care WA, examined:****Ms NATALIE VERNA PANIZZA****Nurse Practitioner, Palliative Care, Royal Perth Hospital, examined:**

**The CHAIR:** We will open the session of the hearing. On behalf of the committee, I would like to thank you for agreeing to appear today to provide evidence in relation to the end-of-life-choices inquiry. My name is Amber-Jade Sanderson; I am the chair of the inquiry. We have Hon Dr Sally Talbot, MLC; Reece Whitby, MLA; Dr Jeannine Purdy, our principal research officer; Simon Millman, MLA; Hon Colin Holt, MLC; Hon Nick Goiran, MLC; and Hon Robin Chapple, MLC. The purpose of today's hearing is to discuss the current arrangements for end-of-life choices in Western Australia and to highlight any gaps that might exist. It is important you might understand that any deliberate misleading of this committee may be regarded as a contempt of Parliament. Your evidence is protected by parliamentary privilege; however, this privilege does not apply to anything you may say outside of today's proceedings. I advise that the proceedings of this hearing will be broadcast live within Parliament House and via the internet. Could you please introduce yourself for the record?

**Ms GLOGOWSKI:** My name is Lana Glogowski. I am the executive officer with Palliative Care WA. On my right is Dr Elissa Campbell. Elissa is a gerontologist and a palliative care physician. Next to Elissa is Natalie Panizza. Natalie is a nurse practitioner working in palliative care at Royal Perth Hospital. On my left is Cait Calcutt. Cait also works for Palliative Care WA and she is also a carer, or has been a carer, so her contribution this afternoon is to share some of her experiences as a carer, and we offer that opportunity to you. She will basically feed off the other presenters and share her experience of caring for her husband, who had a very long term series of illnesses, and eventually the family was offered palliative care. Cait will further explain that that was a significant turning point in their experience of her husband's illness.

**The CHAIR:** Thank you. Do you have any questions about your appearance today?

**Ms GLOGOWSKI:** No, I do not think so.

**The CHAIR:** Before we go through the direct questions, do you want to make a brief opening statement?

**Ms GLOGOWSKI:** Yes, please, if I could. Palliative Care WA is the peak body for palliative care in WA. Our membership includes individuals and organisations that support our mission of the awareness of and access to quality palliative care. Can I share with you that we do not receive any direct recurrent government funding. We are funded project by project by our membership fees, as well as support from sponsors and the philanthropic sector. So we are largely a volunteer organisation. We firmly believe that palliative care should be available to anyone—anyone—with a life-limiting

disease whose quality of life is being impacted by this illness. Palliative care focuses on the holistic needs of patients, so it is very important to recognise that palliative care is delivered not only to the patient, but to the family, as in Cait's story. It delivers care for management of pain and other symptom control, as well as the provision of physical, psychosocial, social and spiritual care. As I have said, it is important that we provide support to caregivers, as well as patients. I am sure you have heard some of this, but I will restate it. Palliative care is broadly divided into specialist palliative care and non-specialist palliative care. Specialist palliative care are services provided by health professional teams who have recognised qualifications or training in palliative care and who provide direct care to patients with complex palliative care needs or provide consultation services to support, advise and educate other healthcare teams who are providing end-of-life care. Non-specialist palliative care may be provided by a person's primary care team—for example, their GP or other doctor, such as geriatricians or oncologists, and other healthcare professionals such as nurses, OTs and social workers.

Recognising the complexity of the questions that you have presented to us and the limited time that we have, we would like to suggest that we deliver a short, overarching response to each of the areas and then, of course, you may follow up with specific questions if our overarching statement has not addressed the questions that you want.

**The CHAIR:** That sounds like an excellent idea.

**Ms GLOGOWSKI:** Do we get a gold star for that?

**The CHAIR:** You do—you get a tick!

**Hon ROBIN CHAPPLE:** No, it is an elephant stamp on the back of your hand!

**The CHAIR:** Okay—advance care planning.

**Ms GLOGOWSKI:** I understand that you had a very lengthy presentation on advance care planning. Obviously, we will restate the definition of “advance care planning”, but I would like to share with you some really exciting work that Palliative Care WA has been doing in this space. Advance care planning is a process by which people can express their values and wishes regarding future medical treatment should they no longer have the capacity to communicate those wishes. This includes discussions with loved ones. Certainly, from the work that PCWA has been doing, we see the discussion as the pivotal part of advance care planning. Advance care planning starts with a discussion and then a whole raft of actions can be taken as a result of that and may include the preparation of a written advance health directive or appointing an enduring power of guardianship. It is not limited to documents alone, with conversations being the critical first step. Advance care planning is a valuable tool to facilitate end-of-life choices that is unfortunately very underutilised in WA and poorly understood by the community and health providers.

