

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
WEDNESDAY, 13 December 2017**

SESSION ONE

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**

Hearing commenced at 11.06 am

Dr KEIRON BRADLEY

Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, examined:

Ms AMANDA JANE BOLLETER

Program Manager, Palliative Care, Department of Health, examined:

Mr LUKE HAYS

Acting Manager, Purchasing and Contracting, Department of Health, examined:

Mrs MARIE BAXTER

Executive Director, Nursing and Midwifery, WA Country Health Service, examined:

Mrs MARION SLATTERY

Director, Nursing and Midwifery, WA Country Health Service, South West, examined:

The CHAIR: Good morning. I declare the hearing open at 11.06 am. Members, I have given permission for the media to film for the first five or 10 minutes and then they will exit the room. To advise people, this hearing is being broadcast live on the Parliament House website.

On behalf of the committee, I 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 and I am the Chair of the Joint Select Committee on End of Life Choices. I would like to introduce the other members: Hon Sally Talbot, MLC; John McGrath, MLA; Dr Jeannine Purdy, our principal research officer; Simon Millman, MLA; Hon Nick Goiran, MLC; and Hon Robin Chapple, MLC. Reece Whitby, MLA, is running a few minutes late and will be joining us shortly. Hon Colin Holt has been delayed by air traffic and will be joining us in the next couple of hours, hopefully.

The purpose of today's hearing is to discuss the current arrangements for end-of-life choices in WA and highlight any gaps that may exist. It is important you 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 that you may say outside of today's proceedings. I advise that the proceedings of this hearing will be broadcast within Parliament House and via the internet. For the purposes of Hansard, just make sure you speak clearly so they can record the proceedings. Do you have any questions about your attendance here today?

The WITNESSES: No.

The CHAIR: Before we begin with our questions, do you want to make a brief opening statement? I understand you have a short 10-minute presentation. I will now ask the media to pack up their cameras and exit.

Ms BOLLETER: Thank you for the opportunity to present to your committee today. In our brief presentation to start this session, we will give an outline of the growing needs in terms of end-of-life care and palliative care; an overview of the current and proposed policy directions for palliative care and end-of-life care in WA; information about the model of care for palliative care in WA; how

services are currently provided; and some examples of current policy initiatives in end-of-life and palliative care.

The WA Cancer and Palliative Care Network, which is part of the Department of Health, leads and influences equitable access to cancer control and end-of-life care in WA through a system of delivering high-quality cancer prevention, screening, early detection, cancer treatment, palliative care and strategic and operational planning. We were established in 2006 to provide state leadership in this area. It is worth noting at the beginning of our presentation that the Department of Health has a system manager role ensuring that the WA health system is safe, effective, efficient and gives value to WA. Clinical care is provided by health service providers and non-government organisations, and the network works happily in partnership with those groups. The palliative care program as part of this network has an advisory committee chaired by Dr Keiron Bradley, which provides advice to us on our work in this area. Dr David Ransom, our co-director, will be presenting to the committee this afternoon.

Looking at end-of-life and palliative care, you can see that there were nearly 15 000 deaths in WA in 2016. Evidence about what proportion of these might be clinically expected varies, but we estimate that it is between 50 and 70 per cent. It is important to note that people with a chronic condition make up a significant percentage of these deaths, and also that cancer is increasingly a chronic condition and is included in the statistics around that. It is also worth noting that it is not just the growth in the number of people who have a condition that might require palliative care but it is also the complexity of the needs of those people. We are seeing that an increasing proportion of the population have more than three chronic conditions at end of life, which adds to the complexity of their care. We know that more than 70 per cent of people would prefer to die at home but across Australia there are mixed results in terms of achieving that. We also know, looking at value for the state, that a significant proportion of health care expenditure is in the last year or last three years of life, and that over \$2 billion a year is spent on older people who die in hospitals across Australia. It is a significant area of health expenditure, and the department is looking at how we meet patient needs, support families and ensure an efficient and effective system.

These are just some examples of the policy documents that guide our work. I will not go into detail, except to say that we have national quality documents around essential elements for safe and high-quality end-of-life care, and a national palliative care strategy, which is currently being revised. In WA, we have models of care which have been in place for a number of years. In the last two years, we have released an end-of-life framework, which looks particularly at end-of-life needs and how they are met in an acute health setting. We are currently finalising a 10-year strategy for specialist palliative care and end-of-life care in WA, which we anticipate will run from 2018 to 2028.

Looking at the priorities that are in that draft 10-year strategy, these are the six priorities that are proposed. I think it is worth looking at definitions and terminology because it can be a very confusing area. For the purposes of our 10-year strategy, we define end-of-life care as being the care that is provided to every patient with a life-limiting illness, their family or carer. It is provided in all health, community and aged-care settings and it is usually direct care for that person and their family. Specialist palliative care is provided to a subset of that population. It is provided for patients who have complex life-limiting illnesses and their family or carer. It is provided by specialist palliative care services and it can be either provided by consultation or by direct care. We will talk more about that model of care on the next slide.

Looking overall at the model of care for specialist palliative care in WA, it has many things in common with other jurisdictions across Australia, but also some things that set it apart because of the large geographic area and dispersed population in WA. We have a strong presence for hospital

consultancy services, particularly in metropolitan Perth, which is a specialist palliative care team based in the hospital, which can provide consultancy and direct care for patients anywhere across that hospital, so the patient does not need to be moved to a palliative care bed to have palliative care input as part of their care. We also have designated palliative care units, which in metropolitan Perth include Bethesda Hospital, St John of God Murdoch and Kalamunda. We have community services. I know Silver Chain is presenting to your committee tomorrow—we will talk a little about their role today—and also the Metropolitan Palliative Care Consultancy Service, which Luke Hays will talk about a bit more in a moment. We fund a rural palliative care program, which works across all rural regions. We might come to that on the next slide in terms of rural service provision. Also supporting all these elements of care, we have a strong reliance on telehealth and telephone advisory services, which, once again, is a bit different from some other jurisdictions. We work very effectively with those models in WA.

A copy of these maps has been provided to the committee already. You can see that we have community services in Silver Chain and MPaCCS that cover the whole metropolitan area, and then consultancy services and inpatient units are noted in the dots on the map. I might move to rural service provision and hand over to Marie and Marion to talk about this.

Mrs SLATTERY: For all of our seven regions, we have a consultancy service from a rural health team with palliative care that has previously been under the palliative care network, with access to a specialist visiting service from a palliative care consultant. That amount of FTE varies for each region. We have also accessed the out-of-hours telephone service to metro. Each of the regions has a regional resource centre where there are some dedicated hospice-style palliative care beds. However, all our hospitals provide palliative care across all the regions. Most have a palliative care room and access for the families and tend to run a small regional service within their district with the oversight and governance of the regional team.

Ms BOLLETER: We might quickly focus on a couple of initiatives that we think are very relevant to the questions that have been asked by the committee. First of all, we wanted to note the initiatives that are provided in WA around education. The Palliative and Supportive Care Education service is based with the Cancer Council of WA but the education it provides is across all diagnoses. That service is partly funded by the Department of Health and by the Cancer Council of WA. PaSCE provides a variety of programs aimed at increasing knowledge and understanding of palliative care in all settings. They publish a calendar twice a year to ensure that that is well publicised. Selected programs are available via videoconference to facilitate rural participation. PaSCE will also go to rural settings to provide specific workshops and education as well to ensure that rural clinicians have access to this training too.