PCWA, as our strategic priority, has decided to engage with the community to have discussions with them about advance care planning. Over the last three years, we have delivered workshops across the state. Unfortunately, we have not got to the Kimberley or the Pilbara yet, but we certainly have been visiting regional centres, as well as engaging with communities in Perth metro. Can I share with you that we have had as many as 80 participants in a workshop. On average, we get 35 to 40 people who come along, and these are members of the general public who have seen our advertising, our question about “Are you good to go?”, and are increasingly responding in their droves. Most of our participants are aged between 60 and 80, so we are getting an older cohort, but that is in part because we are delivering our workshops during business hours, so working people and pre-retirees unfortunately at this stage have not had the opportunity to engage in our workshops. Can I share with you at the outset that our focus was on completing the forms—so, completing the advance

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health directive, the enduring power of attorney, the enduring power of guardianship and all the mechanisms that go with that. Over the three years that we have been delivering our workshop, we have increasingly come to a place where we are saying to people, “It is about the conversation”. We are less focused on the legalese and much more focused on encouraging people to understand why advance care planning can be really advantageous to them. We have pared it right back in many ways and have got increasingly positive feedback from our attendees about that approach. Just to share with you that recently collating all our feedback from our workshops over the last year, 75 per cent of our attendees rated our workshops most satisfying on a five-point scale. I have a report that I could table and share with the committee, but the overwhelming number of our participants have walked out of our door and have said, “That’s absolutely fantastic. That’s what I’ve been wanting to find out. I’ve been trying to trawl the net and I just can’t get my head around all the components.” Probably, I think we need to recognise that they are older people rather than younger people and they are probably used to a face-to-face learning environment, perhaps more than younger people, so our face-to-face, highly interactive, highly responsive service delivery model has worked really well. The only other stat that I would share with you is that 98 per cent of them, and that is just under 500, have said that they would highly recommend our workshops to families and friends. We have a waiting list as well.

**The CHAIR:** That is good!

**Ms GLOGOWSKI:** Yes.

It is a highly effective model. PCWA’s view is that we need to be rolling that out big time. We need to be much better resourced to be able to get this message out, not only in a workshop format, because that is highly labour intensive, but there needs to be a raft of mechanisms to help people understand what advance care planning is and what the potential value of that is in terms of making their wishes known, helping their family to understand what their wishes are, potentially reducing hospitalisations and reducing unnecessary and unwanted treatments.

**The CHAIR:** Do we have any questions about advance care planning?

**Hon Dr SALLY TALBOT:** Did you do any follow-ups to see how many people went on to complete a —

**Ms GLOGOWSKI:** No, that is our next stage. We are potentially getting some more funding from the health department to move into stage 2 and we are working with Associate Professor Moira O’Connor at Curtin University to work up an evaluation process where we do precisely that—that is, we go to the people who have already done our workshops, as well as our potential future attendees, and find out what level of behaviour change the workshop has resulted in.

**Hon Dr SALLY TALBOT:** During the workshops, do you pick up any substantive comments about the process? Do people find it arduous or confusing? You said they cannot find the forms, but are there actually substantive things about the process, apart from not being able to find where it is on the internet?

**Ms GLOGOWSKI:** Yes. You will not be able to see this from where you are seated, but we absolutely recognise the complexity of the advance care planning process, so we have worked up a very simple pie chart or pinwheel that plots the eight main components of advance care planning from our perspective. I have to tell you that our participants have looked at this and have gone, “Thank goodness”—something that is high level that gives them a big picture of how all of these components work together. We repeatedly say to people, “Not all of these components are going to fit for you. Some will be applicable; some you might do now; some you might do later.” Certainly, it is complex; there is a lot of it and so we are really focusing on trying to simplify it as much as we

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can. The other thing in response to your question is that we actually run our workshops over two weeks, so they come for a morning session for three hours and then we give them one or two weeks in between the two workshops and they come back for the second. That allows them time to absorb the material that we have presented in the first workshop. If they have got more questions, they can ask them at the second workshop. We find that works really well in terms of allowing them reflective time to get their head around the complexity of advance care planning.

[2.45 pm]

**Hon COLIN HOLT:** Did you charge for the workshops?

**Ms GLOGOWSKI:** No. We got funding from the Health Department to deliver those workshops. Initially, we got funding from Lotterywest to pilot some workshops to see how they might work. We are on a process of continuous improvement. As I said, our workshops from day one to now look very different, but we are increasingly getting fantastic feedback.

**Hon COLIN HOLT:** Have you done them in regional Western Australia?

**Ms GLOGOWSKI:** We have done Bunbury and Greenough. Can I share with you? We went into some outbuildings in Greenough, in the outdoors, with no technology, no power point, no nothing, and had a conversation with carers in that environment. They, similarly, found the workshops really —

**Hon COLIN HOLT:** Just Bunbury and Greenough?

**Ms GLOGOWSKI:** And Geraldton.

**Ms CALCUTT:** We received funding to deliver in only two regional areas. Can I also respond additionally to your comments—I coordinate the workshops as part of my role with Palliative Care WA, and Lana facilitates them and develops the program—and also from my personal experience? The “advance care planning tool”, as we refer to them, that people struggle with the most is the advanced health directive. Often the feedback is that they do not have the words; they do not know what words to use. Obviously, most people do not have a medical or health professional background, and, really, it requires the assistance of health professionals to be able to complete that form. It is not right for everyone, depending on where you are in terms of your own health trajectory. In my personal case, when doing it with my partner, even though we had a long interaction and had increased our health literacy quite substantially through his eight years of illness, we still required assistance from, thankfully, the Silver Chain hospice doctor to enable us to complete it. We just would not have been able to do it on our own despite both of us being university educated et cetera. That is the challenge for a lot of people. They are worried that they will say the wrong thing. People will also say that if it is not written correctly, then it is not valuable or useful for treating health professionals. When we do our workshops, we recommend that people go to see their GP to talk about the advanced health directive and to ask for assistance to complete it, and that then brings its own set of challenges as well.