PEPA is an education program that provides health professionals with an opportunity to undertake a supervised clinical attachment with a specialist palliative care service. For example, a GP might spend some time with an inpatient palliative care unit to get an understanding of palliative care and how that works. This is a commonwealth government funded program, and in WA it sits with the PaSCE program at the Cancer Council.

Talking about End of Life is a training program for aged-care facilities that teaches staff members to recognise residents with palliative care needs and teaches them about the concepts of advance care planning. We normally contract the provision of that service out but we have trained over 70 per cent of metropolitan aged-care facilities through the Talking about End of Life program. Through the rural palliative care program, we have just noted that education is a significant part of the work of the rural teams. Last year the teams educated over 1 500 health professionals in rural regions in addition to the clinical work that they do.

The next initiative that we wanted to talk about is goals of patient care. Goals of patient care is a form and a system that supports shared decision-making for patients who are in hospital. It aims to improve decision-making and documentation around decisions about what is the goal of care for this patient.

It is a statewide document that was originally developed by Dr Nick Waldron at Armadale Health Service, based on work that has been done elsewhere in Australia. We have now developed a statewide document that is being piloted statewide currently. We also have some specific initiatives around residential care. I will hand to Luke to speak about those.

[11.20 am]

Mr HAYS: Perhaps to just give some context to the committee about levels of government and their responsibilities, aged care is the primary responsibility of the Australian government. Obviously, the public health system is the responsibility of the WA government. In terms of the interface between those two sectors, that is something that is heavily scrutinised because we know that with a growing aged population and the increasing complexity of care needs that there will be movement across that interface quite significantly. That is an area that we focus on.

To provide additional support to that cohort of people who are at risk of having to leave their residential aged-care facility because of their more specialist palliative care needs—they have moved from an end-of-life approach to the point where they need specialist palliative care—there is a specific metropolitan service called MPaCCS, the metropolitan palliative care consultancy service, that provides that specialist palliative care approach to residents of an aged-care facility so that it builds the capacity of the residential aged-care facility staff to manage the care needs of that person so that that person does not need to have to come to hospital, which is generally not an appropriate option for them if they can be managed safely there. That service, in 2016–17, delivered over 6 500 service events and over 925 episodes of care. The other service that we provide around the interface between aged care and the public health system is called the residential care line. It is a much broader service than the specialist palliative care approach as it provides clinical specialist support to residential aged-care facilities around a specific resident and to their clinical health needs and, as such, is an important adjunct to the MPaCCS because they provide that kind of support around the clinical needs as the person moves through their care continuum.

Ms BOLLETER: We have talked quite a bit about the policies and services and initiatives that are in place in terms of specialist palliative care and end-of-life care in WA. You might be interested to know what is the outcome of all of this work. It is a difficult area to measure and assess. One example of data that is available is data from the Palliative Care Outcomes Collaboration. This is a national program that uses standard clinical assessment tools across all states in Australia to measure and benchmark patient outcomes in palliative care. Of course, the most important outcome is what is the outcome for the patient and their family. It is a program that is based at the University of Wollongong and is funded by the Australian government. PCOC data supports services to participate in continuous quality improvement activities with the goal of improving patient and family care outcomes. It is not just about collecting the data, it is about actually using that as part of their quality improvement cycle. Fourteen specialist services in Western Australia submit data to PCOC. Eight of those services are inpatient services and six are community services. There are 22 specialist palliative care services in WA. It is important to note that not all services submit data to PCOC. It is not mandated by any state in Australia to submit this data but we do strongly encourage it as a quality improvement initiative.

You can see, from the slide, the number of episodes of care and the number of patients. Once again, it is just worth noting that is from 14 services, not from all 22 services. The proportion of malignant

disease in WA is 67.4 per cent. About 30 per cent of that care occurred in hospitals and 43.1 per cent of those people died in hospital. For community episode length, the average length that somebody would be with a community palliative care service in WA under this data is 33.3 days. That compares to the national mean of 37.8 days—so fairly similar. The inpatient episode length of stay is 9.7 days in WA and 10.3 days nationally. Once again, they are fairly similar. I think this is very valuable data and very important data. I think we need to be careful not to assume that it is representative of all services in WA because not all services yet report through that. We will provide more information through your questions. We have also brought some resources for you in terms of some examples of the kind of information that is available to members of the public and resources that are available for health professionals. With your permission, we might provide those in the break to members of the committee.

The CHAIR: Yes, please. In the break, if you want to hand them to the committee staff, that would be great. Thank you.

I understand that you have been sent our questions prior so we will move through to those. We will start with just palliative care in WA. You have given us a broad overview there. Do you want to address us briefly on this topic in relation to the questions that we have asked? We will see where we go from there.

Ms BOLLETER: Certainly, thank you. The first question is around the role and availability of palliative care and whether it is well understood by the community. We sought some input from our palliative care advisory committee about this. As I said before, this is the committee that is chaired by Dr Bradley and includes representatives from palliative care services and the palliative care peak body—Palliative Care WA—across WA, so it is a relatively representative group. This committee suggests that public understanding of the role and availability of palliative care in the state can still be improved, noting that the Department of Health has developed a set of palliative care referral information resources to assist health professionals to make timely and appropriate referral to palliative care. Those resources are on our website and we will also provide hard copies of those to you today. In terms of why the role and availability of palliative care may not be well understood, once again, the feedback from our advisory committee suggests that confusion about definitions and time frames of palliative care and lack of clarity about pathways for accessing palliative care all contribute to the current level of public understanding. We quite consciously included those definitions around end-of-life care and specialist palliative care in our presentation because there are multiple terms used to describe similar things and it can be confusing. It is confusing for us sometimes as policymakers and service providers so it must sometimes be confusing for members of the public. It is not a problem that is confined to WA. We have the same debates on a national level in Australia.

The next question is whether the current palliative care services are adequate. Palliative care services in WA provide timely, appropriate and high-quality care for their patients. The services are staffed by specialist health professionals from a range of disciplines and are informed by a high level of expertise. The model for palliative care service delivery in WA has a strong emphasis on consultancy and capacity building as well as direct care. This model is appropriate to a state that has its population distributed over a wide geographical area. Feedback from the palliative care advisory committee is that the model for palliative care in WA is sound, but there are some concerns about equity of access across geographic areas and population groups. The advisory committee also suggested that there needs to be more communication about what palliative care is and what services are available.

The CHAIR: Is there any specific data on the shortfall of that access?

Ms BOLLETER: There is no specific data. We are aware of those geographic gaps, but we do not have specific data around that.

The CHAIR: Can you provide some more information about where those geographic gaps are?

Ms BOLLETER: Some of that might be covered by my colleagues from WACHS in a moment. In relation to metropolitan Perth, the advisory committee identified recently that there are some gaps for access to palliative care in general hospitals, which are often in the outer metropolitan area. There sometimes is not a specialist palliative care service based in those hospitals. I think it is important to say that not everybody who dies an expected death needs specialist palliative care. The WA model, I think, does very well at promoting good end-of-life care. There is no exact data about what proportion of people who die an expected death needs specialist palliative care. There is not a need for every health service to have a specialist palliative care team.

The CHAIR: According to the submission, the roll-out of a system to enable accurate capture of palliative care data in WA is currently underway. When will this be fully functioning?