**Ms GLOGOWSKI:** If I can add to that, in our next raft of workshops we are planning specific workshops to assist people to complete the documentation, so we will have expertise on site to actually sit down with people one-on-one and help them complete that documentation.

**Hon NICK GOIRAN:** These workshops have been going on for three years?

**Ms GLOGOWSKI:** Yes.

**Hon NICK GOIRAN:** The purpose of them is to better educate the community. Is an assessment done at the start of the workshop to gauge their level of understanding?

**Ms GLOGOWSKI:** Yes. We do pre and post-surveys. All of that data is included in the report that we will give to you. The pre-data indicates a reasonable level of awareness around enduring powers of

attorney and the importance of completing wills. Awareness of advanced health directives and enduring power of guardianship is very low.

**Hon NICK GOIRAN:** Is there ever any conversation as part of that on euthanasia and assisted suicide?

**Ms GLOGOWSKI:** Yes. Right at the outset, I am very forthcoming and I name the “elephant in the room”; I use those terms. We present this workshop. We try to establish an environment that is as safe and comfortable for people as possible, because we say to them that it is about you and it is about your advance care plan and helping you to complete that. We try to establish a very comfortable environment. In that I say to them very honestly, “If you would like to talk about euthanasia and voluntary assisted dying, then we are very open to doing that.” Can I say to you that we have had a few conversations about it, but over the 17 workshops that we have run this year, it has come up only one or two times. I think what happens is that, mostly, people are focused on getting their head around the complexities of advance care planning, and many of them are actually excited at the opportunity because many of them say, “I just didn’t know these opportunities were available.” I think they get so involved and focused and are getting their head around that information that they are probably not freed up yet perhaps to have those other conversations.

**The CHAIR:** Can you talk to us about palliative care in WA? We know what palliative care is, I think, so can you just give us an idea from your perspective as a peak body where the gaps are?

**Dr CAMPBELL:** Unfortunately, there are a lot of gaps in palliative care in Western Australia. We know that specialist palliative care—for example, Silver Chain hospice and the services available in a few of the hospitals—provide very good results. But, unfortunately, most people who might benefit do not have access to specialist palliative care. This is backed up by data from the Palliative Care Outcomes Collaborative, which you are aware of. It has been estimated that 60 per cent of people who may benefit from palliative care do not get access, and also from our anecdotal experience, the specialist palliative care services are very stretched and are either declining referrals or discharging patients. Also, the barriers can be geographic, demographic, diagnosis-related and socioeconomic. In terms of geography, there are certain places even within the Perth metropolitan region where there is not really good access to specialist palliative care, particularly as an inpatient or in a hospice, or as a consult service in a hospital. For example, Joondalup hospital, Midland, Peel, even places like Fremantle and Bentley, do not have access to specialist palliative care. Then, obviously, that is even more of a problem once we get outside the metropolitan area, where services are quite patchy.

In terms of diagnoses, we have research from WA showing that people with cancer get much more access to specialist palliative care than people with other life-limiting illnesses—even for those people who would benefit definitely, they have just as high symptom burdens as people with cancer. There are a lot of reasons they are not getting that access. It is partly related to education of health professionals and the public, and some misperceptions that palliative care is only for people with cancer. Importantly, I work mainly as a geriatrician, so I look after a lot of people with dementia, and it is certainly a struggle to get specialist palliative care involved for people with dementia, even though it is the second biggest cause of death in Australia.

**The CHAIR:** Why do you think that is?

**Dr CAMPBELL:** Traditionally, the palliative care model started in the hospice movement, and it was for people who had an illness trajectory where they became very unwell in their final weeks of life, generally with diseases like cancer or AIDS, so palliative care services would really come into play in those final weeks. But for people with dementia and age-related illnesses, like frailty, often their decline is a lot slower over a longer period of time, and it can be very difficult just to provide the level of support required over that period. Also, with the current changes in aged-care funding in

Australia, a lot of people are missing out on aged-care packages to keep them at home. The specialist palliative care services just do not really have the resources to fill the gaps there.

**The CHAIR:** What about groups with specific needs, or vulnerable groups like CALD communities, people living in aged-care or disability facilities, residential, rural and remote communities, Aboriginal and Torres Strait Islanders, children and young people, patients suffering non-malignant illnesses—whom you have talked about—patients with intellectual and developmental disabilities, and people with mental illnesses and in prisons?

**Dr CAMPBELL:** Yes, we would say that all those people have poor access to palliative care. The PCOC data shows that wealthier and better educated Australians get better access to palliative care. For example, there are paediatric palliative care services for children who attend Princess Margaret Hospital, but outside the metropolitan area, again, that is quite patchy. There is a service called MPACCS, which goes to some aged-care facilities, prisons and homes for people with disabilities, but that again relies on the facility actually making the referral to the specialist service. It is not a blanket referral or a shared-care model where the GP and the palliative care service are working together from the get-go. Also, the environment in itself limits the ability to deliver palliative care. I have visited Casuarina Prison to see patients there who have palliative care needs, and the actual environment of the prison can make it very difficult to deliver palliative care, even though the nursing staff there are wonderful. Yes, there are barriers there.