Ms BOLLETER: The system you are asking about there is called ePalCIS, the electronic Palliative Care Information System, and it is a statewide database for specialist palliative care services in WA. It is for services that are publicly funded. There are three streams of reporting for this system. The first is palliative care in-patient episodes for activity-based funding. These episodes need to be captured so that they can be reported to the commonwealth to attract activity-based funding to the state. There is also the Palliative Care Outcomes Collaborative—we spoke about the data for that before. The roll-out of ePalCIS will help services to provide that data to PCOC and help facilitate the uptake of PCOC across all services in WA. The other purpose for the database is general service activity to provide reports around things like separations, referrals and demographic data.

The system is currently being rolled out. As I said, there are 22 WA Health sites in scope for ePalCIS. Currently, nine of those sites across metropolitan and rural are using the system to report in-patient episodes, and seven of those nine sites are using the system to report data to PCOC. We still have more work to do in terms of the roll-out across all 22 services and in terms of the third element of general service activity. We expect this to continue throughout 2018 and expect that it should be completed by the end of 2018.

The CHAIR: Are current palliative care services sufficient to accommodate the preferences of patients in WA? What do you think are the obstacles to patients being cared for and dying in their place of choice?

Ms BOLLETER: I will provide a little bit of information on this and then refer to Marion in terms of rural services. In terms of accommodating the preferences for place of care in metropolitan Perth, the Department of Health funds the Silver Chain group to provide community-based specialist palliative care, and I think Luke will talk about this more later. This service provides care to people in their own homes. It is important to note when we are talking about preferences of patients that sometimes the focus is very much on preference of place of death, but it is actually important to look at what is the patient's and family's preference around place of care, and to work to meet that. It is not just about where the person dies. Most people spend most of their last year of life at home, so it is very important to provide care in that setting.

In 2016–17, Silver Chain provided care to 5 170 people with a life-limiting illness in the metropolitan area. The average length of stay from referral to death or separation was 85.28 days. There were 2 163 Silver Chain patients who died in this period and 74.8 per cent of these patients died at home. By contrast, national PCOC data for the period July to December 2016—just note they are not

exactly the same periods—showed that 23.7 per cent of deaths occur in the community. So in metropolitan Perth we have a significantly higher rate of death at home than the national average.

The CHAIR: What would be the obstacles for people who are not able to die at home, if that is their preference?

Ms BOLLETER: Speaking about metropolitan Perth, some of the feedback we have had around this is that there can be gaps in accessing commonwealth-funded HACC packages at an appropriate level and in a timely way for palliative care patients. Our advisory committee noted this in their feedback to us. They also noted that particular responses are needed to meet increasing complexity of needs and fluctuating needs of people with conditions like cardiac disease. Traditionally, palliative care is associated with cancer care, and traditionally in cancer care you have a more expected trajectory of care. For conditions like cardiac disease, you often see fluctuating patterns of ill health and wellness, and that can be more complex to respond to from a service point of view. I will hand to Marion for the second part of that question.

Mrs SLATTERY: On the first question, about the current palliative care services, from a rural perspective, we have the rural palliative care model, which delineates the service that can be provided with appropriate care within the regional setting, and that is either at home, a local facility or having to move to a regional resource centre or tertiary. That is dependent on the level of care that is required. However, it is also dependent on the availability of resources within the region, which can vary. As I said previously, we have access to a visiting palliative care specialist, we have the regional team, and we have the local teams that will coordinate care for the patients to manage them at home wherever possible. We try to keep the patients at home or in a hospital close to home, as in their local district site, but sometimes they need to be referred to the secondary service, which is delineated within the model up to the regional resource centre, and occasionally tertiary, as Amanda alluded to, not just for cancer—there are complexities of care.

With regard to the obstacles for patients being cared for dying in their place of choice, we try to accommodate care at home wherever possible, or at the local hospital, because that is more of a home environment. The obstacles are the complexity of the patient care that is required, just the same as in metro, and the availability of resources. That is needing to have the full team. We have a nursing team, but we also need medical allied health, and the associated budget. There are some issues with managing patients in their own home with equipment and for us to be able to facilitate the purchase and delivery of equipment into remote locations. For an on-call service within a certain radius of a hospital, that can be managed, as long as we have the funding capacity, but the tyranny of distance for an on-call service is not always possible, which is why we always have the conversation with patients about transferring to the local hospital if that extra level of care is required. Sometimes, if they have good family support, we can give day support to the family and then we offer respite for the family into the local hospital. We are actually just starting a trial in the wheatbelt for iPad telehealth education and access to medical advice and nursing advice within the home. So, again, we are trying to keep the patients at home for as long as possible. Our biggest issue, as I said, is limited outreach services. Most of them are only within hours. From the regional resource centres we can offer a limited on-call service into the community, and, again, limited transport options, particularly when you go up to the Kimberley. If patients are being managed at home and then they deteriorate, it is how we then get them to the local regional resource centre in a timely way.

The CHAIR: I want to go now to some specific groups of people. Some of them you have already covered, so we will just go over some of the ones that you have not. Do current palliative care services in WA meet the needs of the following groups, and how is that assessed: CALD

communities; Aboriginal and Torres Strait Islanders; children and young people; patients suffering non-malignant and chronic diseases; patients with intellectual and developmental disabilities; people with mental illness, specifically people detained involuntarily under the Mental Health Act; and prisoners and others in detention?

Ms BOLLETER: I will give a brief opening statement and then hand to Luke to talk about residential aged care and then come back to the other groups, if that is okay. The population groups that you have identified are very similar to the population groups that are commonly identified in statewide and national palliative care policies as requiring a particular approach in terms of palliative care, and a very similar group of populations is identified in the draft strategy for WA from 2018 to 2028.

Mr HAYS: The WA Department of Health does not have any data on whether the quality of palliative care services delivered to residents of an aged-care facility is adequate. That is really held by the commonwealth—the Australian government. But we can make comment on those clients or patients who cross that interface, in terms of the support that they need, to the public health system. As I mentioned before, the MPaCCS service delivers that specialist palliative care to residential aged-care services. That is a referral-based service, so the need would have to be identified by the aged-care facility to trigger the referral into MPaCCS and then delivery of that service. As noted, over 6 500 service events were delivered by that service in the Perth metropolitan area in 2016–17.

Of the MPaCCS activity, seven episodes of care were delivered to Aboriginal clients but we do not have broader data on that. That represents, I understand, about 0.8 per cent of the total MPaCCS activity that they delivered in that time frame. The other service that I mentioned before that is perhaps an indicator of another group that requires that specialist clinical input, the Residential Care Line delivered over 12 000 service events to residential aged-care facilities in the Perth metropolitan area in 2016–17, supporting people with deteriorating health needs in that sector.

[11.40 am]

Ms BOLLETER: In relation to culturally and linguistically diverse communities, specialist palliative care professionals should have awareness about different cultural approaches to death and dying and incorporate this into their care for the patient and family. Patients receive culturally sensitive care and have access to interpreter services as required. The Palliative and Supportive Care Education service offers education about culturally sensitive end-of-life care for aged-care providers. It is worth noting as well that the advance care planning resources, which are published by the Department of Health, are available in multiple languages and formats. My colleague Kim Greeve will talk about that in his session this afternoon. We do not hold specific data about access to palliative care for people from culturally and linguistically diverse backgrounds, so I cannot give you specific data on that.

The CHAIR: What about Aboriginal and Torres Strait Islanders?