**Hon ROBIN CHAPPLE:** You talked about a lack of services outside the metropolitan area. Do you actually have any data on that?

**Dr CAMPBELL:** No, not on me. I could get back to you.

**Hon ROBIN CHAPPLE:** You cannot name hospitals outside the metropolitan area that would not have it?

**Dr CAMPBELL:** I can name the ones that do have it.

**Hon ROBIN CHAPPLE:** That would be useful.

**Dr CAMPBELL:** Bunbury hospital has access to a palliative care specialist and the St John of God Bunbury Hospital has a palliative care unit, which is available to public and private patients. Busselton has a hospice that is serviced by the Bunbury staff. Albany has a hospice and a palliative care specialist. Geraldton has a palliative care unit, but they do not have a palliative care specialist based in Geraldton; they visit in and out. The rest of the state is covered by regional palliative care services based in major, I guess, towns within those areas, so it is quite variable.

**Hon ROBIN CHAPPLE:** But it is nothing like you have just articulated? So Broome, Kununurra, somewhere like that, would have some level of service but not based there?

**Dr CAMPBELL:** The Kimberley has a visiting palliative care specialist. I cannot say exactly how often she visits, but she goes for a few days maybe once a quarter. But it might be different.

**Hon NICK GOIRAN:** A few days once a quarter?

**Dr CAMPBELL:** Yes.

**Hon NICK GOIRAN:** So in every three months there is a palliative care specialist who visits for a couple of days?

**Dr CAMPBELL:** Yes. For example, I know Esperance has a palliative care specialist twice a year for one day; Kalgoorlie, one day once a month. Obviously, it is not just about the doctor, but there is also —

**Ms PANIZZA:** There are regional coordinators, so there is nursing staff in each region—so the mid west, Kimberley and the Pilbara have nursing staff allocated to those regions, who then try to facilitate palliative care requirements for the patients in those areas. We have a great deal—certainly from my workplace, you know, discharging patients back to country and trying to access in the services. Each region has its really unique challenges, but it is very much a consultative service. There are not the really intensive, in-home services that can be provided in Perth, and that is a huge limitation for people in country areas. You do not need to go too far away to find country areas that cannot, unfortunately, support patients who want to be at home.

**Hon ROBIN CHAPPLE:** I have been made aware that whilst there are very limited services, they are actually quite good in their limitation, and that a lot of the services are delivered over the phone in that sense.

**Hon NICK GOIRAN:** Somebody said earlier that 60 per cent of people do not get access. What is the source for that?

**Dr CAMPBELL:** That is from PCOC, and it is an estimate based on a methodology developed in the UK by Dr Fliss Murtagh. I do not have the exact reference on me, but the Palliative Care Outcomes Collaborative has widely published on that.

**Hon NICK GOIRAN:** PCOC is Australia-wide?

**Dr CAMPBELL:** Yes.

**Hon NICK GOIRAN:** How much weight can the committee give to that 60 per cent figure to Western Australia?

**Ms PANIZZA:** I would say it is fairly robust.

**Dr CAMPBELL:** There is no reason to suspect that things would be better or worse. We can look at things like the number of, say, palliative care specialist doctors in different states, and we have slightly fewer than the national average, but it is not a huge difference. But I do not think we could say that WA is any better or worse than other states from that figure.

**Hon NICK GOIRAN:** Having said that, there is a view, I take it, that Western Australia is better than other places because we have things like Silver Chain that are the envy of other states.

**Dr CAMPBELL:** Silver Chain hospice, yes, is internationally recognised and is the envy of other states in that 70 per cent, I think, of their patients die at home. But that is not all Western Australians who die; they are just the ones who get access to Silver Chain hospice specialist palliative care. If we look at it, 15 000 Western Australians die each year and less than half of them get seen by Silver Chain hospice.

Not everyone who dies would benefit from palliative care. Some deaths are unexpected but most deaths—estimates are between 50 and 70 per cent—are expected and would benefit from palliative care.

[3.00 pm]

**Hon NICK GOIRAN:** You are saying that we can rely on the PCOC data as best as we can. We do not actually know the situation in WA, but if we rely on it, for every 10 Western Australians, we are saying that six do not have access to palliative care. Four out of 10 people have access and six are missing out.

**Dr CAMPBELL:** To specialist palliative care—yes. Some may be having palliative care provided by, say, their GP or other providers but others are definitely missing out. That could be for a number of



reasons. Maybe they are not getting referred because their health providers are not aware to refer them or they want palliative care but they just cannot access it because it is not available to them.

**Hon NICK GOIRAN:** It is a big problem.

**The CHAIR:** You talked about some of the systemic limitations of palliative care. What about some of the medical limitations? Would you say that when somebody is able to access palliative care by Silver Chain or one of the major hospitals, it is 100 per cent effective for all patients?

**Dr CAMPBELL:** No. No medical treatment is 100 per cent effective, but palliative care is highly effective. Again, going back to PCOC, say we look at the symptom of pain, PCOC data shows that at the time of referral to palliative care, over seven per cent of people report severe distress due to pain. At the time of death, that is down to two per cent of people. If we say that palliative care is 98 per cent effective, that would be the envy of many medical treatments to be effective.

**The CHAIR:** Would you say that it is around 98 per cent effective?

**Dr CAMPBELL:** If we are talking about, for example, pain as a symptom?

**The CHAIR:** Yes, relieving pain and suffering. There is, say, two per cent in your experience, where it is not —

**Dr CAMPBELL:** Yes. That is consistent with my experience as well.

**The CHAIR:** And Ms Panizza?

**Ms PANIZZA:** Yes, the same.

**Hon COL HOLT:** That would be relative to the patient's desires. For example, I could see a situation where they want to remain quite cognisant and be awake and interacting and put up with a bit of pain to do so, whereas others might be going, "Just knock me out and I will go to sleep" or whatever it might be. Is it 98 per cent effective in terms of managing the pain or delivering the outcome desired by the patient? That would be a better question, I think.

**Dr CAMPBELL:** Yes. That is an excellent point. That data from PCOC just refers to the pain. It does not take into account that some of that two per cent of people actually choose to not have the painkillers, either because they do not want to be sedated, as you say, but sometimes for other reasons—like religious reasons.

**Hon NICK GOIRAN:** Would some of the two per cent fall into the category of the 60 per cent of people who do not get access to palliative care in the first place?

**Dr CAMPBELL:** No, because this data is only from people who are receiving access to specialist palliative care.

**The CHAIR:** In terms of some of the practices of palliative care, we have touched on the refusal of medical treatment. Can you talk a bit about refusal of medical treatment and palliated starvation and dehydration in your practice?

**Dr CAMPBELL:** Before addressing those two practices, which are not necessarily terminology which we would use in palliative care —

**Hon ROBIN CHAPPLE:** Could you identify what terminology you would use?

**Dr CAMPBELL:** I think refusal of medical treatment is quite pejorative and it implies that the person with palliative care needs is being difficult or irrational, whereas usually what is described as refusal of medical treatment is actually making a decision—an autonomous person weighing up their wishes and values and what they consider to be in terms of side effects and potential benefits of the treatment, what fulfils their values and wishes.

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**Hon ROBIN CHAPPLE:** Thank you.

**Dr CAMPBELL:** It is important to understand that palliative care respects the informed patient choice with an emphasis on very detailed communication between the palliative care professional and the person, to make sure that we do respect their wishes and values and support them with their decision-making. Ideally, we would also involve the loved ones and make sure that the person is informed about all the potential benefits and the potential side effects of the treatment or of not having the treatment. Obviously, if the person lacks capacity to make that decision themselves due to their illness, the person responsible, via Western Australian law, would make that informed decision on their behalf. If there was an advance health directive in place, that would be followed.

In palliative care we obtain either implicit or explicit consent from the person or the person responsible before initiating any treatment—not just the ones that we have been specifically asked about. For example, if someone is being started on a pump to deliver their medications, we will always explain to the patient or the family why that is being commenced—that the intention is not to hasten death or to prolong death. It is common in palliative care to have that ongoing communication at every stage and discuss every treatment. That allows a lot of trust between the palliative care professional and the patient and family. Also, these decisions in palliative care are generally made in the setting of a multidisciplinary team. It is not just one doctor; it is a doctor or a group of doctors, nurses and allied health professionals, all supporting that person to make the decision. Specifically, going on to what might be described as refusal of medical treatment, as I said, it implies that the person is maybe being a bit irrational, but generally they are made by rational people who are exercising their autonomy to make decisions, as long as they are informed about those choices. Some examples might be a person with end-stage kidney disease who has a choice of having dialysis or not. They may feel the benefit of dialysis, which is living for a few extra months. It is weighed up against the cost, which is going to dialysis three times a week and having significant side effects from that treatment. There is a whole list of different treatments that I could talk about in that similar situation.

**Hon ROBIN CHAPPLE:** We had an Aboriginal gentleman at Newman who went through that whole process and decided not to and went back to country.

**Dr CAMPBELL:** I think that saying he is refusing medical treatment is quite a biased way to describe it. He has made a choice to put quality of life and return to country over having a small bit of extra time.

**The CHAIR:** Where patients are receiving artificial nourishment and hydration and they refuse the continuation of that, is that a common occurrence in your experience?

**Dr CAMPBELL:** Most of the cases that we see are people who are dying—their appetite naturally decreases. They do not have that same need for that energy because they are not as active as they once were. Often they are in bed and are not very active. Also, with hydration, often it is not keeping a person alive. It is very uncommon that someone would refuse hydration or nutrition that is keeping them alive. They just do not have that desire for it near the end of life or the need for it.

**Hon ROBIN CHAPPLE:** You are not getting requests like, “I do not want any more water. I do not want any more food. Just let me go”?

**Dr CAMPBELL:** That would be extremely rare and usually we would explore it with the person and ask why they are saying that and explain to them what the process would look like of not eating and drinking.

**Hon ROBIN CHAPPLE:** It is not going to be a good outcome.

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**Dr CAMPBELL:** That is not a very common request, but requests like that are a good prompt for us, as palliative care professionals, to talk to the person about what their wishes are and to maybe commence the advance care planning process with them. It is often expressing some other need that they have.

**The CHAIR:** Can you describe to the committee the practice of terminal sedation and under what circumstances a patient would be provided with terminal sedation?