Ms BOLLETER: The data that we have for this is really data from the rural palliative care program, which shows that in 2016–17, of the 1 410 referrals to the program, 10 per cent were for Aboriginal people. This equates to 140 patients. Luke talked about the proportion that are seen by MPaCCS and it is worth noting that the Palliative Care Outcomes Collaboration publishes that the national average for percentage of referrals that are provided for Aboriginal people is 1.4 per cent, so there are some significant differences between what is provided in a rural setting in WA and nationally, and I think also perhaps in metropolitan Perth, but we do not have further data around metropolitan Perth to really provide that picture clearly. I think it is important to be cautious in making comparisons between the 10 per cent figure for the rural palliative care program and the national 1.4 per cent figure. We would want to look at that more closely in terms of the population

differences and how that works. But, certainly, it is a relatively significant part of the work of the rural palliative care program, which also has regular meetings with Aboriginal organisations—161 meetings with Aboriginal organisations in 2016–17—so it is an area that is consciously focused on by that program.

In terms of children and young people, the paediatric palliative care program is available statewide to provide consultancy and capacity building for health professionals who are caring for children with a life-threatening condition. There are some questions on this a little bit later in this session, so I might come back to that in more detail.

In terms of patients suffering non-malignant and chronic illnesses, all specialist palliative care services have skilled and qualified staff that can anticipate and respond to the needs of people with non-malignant or chronic conditions. We have referred here to the work of Lorna Rosenwax and her colleagues. In 2016, she published an article based on data from 2009–10 and that article shows a small but significant increase in access to specialist palliative care services in the time period from, I think, 2005. She notes that this is specifically in patients dying with non-cancer conditions, so we are seeing some changes there in terms of access.

In terms of patients with intellectual and developmental disabilities, Luke talked before about the NPCS service, which is available to provide specialist capacity building for staff in metropolitan disability services who are caring for residents at end of life. Similarly for people with mental illness, NPCS is available to provide that capacity building in those facilities, including psychogeriatric facilities as well.

For prisoners and others in detention, NPCS is available to provide this capacity building for staff in metropolitan prisons. I think it is specifically Casuarina?

Mr HAYS: Yes.

Ms BOLLETER: It is for staff who are caring for prisoners at end of life. It is a pretty small part of the work of NPCS; 1.03 per cent of the NPCS activity in 2016–17 was for people in correctional facilities. I think it is just worth noting there that some prisoners are transferred directly from prison to hospital at end of life or to receive palliative care, so that figure of the NPCS data is not representative of the whole WA prison population. I would suggest that further questions around prisons are probably best directed to the Department of Justice.

The CHAIR: We will probably come back to some of those groups in more detail as we move through the day. I will just move on. How does the health department view palliative care services in WA compared to other Australian jurisdictions?

Ms BOLLETER: I think we need to be careful about making comparisons, of course, but the Australian Institute of Health and Welfare publishes an annual report of data about palliative care across all states and territories. The most recent report, which was based on statistics from 2014–15, showed that WA's average length of stay in palliative care was slightly lower than the national average. The WA average length of stay was 10.3 days and the national average was 10.6 days, so once again, they are very similar figures, I think. WA has the highest level of activity in private hospitals compared with other states. This simply reflects the contracting of public palliative care beds to private health services. It is true across metropolitan and rural settings that a significant number of public palliative care beds are purchased from private entities and that influences that data. It is worth noting that in the most recent report from the AIHW, the largest average annual increase for public admitted palliative care patients was in WA. There was a 9.8 per cent increase. This was double the national average, which increased by 4.8 per cent. Once again, this I think reflects, to a large part, the data. It is attributed to better coding and recording practices within hospitals. This is

an area that the Department of Health has been focused on quite significantly in the last couple of years, knowing that it needed improvement, and we are starting to see that now showing in that national report. It is worth noting that the Palliative Care Outcomes Collaboration data does not provide comparisons between the states, but it does show that the vast majority of all WA services participating in PCOC have met relevant benchmarks for timeliness of care, responsiveness to urgent needs, symptom management and family carer problems.

The CHAIR: Thank you. We have touched a bit on the data and some of the projects around data. I am going to go to the next question: does the department keep a record of medications prescribed and dispensed during palliative care?

Ms BOLLETER: The department does not keep a separate record of medications. These records are kept by individual health service providers and non-government organisations. Records of all schedule 8 medicines, including all opioids, and schedule 4 restricted medicines, including benzodiazepines, sedatives prescribed in the community—note in the community, not in health services—are kept by the pharmaceutical branch of the department.

The CHAIR: Are there protocols for prescribing opiate or derivative or any other sedating or pain-relieving medications for the purposes of palliative care?

Ms BOLLETER: The department publishes evidence-based clinical guidelines for adults in the terminal phase and also an essential palliative care medications list for community pharmacists and GPs. They are not quite protocols, but we do provide guidance around that.

The CHAIR: I will just ask a final question before I hand over to members. Can you recommend any sites in the metro area or regions that would be appropriate or beneficial for the committee to visit?

Ms BOLLETER: We would recommend a mix of rural and metropolitan services, and ensuring that you reviewed services that are based in the community, inpatient services and also consultancy services. We think that would give you a broad picture about how palliative care is being provided in WA.

The CHAIR: Okay; the committee staff might follow up with you more directly on those services.

Ms BOLLETER: I am happy to do that.

Hon ROBIN CHAPPLE: I am sorry; I am terrible at remembering names, so I am going to look at people. When it comes to palliative care in the regions—I am referring more to the remote regions; say, the Kimberley—what is the level of service provision in staffing for palliative care in the Kimberley?

[11.50 am]

Mrs SLATTERY: We have a rural team which consists of a nurse manager, a social worker, a clinical nurse and an administrative assistant for each of the regions, and —

Hon ROBIN CHAPPLE: When you say “the regions” is that —

Mrs SLATTERY: Seven regions—the Kimberley, Pilbara, wheatbelt, goldfields, south west and great southern et cetera. They provide the governance and the support to the nurses and medical staff within each of the hospitals in each of the district sites. As Amanda said earlier, part of that role is for education. That is work that has been going on for about 10 years now, so we have quite a strong workforce that is well skilled. If the local team —

Hon ROBIN CHAPPLE: When you say “hospitals”, because a lot of the services that are provided out there are actually regionally based medical services associated with the community, are they getting that level of support?

Mrs SLATTERY: Yes, from each of the teams. A lot of the regions have very small hospitals.

Hon ROBIN CHAPPLE: So Kalumburu, somewhere like that?

Mrs SLATTERY: Yes.

Mrs BAXTER: They will be able to access. The key to good palliative care support in rural and remote regions is down to good anticipatory planning.

Hon ROBIN CHAPPLE: So does that anticipatory planning that mean taking the person out of that community or actually keeping them in there? It is very important to Indigenous people.

Mrs SLATTERY: That is right. It is a good assessment and we work very closely with the elders and the Aboriginal health workers as well, who work with the families.

Hon ROBIN CHAPPLE: I am aware of a number of communities where we actually get to that stage and we then take people out of the community and bring them down to Perth, which actually creates an immense amount of distress.

Mrs BAXTER: We aim to keep all patients as close to their home as possible, so if it is not in the home, it is to the nearest local facility. Again, depending on the specialist requirements that may be needed, they may be then transferred to a regional resource centre or to a metropolitan service, whether it be a general hospital or tertiary.

Hon ROBIN CHAPPLE: And that palliative care follows them?

Mrs BAXTER: Yes.

Hon Dr SALLY TALBOT: I have two quick questions. Just working backwards, the Chair asked you a question about protocols for prescribing and you said that there were a set of protocols, whether you call them that or not. Are they made public?

Ms BOLLETER: They are. They are available on our website and I think we actually have copies in the resource packs for you today; I will double check.

Hon Dr SALLY TALBOT: My second question is about data collection, because obviously this is key to all this in a policy sense. In your slide presentation, you said that only 14 of the services are reporting to PCOC. Why is every service not reporting?

Ms BOLLETER: It is a decision for individual services about whether they decide to report to PCOC, so it is entirely voluntary. The Department of Health does not have jurisdiction over individual services to mandate that they report PCOC data, so it is not a Department of Health dataset as such; it is a dataset that is held by the University of Wollongong through contract from the Australian government. We encourage it, and that is one of the reasons we are rolling out the ePalCIS database—to make it a little more straightforward for services to report that PCOC data. Some services have found just the mechanics of reporting that data difficult because of their own data systems, and ePalCIS will make it more straightforward and should involve less clinician time to complete the data. I think that is the feedback we often hear from clinicians; it is a significant amount of time that it takes to collect and report any form of data, including the PCOC data, and that can be a factor.

Hon Dr SALLY TALBOT: Not only clinicians, but people working right across service provision.

Ms BOLLETER: Yes.

Hon Dr SALLY TALBOT: So you have your own data collection system. Do 100 per cent of the services report to that?

Ms BOLLETER: Once ePalCIS is rolled out, then 100 per cent of specialist palliative care services in WA will report through that, so it will be rolled out to all —

Hon Dr SALLY TALBOT: How many are reporting now?

Ms BOLLETER: Nine are reporting now.

Hon Dr SALLY TALBOT: Nine out of?

Ms BOLLETER: Twenty-two. The reason that the remainder are not yet reporting is that the system has not yet been rolled out to them. There has actually been very good take-up and a lot of enthusiasm, I think, for that database, but it is being rolled out by the Department of Health and it takes time to do the education and the rollout across all of those services.

Hon Dr SALLY TALBOT: And of those nine that are currently reporting to the Department of Health and the 14 who are reporting to PCOC, how many of those are private contractors?

Ms BOLLETER: I would have to take that on notice and get back to you, if that is okay.

Hon NICK GOIRAN: First of all, thanks for the presentation. I have to say at the outset that it is like trying to drink from a fire hydrant to try to absorb all the information you have given us, so just bear with the committee if you will. You mentioned a few times that you—presumably the department—have received feedback from the palliative care advisory committee. Was that feedback documented?

Ms BOLLETER: We discussed some of these topics at the most recent palliative care advisory committee, and there are minutes of that meeting.

Hon NICK GOIRAN: Are those minutes publicly available?

Ms BOLLETER: They are not normally publicly available; I could take it on notice if you are asking for them to be provided to the committee and respond to you once we take that on notice.

Hon NICK GOIRAN: Okay; thank you. You mentioned at one stage in response to a question from the chair about whether the role and availability of palliative care is well understood by the community, and you indicated that you had received feedback from the committee and one of the issues was confusion around definitions. Which definitions do we say are being confused?

Ms BOLLETER: I think there is sometimes confusion about the term “palliative care” and I think if you asked different people in the community what their understanding was of palliative care, you would be likely to get different responses. Some people still think that it is associated primarily with cancer; some people think that palliative care is only in the last days or weeks of life. So there are different views about what palliative care is and there is quite a lot of evidence and research that shows that public confusion around what palliative care is. I think it is worth saying that some of that confusion and difficulty around definition also relates to the difficulty of the subject matter. It is a difficult subject to talk about; it is very difficult to receive a referral to a palliative care service for a patient and their family. So, not surprisingly, it is an area that often people do not want to know much about or understand until it is actually happening to them, and that can make it really difficult to ensure that there are clear definitions and messages for members of the public. We are also aware from discussions at a state and national level that there can be confusion between the terms “end-of-life care” and “terminal care”, and they are often used interchangeably. We are working hard with the 10-year strategy to really get that much clearer, so when we talk about end-of-life care, we are talking about the period of time after which someone is diagnosed with a life-threatening illness. That period of time can vary significantly. A number of clinicians use what is called the “surprise question”, which is: would you be surprised if this patient died in the next 12 months? If the clinician would not be surprised, it might be time to think about a referral for

palliative care or to think about providing end-of-life care, but you often hear different time frames associated with palliative care or terminal care or end-of-life care.

Hon NICK GOIRAN: That is helpful. Further to that —

Hon ROBIN CHAPPLE: I will just jump in on that, if I may. Could you actually provide us with some guidelines about those time lines and how they are determined? Maybe not here.

Ms BOLLETER: Yes, we could take that on notice and provide you with an overview around the different definitions. I think it is important to focus this around: what are the patient's and family's needs, and do those needs require referral for palliative care? Traditionally, we had a stronger focus around time frames, but particularly when you are looking at non-malignant conditions, those time frames can be very unpredictable, so we are moving away, in a policy sense, from talking too much about time frames, because it is more about assessing the patient's and family's needs at that point in time and making a decision about how best to meet them.

Hon ROBIN CHAPPLE: Yes, but if you did have a time frame analysis, that would be useful.

Ms BOLLETER: We can provide you with some more information around that.

The CHAIR: Members, I will just introduce Reece Whitby, MLA, who has just joined us.

Mr R.R. WHITBY: Yes, apologies for my lateness today. Thank you.

Hon NICK GOIRAN: Just following on from this issue of definitions, you mentioned earlier, particularly in aged care I think it was or residential care perhaps, that there comes a time when we move from an end-of-life approach to specialist palliative care. Can you just explain the distinction between the two?

[12 noon]

Ms BOLLETER: Was that one of your questions, Luke?

Mr HAYS: Yes; it is a comment I have made. Perhaps it might be useful to clarify that. In some cases, people move from an end-of-life approach to their care to needing a specialist palliative care response. As I think Amanda mentioned earlier, not everyone who dies requires specialist palliative care, so just to clarify that point. But the definitions around end-of-life care and specialist palliative care are fairly well understood, certainly from a policy sense.

Mrs SLATTERY: I think, to make it clearer, it is dependent on the complexity of needs of the patient. You are quite right about end-of-life care. We have a care-of-the-dying pathway, which a lot of us use within the acute care and the community setting. That can be managed with the GP and the nursing staff. But if the patients have particularly complex needs or reach a crisis, we would call in specialist palliative care, if that helps.

Hon NICK GOIRAN: Yes, that does help. This is going on from the question from Hon Sally Talbot with respect to the 14 specialist services that are submitting data out of the 22. You have explained that it is effectively a voluntary process. The question I have is should that data submission be mandated?

Ms BOLLETER: My understanding is it is not mandated currently by any state government in Australia for services that are funded by any state government in Australia. I think this would probably be a good question to put to the Palliative Care Outcomes Collaborative because it is also around their policy on this; it is not just about the Department of Health.

Hon NICK GOIRAN: Sorry to interject. The collaborative, is that the 22 services?

Ms BOLLETER: No, that is the University of Wollongong. That is the central point for PCOC. So I think that would be a question more appropriately directed to them.

Hon NICK GOIRAN: Is it permissible for the committee to be told who the 22 specialist services are and who the 14 are that are reporting?