**Dr CAMPBELL:** Terminal sedation is sedation given to a person in the terminal phase—the last hours or days of life when they have symptoms that are unable to be managed by other methods. The medications that we usually use are not working. In discussion with them, they say they wish to be sedated so that they are no longer experiencing those symptoms.

**The CHAIR:** Can this hasten death?

**Dr CAMPBELL:** We looked at the medical literature to get an answer on this because we wanted to give you accurate information. We looked at a systematic review and there was no evidence to show that it actually hastens death. In addition, if we do not treat someone's distressing symptoms at the end of life, that in itself can hasten death; having uncontrolled pain or agitation can hasten death and shorten life.

**The CHAIR:** Is the patient's consent required?

**Dr CAMPBELL:** Yes.

**The CHAIR:** Or the decision-maker?

**Dr CAMPBELL:** Yes. Again that is something that in palliative care we would always be discussing along the way.

**Hon NICK GOIRAN:** I would like to take this up. We have talked quite a bit over the last two days about this concept of terminal sedation. The more I hear of it, I think the name is unhelpful. I would be interested in your perspective on this. When we talk about terminal sedation, it gives the impression that the sedation is terminating somebody. I much prefer the way that you explained it, which was that it is sedating somebody in the terminal phase. It is not the sedative that is terminating somebody. What is happening is that this person is terminal and they are being sedated in order to relieve them from their suffering. The sedative is not killing the person.

**Dr CAMPBELL:** That is correct.

**Mr R.R. WHITBY:** When you communicate with the patient, would you use the term "terminal sedation" or would you say, "I am going to sedate you so that you no longer have to put up with the symptoms"?

**Dr CAMPBELL:** That would depend on the individual clinician. I personally would not use those terms because they are very medicalised. I would explain exactly to the person what we are doing: we can give you medication so that you are asleep and you are not aware of the symptoms, but realising that you are unlikely to wake up from this.

**Mr R.R. WHITBY:** Given that it is happening so close to death, it is effectively their last conscious moments, is it not? They are made aware of that and that is a point of goodbye for loved ones as well. Although it is not a terminal sedation literally, effectively, when they receive that sedation, they are not going to wake up from that point.

**Dr CAMPBELL:** That is correct.

**Hon NICK GOIRAN:** Once you receive the sedative, people do not come in and out of the sedated phase?

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**Dr CAMPBELL:** If they have that degree of suffering that they want to be unaware of the symptoms, we gradually increase the doses of medication so that they are no longer coming into consciousness.

**Mr R.R. WHITBY:** They would be very aware of what is happening and they would be made aware of that?

**Dr CAMPBELL:** Yes. In many of the cases, the person themselves is unable to have capacity at that time. It is the family members that we are having a discussion with. If the person themselves is aware, they have that opportunity, obviously, to say goodbye.

**Mr R.R. WHITBY:** That is almost the point of death in some ways—not technically, but that is their last conscious moments and their last contact with loved ones et cetera.

**Dr CAMPBELL:** Without terminal sedation, which is quite uncommon, most people in the dying phase are unconscious for the last days.

**Mr R.R. WHITBY:** It is a decision, as you say —

**Dr CAMPBELL:** It is not like on TV where people are talking and then suddenly—like that! Sorry, you probably cannot document that in *Hansard*.

Most people do not go from consciousness to death very quickly. They are usually unconscious or not able to communicate for the last days of life.

**Mr R.R. WHITBY:** Often they are in a semiconscious state but suffering and you want to relieve the suffering. Sometimes it is with their knowledge and sometimes it is with the consent of the family.

**Dr CAMPBELL:** That is in specialist palliative care. I cannot speak for non-specialist palliative care.

**The CHAIR:** Do you think that increasing the amount of medication to what would be relatively high levels for an individual if you are putting somebody into a sedate state—there is a view amongst some practitioners that it can hasten death—that that is in conflict with the Criminal Code?

**Dr CAMPBELL:** Again, we went to the palliative care literature for this. There is an Australian study from a palliative care unit that looked at doses of sedating medications and opioid medications in people in the palliative care unit who died. There was no evidence that the doses of the medication were related to the life expectancy of the people in the hospice. We think that in good quality palliative care that the use of these medications is not hastening death.

**The CHAIR:** Do you think, as a practitioner, that the law is very clear for practitioners working in this area?

**Dr CAMPBELL:** I think it is for specialist palliative care practitioners. I do not have data from WA, but a study that looked at knowledge around these sorts of end-of-life laws in some other Australian states showed that palliative care specialists and geriatricians have a better understanding of these laws than medical specialists from five other specialties, like oncology, emergency and intensive care. I think that across the board in health maybe the laws are not very well understood, but within specialist palliative care, where it is our day in, day out work, they are.

**Hon ROBIN CHAPPLE:** I will most probably go completely out of my depth here, but when we talk about sedating somebody, if somebody is on pain relief, do you use the same medication and up the dose of pain relief to reach sedation, or do you use a different drug for that purpose?