Ms BOLLETER: Yes. That information is publicly available. The PCOC annual reports include the list of services in WA that report, and the maps of specialist palliative care that we have provided to committee staff previously list the 22 services.

Hon NICK GOIRAN: The other question I have, following on from the question you had from Hon Sally Talbot, is with respect to the prescribing and dispensing of medications. Are you able to advise if there have been any misconduct investigations with respect to the prescribing and dispensing of medications?

Ms BOLLETER: I do not have that information to hand. I think we would need to take that question on notice.

The CHAIR: You will take that on notice? Okay. Members, we have covered a fairly broad area under care for older people, and chronic disease. We may come back to that. I am just conscious of the time. I would appreciate it if you could now address us on the funding of palliative care services in WA. For the purposes of the public record, would you please indicate where you feel unable to provide the information sought, and the basis on which you may decline to respond.

Ms BOLLETER: I think the first question related to regional and rural palliative care, so I will refer that to my colleagues.

Mrs BAXTER: The response that we have is as reported in *Hansard* in August of 2013. The funding for palliative care at that time was \$5.9 million. That was inclusive of all purchased funding.

The CHAIR: So you do not have a funding figure for the current financial year that you are able to provide?

Mrs BAXTER: I am not able to comment at this time.

The CHAIR: Can you give us the basis on which you are unable to provide that information?

Mrs BAXTER: We are advised that we are unable to comment due to commercial-in-confidence requirements.

The CHAIR: Okay.

Hon NICK GOIRAN: Can I take that up? You indicated it was \$5.9 million as at 2013. Was that just for that financial year?

Mrs BAXTER: That is my understanding; it was for that financial year.

Hon NICK GOIRAN: You are not able to provide the figure for 2017. Why was the figure able to be provided for 2013?

Mrs BAXTER: I cannot comment on that one. I was not party to that discussion.

Hon NICK GOIRAN: Can the figures be provided for 2014, 2015 and 2016?

Mrs BAXTER: We can take that question on notice and respond.

The CHAIR: You will take that on notice. On what basis is the funding for regional and rural palliative care allocated relative to the funds for metropolitan-based services?

Ms BOLLETER: We are unable to provide a comparison for the same reason that we just spoke about. As we said earlier, because a significant proportion of public palliative care is contracted to private organisations in metropolitan Perth and across regional WA, we are restricted by commercial-in-confidence requirements from providing that information.

The CHAIR: Just to summarise, you are not able to provide the funding for regional and rural palliative care relative to metropolitan-based services on the basis of commercial-in-confidence?

Ms BOLLETER: That is correct. That is the advice we have received.

Hon ROBIN CHAPPLE: Just on that, although we are dealing with commercial-in-confidence and private providers, why can you not provide the percentage of variation between country and metropolitan without actually providing us with names and addresses?

Ms BOLLETER: The advice we have had from our legal service is that we cannot provide this information today due to commercial-in-confidence. I am happy to take the question on notice and see what can be provided at a future time.

Hon ROBIN CHAPPLE: Really, it is a percentage I am after.

Hon Dr SALLY TALBOT: The commercial-in-confidence advice presumably relates to the private contracting of services. Can you give us the data that we are looking for for the public facilities or services?

Ms BOLLETER: We can take that question on notice. I think it is important to note, though, that if we separate public beds that are provided in a private facility and services that are funded through health service providers—so, purely public services—we are at risk of not giving the committee an accurate overall figure about palliative care funding in WA.

Hon Dr SALLY TALBOT: But could you give us the funding for the last five years for Albany hospital, for example?

Ms BOLLETER: I think we would need to take that question on notice and see what the advice we are given is.

Hon Dr SALLY TALBOT: If the answer is that you can provide it, could we ask for it to be broken down by service?

The CHAIR: Yes. That was my next question—by service and service provider. Hon Nick Goiran, did you have a question on this?

Hon NICK GOIRAN: No, I think that covers it. That is good.

The CHAIR: Which organisations currently provide services under contract for palliative care, and can you provide the breakdown for each spend for those organisations?

Ms BOLLETER: We can provide the names of the services. They are Silver Chain, St John of God Health Care, Bethesda Hospital and Ramsay Health Care. They are the services that are providing direct service delivery. There are also contracts with organisations like Cancer Council WA in terms of education.

The CHAIR: Are you able to provide the breakdown of spend on each organisation?

Ms BOLLETER: Not at this point in time, due to commercial-in-confidence requirements.

Hon NICK GOIRAN: Further to that, you mentioned earlier that \$5.9 million was spent for 2013; that is already on the public record. Are we able to have a breakdown of who received what portion of the \$5.9 million in 2013?

Ms BOLLETER: Yes. We would need to take that on notice.

The CHAIR: We will also take that one on notice. Are you aware if any of the \$8.3 million of the 2017–18 federal budget that has been allocated over three years to boost funding for palliative care through primary health networks will be spent in WA?

Ms BOLLETER: The 2017–18 federal budget papers do not provide information on how the program’s funding will be allocated across jurisdictions, but there is a statement in the federal budget papers that the program’s funding will be distributed among primary health networks. The commonwealth, we are advised, is yet to make a decision about which PHNs will receive funding, and more information is expected by January 2018.

The CHAIR: Thank you. If members have no further questions on funding, I will move to the questions on limitations of palliative care. I understand that Dr Bradley is the most appropriate witness to address this area, with the assistance of Ms Bolleter. Would you like to address us on this issue?

[12.10 pm]

Dr BRADLEY: Generally speaking on the limitations, I think palliative care aims to prevent and relieve suffering for those living with life-limiting illnesses. It provides patients with a very wide range of medical conditions and care requirements. I believe that the limitations, therefore, are often similar to all other areas of medical care because of the wide variety of patients we care for and the conditions they have. A number of the systemic challenges have already been covered this morning so I will not go into further details about those. I think the availability of palliative care services that have been discussed is one of those issues. Awareness of time-appropriate referral is also another area I think we highlighted this morning.

Medically, I believe that we use the medications and treatments that are available to patients to the best of our abilities. However, this could be improved by ongoing high-quality research to continue to explore options to provide exemplary palliative care at end of life. I think medical limitations are best considered on a case-by-case basis rather than as a generalisable topic. Do you want me to continue?

The CHAIR: Yes.

Dr BRADLEY: The question was then whether it was —

Hon ROBIN CHAPPLE: Madam Chair, I am also having trouble hearing.

Dr BRADLEY: Sorry.

The CHAIR: Can you do your version of shouting. That is generally how we communicate!

Dr BRADLEY: Okay, I will try. The question was whether palliative care is 100 per cent effective for all patients. I think no treatment is ever 100 per cent effective for all patients, including palliative care. However, I think palliative care is incredibly effective in treating pain, breathlessness and other symptoms patients are experiencing at the end of their lives. I think there is not a lot of robust evidence regarding the effectiveness of palliative care because of the complexity of the patient population and the conditions that we are dealing with and because it is very difficult to compare apples with oranges. There are certainly studies to look at palliative care being cost effective and that it also improves quality of life for patients significantly and that palliative care is proven to be more effective than standard approaches to care. I think all assessments of palliative care need to be based on quality-of-life assessment. I think that is the bottom line and that is very much an individual patient question rather than a whole population question.

The next question was: if it is not 100 per cent effective, how effective is it? It is impossible to put a figure on that for the reasons I have already outlined. There are too many variables that we deal with on a day-to-day basis to do that and that is including the diagnosis, individual patient factors and the treatment options we have available and the variety that patients will have, depending on where they are. Again, quality of life is vitally important to consider.

The CHAIR: Does the department have goals or standards for effective palliative care?

Dr BRADLEY: The department expects the services to comply with the relevant national standard regarding palliative care and end-of-life care.

The CHAIR: That is how those standards are measured as practice against the national standards?

Dr BRADLEY: Yes.

The CHAIR: Are the current laws too constraining on health professionals providing palliative care and, if so, what could be improved?

Dr BRADLEY: This is very much a personal opinion but I do not believe that they are. I think the laws are okay as they are in that they are not constraining. What could be improved on that? Again, it is a personal opinion: I think that although the laws cannot not necessarily be improved, I think it is really important to continue to educate health professionals on what the current laws are and how they relate to palliative care and that the onus is always on the health care professionals to be aware of what the laws are and to follow the laws.

The CHAIR: Submissions received by the committee indicate that there are people in the community for whom palliative care is not an adequate treatment option, and they choose to take their own lives. The Victorian State Coroner has reported on the frequency of suicides among people experiencing irreversible physical deterioration caused by disease and injury. Does the health department monitor and report on patients who suicide as outlined by the Victorian coroner?

Ms BOLLETER: The department does not report on the frequency of suicides among people experiencing irreversible physical deterioration caused by disease and injury. It may be that the WA coroner collects such information.

Hon Dr SALLY TALBOT: My question is to Dr Bradley. The Chair is asking you specifically about the limitations of palliative care. I entirely appreciate that it is appropriate, in one sense, for you to respond in general terms using some fairly decontextualised language. But it might be very helpful for the committee if you could just give us, obviously without breaching any patient confidentiality, just a couple of empirical examples where you may have come across patients or types of patients for whom it is reasonable to say that palliative care is too limited an option for them.

Dr BRADLEY: I am just putting my brain to work. I think —

Hon Dr SALLY TALBOT: I was going to buy you some time.

Dr BRADLEY: Okay, go for it.

Hon Dr SALLY TALBOT: You said that it depends on the individual's expectations about outcomes; it depends on their idea about quality of life, and those decisions can only be made in an individual context. That is what I was hoping you could flesh out for us.

Dr BRADLEY: I can think of a couple of examples. Obviously, off the top of my head, one would be—we have already mentioned—is the patient's place of care at the end of life; a significant number of patients do want to die at home. What we face is that because a lot of the carers are elderly, as are a lot of patients but not all, the support the family can provide is limited and therefore they would need extra support to provide the palliative health care needs they have at home. Silver Chain and other services would come in and back up that support but, actually, the limitation is more to do with the hands-on, day-to-day care of patients in their home to enable them to remain there. Although I do not know that it is specifically the terminology of palliative care as such, but it is limitation of our current system, we find that there is not that hands-on care to enable people to be cared for at home when their families are unable to provide that care. That is one thing that comes to mind and certainly something we deal with in my clinical work on a weekly basis.

Hon ROBIN CHAPPLE: Is there a percentage around that?

Dr BRADLEY: I am not aware of any figures.

Hon ROBIN CHAPPLE: Anecdotally, from your own experience?

Dr BRADLEY: I think the figures that have already been quoted would suggest the number of patients who would prefer to die at home versus the number that do, so I suspect there is some sort of evidence there. But I think it is a much more complicated situation than that in that, although if you ask a set of patients where they would like to die, actually when push comes to shove at the end of their life, there is a whole lot of other circumstances that will change that decision. Although we all dream we would like to die at home in our own beds, unless you are doing that in your sleep without a lot of symptoms to deal with or hands-on health-care needs to deal with, the reality is very different. If you are dealing with symptoms at home and other things that impact on that, that changes people's decisions about where they would like end-of-life care to happen.

Hon ROBIN CHAPPLE: I apologise to Hon Sally Talbot for jumping in there.

Hon Dr SALLY TALBOT: That is okay.

The CHAIR: I have a follow-up from that. You have identified the systemic challenge with managing people at end-of-life care, but what about the medical limitations and examples of that?

Dr BRADLEY: There are certainly circumstances where our medicines are not 100 per cent effective. We would certainly never say that our pain relief options will give good pain relief for 100 per cent of patients. I think they provide adequate, but not necessarily exemplary, pain relief for 100 per cent of patients. That is a limitation on the medications we have available and it is based on the potential side effects that patients get from the medications we have available. There are other medical conditions that may impact on that as well. From that point of view, going back to my comment on research, I think there is still a lot of work to be done to improve the medications we have available to give better symptom control. There are medications that are not necessarily easily available, as well, and that can limit access.

[12.20 pm]

Going back to the other question that you raised about limitations, I think the other one can often be a patient expectation of what palliative care can actually provide, and I think that often comes down to when people are wanting very, very active treatment of the underlying condition and trying to find that balance between palliative care and active management of other conditions. From a palliative care point of view, we prefer to be involved very much sooner in a patient's disease trajectory so that we can start to talk about quality of life and other things that are important for patients, even right from diagnosis onwards for a lot of conditions. Unfortunately for us, we often do not get involved until very late on in the patient's disease process, and that can make it a lot more difficult then to start to look at what patient expectations are and the sorts of treatments that they might want and how they then are appropriate for, one, the health care that is available to them, but also what is medically appropriate as well.

Hon SALLY TALBOT: Chair, I think Mrs Baxter was seeking the call.

Mrs BAXTER: You asked whether there was a specific response that we could give that would not be breaking any patient confidentiality around whether palliative care is too limited an option. It goes back to what I said earlier. From a rural and remote perspective, good early communication and anticipatory planning with consultation and collaboration with health services is crucial for us. An example is that we have a young woman who was a single mother of a nine-year-old child who has recently been advised that she is now towards preparation for end of life, and she lives in the

Kimberley. We have supported this colleague to return to the Kimberley and commence her end-of-life management there, but with that good consultation and collaboration about what family support she may need, later it may require her to move back to family in Perth, and that has worked quite well. We try not to think that we have got limitations on the options, but that we have opportunities to explore as many options with our patients so that they can stay in the area they want to for as long as they can, supported by the services that are there.

Hon NICK GOIRAN: Dr Bradley, you are the chair of the advisory committee. How long have you been the chair for?

Dr BRADLEY: Since February this year.

Hon NICK GOIRAN: Had you been on the committee before that?

Dr BRADLEY: No.

Hon NICK GOIRAN: How long have you been practising in palliative care?

Dr BRADLEY: I have been practising in palliative care for 15 years.

Hon NICK GOIRAN: You have said a couple of powerful things this morning: firstly, that palliative care is incredibly effective; and, secondly, that there is adequate pain relief in 100 per cent of cases. That is obviously not a view shared by everybody in the community, so somewhere there is either a lack of education or understanding, or there is a perceived problem. Do we keep any records or data on the cases in which there is a perceived problem?

Dr BRADLEY: Not that I am aware of.

Ms BOLLETER: When you say perceived problem —

Hon NICK GOIRAN: If somebody says that the palliative care has been ineffective in a particular case, does anyone keep any records or data to identify what the person says was the problem and is there some kind of—I hesitate to use the word—almost post-mortem—type assessment done afterwards to say, “Well, look, where did the system break down? Was this person one who should have been referred to a palliative care specialist and was never referred to a palliative care specialist and it is no wonder, then, that the person has perceived there was a problem?”