**Dr CAMPBELL:** There are a couple of points. The two most common symptoms for which people receive terminal sedation—again, according to the medical literature—are delirium, which is often with agitation, and breathlessness. Pain is not one of the top two. But also the choice of medication—I guess if someone is on strong painkillers and they are getting drowsiness as a side effect, the discussion we would have with them would be, “Do you want us to increase the dose of

these pain medications, taking into account that you may become sedated?” But in other cases, we would use other sedating medications, not the painkillers themselves, because the medication is being used to treat the symptom. If someone had pain and they were on, say, morphine, and the morphine was partially treating the pain but with drowsiness as a side effect, we would discuss with the person and say, “Would you like us to increase the dose, which will control your pain but may sedate you?”

**Hon ROBIN CHAPPLE:** And then that would lead to unconsciousness?

**Dr CAMPBELL:** Yes.

**Hon ROBIN CHAPPLE:** So there is no hard and fast—you move from one drug to another one?

**Dr CAMPBELL:** Yes.

**Hon ROBIN CHAPPLE:** In some cases you would?

**Dr CAMPBELL:** Yes. Our choice is generally based on the patient themselves and the side effect profiles of the medications, and what other medications they have been having in the past and whether they are already on high doses of a certain type of medication that might not be effective.

**Hon ROBIN CHAPPLE:** I thank you for your answer, because you did not confuse me!

**Dr CAMPBELL:** I am glad to hear that!

**Hon NICK GOIRAN:** This is more of a question to my fellow committee members. I think that is consistent with what we heard earlier from Silver Chain—that you might need to have a separate channel, because otherwise there could be some problems with respect to the concoction, if you like, of drugs?

**Dr CAMPBELL:** Often people who are in a dying phase, even if they are not receiving terminal sedation—which, again, is a very small percentage of people—will be on multiple medications. If they have got a syringe driver or a pump running, often there will be more than one medication to control different symptoms. There might be something to control pain and something to control nausea, for example.

**Hon COLIN HOLT:** Would I be right in saying that once the patient goes into a sedative state and you manage that with dosages, there is no real knowledge of when death occurs? You cannot really predict it, except you know it is imminent? I know it is probably variable among a lot of patients.

**Dr CAMPBELL:** The closer death becomes, the easier it is for us to say when it is going to be. We always say to the families that we cannot tell you exactly when this will happen. But usually we can give a gauge in terms of whether it is going to be hours or days or weeks or months, not in the case of sedation but just in general, when telling patients or family members.

**Hon COLIN HOLT:** Because you go along a time frame and you get a more accurate idea?

**Dr CAMPBELL:** When a person is sort of hours from death, it becomes much easier for us to tell. But, again, it is quite imperfect and often we do get it wrong as well. Would you agree?

**Ms PANIZZA:** Yes, I would.

**The CHAIR:** You said that you understand that terminal sedation is very rare. Is it recorded or reported? How do you quantify how often it is used?

**Dr CAMPBELL:** No, there is no register for it, so we, again, have to go back to the medical literature—I do not know of any that is specific to Western Australian—and our clinical experience. I would probably defer to Natalie, who has many more years of clinical experience than me.

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**Ms PANIZZA:** I would say the same. It is just recorded as part and parcel of our everyday care in the hospital. The medications are registered on the hospital medication charts. There is documentation in the notes—patient is restless; patient has received these medications to abate symptoms; has it been effective or has it not? That would be all in the hospital records. But there would not be a subheading that would say “terminal sedation”, because that is an expression we do not use. It would be more about clinically, this is how the patient has responded; patient has needed more medication, or patient has needed less medication, to be comfortable. It would just be integrated as part of our everyday documentation.

**Hon ROBIN CHAPPLE:** We will just pull all the medical records!

**The CHAIR:** Are there any more questions for these witnesses?

**Hon NICK GOIRAN:** With regard to recording, I am interested to know what is the mistake rate in palliative care. Palliative care practitioners, doctors or nurses, will make mistakes, because they are humans, not robots. Is there any research or data with regard to what the mistake may be? “Mistake” might be the wrong word to use.

**Dr CAMPBELL:** I do not really understand what you mean by “mistake”. Do you mean like administering the wrong drug?

**Hon NICK GOIRAN:** Imagine a scenario where somebody should have been referred to a palliative care specialist and was not. Are there circumstances in which the frequency of that happening would be known, where that was poor judgement on the part of the GP, for example?

**Dr CAMPBELL:** For that, we just need to look at population-based data of what percentage of people die with diseases that would potentially benefit from access to specialist palliative care. There is some recent WA research that was published—it was actually Australian research, but the primary author, Samar Aoun, is a Western Australian, and some of the participants were from WA. They did phone interviews with bereaved relatives of people who had died. They found these bereaved relatives via funeral directors. They compared people who had received palliative care with people who had not, and they found that 64 per cent of people who had died from cancer had received palliative care but only four to 10 per cent of people who died from other diseases, such as motor neurone disease, dementia or heart failure, had received palliative care.

**Hon NICK GOIRAN:** That might not be necessarily a mistake of a health practitioner as to why that person did not get access. They might not have had access because they chose not to, or they were too far away from a service. I am more interested in circumstances not necessarily of medical negligence, but, as I say, complaint, mistake, complications.

**The CHAIR:** Misdiagnosis.

**Hon NICK GOIRAN:** Yes. Maybe I need to ask a professional indemnity insurer.

**Dr CAMPBELL:** I do not think that failure to refer to palliative care is something where—the person themselves would not be making the complaint, usually, because they have probably died, and I do not think the families would often make complaints about that sort of thing. I know anecdotally that we get a lot of phone calls to the office from people saying, “I want my mum to get palliative care. How can I arrange it? The doctors don’t want to.” I can share the case of a patient I had recently. She gave me permission to share her story, and so did her children. This is a woman in her 80s with lots of chronic health issues, including lung disease, who was living at home. She had appointed her daughters with enduring power of guardianship. She got pneumonia—she had had pneumonia in the past—and she wanted palliative care at home so that she could die at home. The daughters called a locum GP, because her GP was away, and he was not confident with referring to Silver Chain hospice, so he sent her to the emergency department. In the emergency department, the doctors

again were not really comfortable with palliative care and sent her to the respiratory ward for treatment. She had quite a bad infection, so she received a lot of antibiotics, and she became delirious and very confused. She was transferred to my care, because we look after people with delirium in our ward, and after a 53-day admission at a tertiary hospital, she was discharged to a nursing home, which was not her wish. She has said that although she does not want to end her life now, she definitely does not want to come back into hospital and she wishes that what had happened had not happened. That sort of thing is not recorded. There is no sort of clinical incident that I can report.

**Hon NICK GOIRAN:** Maybe I am better off asking this question. Practitioners want to continuously improve themselves. Is there a system to identify that we had such and such a case and we could have improved by doing this?

**Dr CAMPBELL:** There are lots of tools to help practitioners identify who would be suitable for referral to palliative care. But we just need a lot of education, both for the public but also very much for healthcare professionals, to make them aware of this and to try to bust some of the myths about palliative care, like that it is only for people in their last hours or days of life.

**Mr S.A. MILLMAN:** I have a question on that, because it seems to come up quite a bit. It seems as though there is a cultural mindset—forgive me for saying this—among health practitioners in WA that if you have cancer, you get referred to palliative care, but if you have other non-curative conditions, there is not the same automatic referral to palliative care. I do not know whether you studied locally, but how does palliative care influence the undergraduate program for medical students and so forth?

**Dr CAMPBELL:** It is quite limited, given that all of us, no matter what specialty we work in, are going to be looking after people with palliative care needs. Unfortunately, even in obstetrics, you have neonatal palliative care. At the University of Western Australia, the final year students do one week of palliative care attachment, which often, if there is a public holiday, is only four days, and one day is lectures, so they actually get only three to four days of one-to-one contact. Notre Dame University has a two week palliative care attachment for final year students. Across Australia, it is not necessarily mandated even to have that. I cannot really speak to the other health professional courses.

**Mr S.A. MILLMAN:** Is that a source of frustration for your organisation and is it something that you would like to be able to do something about and remedy, like in terms of getting in front of university students or practitioners and saying this is why palliative care is important?

**Dr CAMPBELL:** Yes. Another shortfall that some colleagues and I recently identified is that there is no formal teaching of advance care planning, at least in the UWA medical school curriculum. It just sort of gets taught ad hoc in palliative care or geriatrics. We would absolutely love to have more education for the medical students. Part of the barrier to that is even if the universities would give us more time—because it is always a fight—because the palliative care services are so stretched, it is quite an impost on them to take more medical students as well. But, yes, absolutely we would love for more health professional education, as well as public education, about the importance of palliative care.

**Ms CALCUTT:** Can I just add to that. We have a lot of calls that come into our office, even though we do not receive any funding, but people look up “palliative care” and they find Palliative Care WA and they ring us, and it is often me on the end of the phone. There are a lot of people who are calling, even those who do have a cancer diagnosis, but because they have been given only a six-month trajectory, their GP has not actually talked to them about palliative care or referred them for palliative care. So a lot of education needs to happen, as we were saying, and then what happens is

that the family member suddenly deteriorates, because illness is not predictable, and they are within a month or so of dying and they are still not within a palliative care service and their pain and their discomfort is not being managed.

**Mr S.A. MILLMAN:** Do you mean a six-month life expectancy?

**Dr CAMPBELL:** Yes.

**Hon ROBIN CHAPPLE:** Madam Chair, I am aware of the time, but I am also aware that Caitlin Calcutt would like to give us a personal explanation of her situation. I do not know whether we have time for that?

**The CHAIR:** We do have the Chief Psychiatrist waiting to give us evidence. We could invite Caitlin back to a subsequent hearing, because we will be holding more hearings.

**Hon ROBIN CHAPPLE:** I thought that might be really useful for the committee and generally

**The CHAIR:** Yes, it would, but I am afraid we are very pushed for time. We will certainly be in touch about getting you back to do that. That would be wonderful. Thank you.

**Hon ROBIN CHAPPLE:** Thank you very much indeed.

**The CHAIR:** Thank you for your evidence before the committee today. A transcript of this hearing will be forwarded to you for correction of minor errors. Any such corrections must be made and the transcript returned within 10 working days from the date of the email attached to the transcript. If the transcript is not returned within this period, it will be deemed to be correct. New material cannot be added via these corrections and the sense of your evidence cannot be altered. Should you wish to provide additional information or elaborate on particular points, please include a supplementary submission for the committee's consideration when you return your corrected transcript of evidence. The committee will write to you with the questions taken on notice during the hearing. In addition, we will include any proposed questions that we were unable to address due to time constraints. Thank you very much.

**Hearing concluded at 3.28 pm**

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