Ms BOLLETER: In terms of departmental policy around this, the Department of Health has in place a mandatory policy that requires health service providers to undertake a review of death to ensure that quality of care provided is appropriate and to help identify where we could have done better. Hospitals may establish their local processes for facilitating this. That is often through a department or hospital-level mortality and morbidity meeting. So, there is a statewide Department of Health policy around the need to review deaths to determine whether there are improvements.

Dr BRADLEY: I was just going to go back to my comment about pain relief in that I think we can provide pain relief to everybody, and I think we do an okay job. As I have already said, we do not treat pain 100 per cent; I do not think you can ever do that, and there is always going to be pain that is not fully controlled. That will either be through limitation of the medicine itself or because of side effects of the medicines, so although you may be able to get very good pain relief for most people, they then may get side effects that they do not want or do not feel are appropriate for what they want to be able to do for their life. I think that may be where that difference—I am not saying that 100 per cent of pain will be completely got rid of but that we can provide pain relief to everybody. It is just whether the pain relief that we provide meets the needs of those individual patients.

Mr R.R. WHITBY: Thanks, Dr Bradley. I was following up, too, on your comment about adequate pain relief in 100 per cent of patients, because it does jar with some the evidence we are getting in submissions from people talking about their loved ones passing away in pain, essentially, in agony.

Is your definition of “adequate pain relief” one that the patient may share as being adequate, do you think?

Dr BRADLEY: I think that is always incredibly difficult to really define, because I think people’s definitions will change even through their illness and also, often in reflection, of something that may have been quite emotionally fraught as a process for families and patients as well. I think that from the point of view of “adequate”, we can go by using pain scores, which can be helpful for looking at reduction in pain measurements for patients. That can guide us in whether there has been some improvement. I think it is always going to be a subjective assessment by the patient, and it is ultimately the patients who will comment on that. From a medical point of view, we will work hard to provide the best pain relief we possibly can, or best relief of suffering we possibly can, within the limitations of the medications that we have.

Mr R.R. WHITBY: Of course. I think you probably clarified your earlier comment with your subsequent response to Hon Nick Goiran in terms of the fact that you cannot treat pain 100 per cent, so I guess you are talking about what you are not able to treat, is it not—what impact that has on the patient?

Dr BRADLEY: Absolutely. I think the concept of pain is also quite a difficult one, because it is not just a physical experience. Pain also encompasses psychological, spiritual and other issues that impact on that person’s suffering. I think from our medical point of view and from a holistic team point of view, we obviously can use medications and we can use approaches to deal with all of those things, but they all are part of that experience for the patient of what their pain is.

Mr R.R. WHITBY: So, what a medical professional might view as an adequate or a tolerable amount of pain in one patient may actually have a much greater impact on another because of their mental state and their ability to handle that.

Dr BRADLEY: Absolutely, yes, and all of the other issues that they are dealing with that may be physical, psychological, spiritual and existential—all of those things impact too.

Hon NICK GOIRAN: Further to that line of questioning, when the patient does have that situation and there is some impact on their mental state, what processes are in place to ensure that the patient is still able to give informed consent now that their mental state has been affected?

Dr BRADLEY: When I was talking about mental state, I suppose I was talking more about distress rather than their capacity to make decisions. From the point of view of any decision, we always are assessing capacity for the patient and whether they are able to make those decisions. I come to that in one of the other questions, but if we are talking about relief from pain and suffering, patients are not always able to have capacity to give permission for treatments, but from a medical point of view, we would be first wanting to relieve that suffering in the best way we possibly can and then, if it is appropriate to gain further information from the patient or family, we would do so.

[12.30 pm]

But obviously if we are faced with a person in front of us who has excruciating pain and they are not currently able to consent, we are not going to leave them there in pain while we wait for the appropriate consent.

Mr J.E. McGRATH: I am also interested in the same subject that you raised about the level of pain relief that can be offered to patients. All the submissions and what we hear as MPs from people in our electorates talk about the pain that their loved ones went through before they passed on. I understand also the reasons why sometimes you cannot provide that level to certain patients. But, as a rule, would you say that pain relief is the biggest factor that is raised with the Health Department when people pass on, when their families want to talk about the manner in which their

loved ones passed away? If we asked you what would be the biggest challenges facing the Health Department and the system in general, would it be the inability to provide in a lot of cases adequate pain relief, and how would that compare with, as you said earlier, the many people who cannot get access to palliative care? What would be the two biggest issues if we asked you to define the greatest needs in this area?

Dr BRADLEY: Do you mind repeating that first part, and then I will come to the second part?

Mr J.E. McGRATH: The first question was: is pain relief the issue most raised with you by families who have lost a loved one? Is it the fact that their loved one died in agonising pain that they could not be relieved of?

Dr BRADLEY: I suppose I can answer from my point of view as a clinician first. No, I do not think lack of pain relief is the main issue that families face when they come to talk to me after someone has died. I think it is actually the emotional issues that come with losing a loved one. It is often to do with how they then move on with their lives. It is a lot to do with their bereavement rather than necessarily the clinician situation around their loved one's death. That is certainly my personal experience.

I think levels of distress, rather than pain, as a specific topic, is probably the bigger thing. It is often emotional distress for patients not being able to do with their lives what they had imagined they would be able to do. That can happen in 18-year-olds, but it can also happen in 94-year-olds—it is not limited to younger patients. People are emotionally distressed by not achieving what they wanted to do. I think that is where that, I suppose, holistic idea of patient care is really important. We would always aim, with time, to try to cover all those causes of suffering and distress at the end of life. Often we come in as a specialist palliative care provider only quite late on. In an ideal world, we would love to be involved very early on and to be part of these discussions. But if we come in right at the end of someone's life, it is much more difficult to put in place the supports and the ongoing treatment that patients and their families need to meet all those causes of suffering. Physically, I think it is actually easier to get on top of a lot of those things than it is to do a lot of the other causes of distress and suffering. It is not 100 per cent for physical as well, as I have already said. But, particularly if we have time, we have a much better chance of being successful.

Mr J.E. McGRATH: Further to that question, we get a lot of people saying that palliative care has been great for them and for their loved ones. But you have indicated that a lot of people cannot access palliative care. How big an issue is that for our state and our public health system? How many people are out there who probably should be getting palliative care but cannot access it?

Dr BRADLEY: I think it is an issue, and it is an issue that we are very aware of. We are working very hard to try to improve access to palliative care. From the point of view of access, it is sometimes awareness from the patient and the family, but also awareness by other health care professionals of palliative care. We have already talked about how the care of people with life-limiting illnesses will often be done in a general health care setting. That will be done by GPs, nurses and a whole host of different health care providers. But sometimes there is a recognition that there may be other issues that are not be met or being addressed where specialist palliative care services can come in and provide that degree of support and oversight of the patient's and the family's quality of life and work with them to improve that. I think that access is really important, but also the timely access to it is important.

Hon Dr SALLY TALBOT: I want to ask about the comment that several of you have made about education and early connection with palliative care services. Do you have a way of engaging with people before they have a diagnosis of a terminal disease? Can people engage with palliative care services in a practical way before they have a diagnosis as part of their advance care planning?

Ms BOLLETER: I think advance care planning, which we will talk about more this afternoon, is a process that anybody at any point in their life can undertake. It is entirely appropriate for somebody who is completely well and has no diagnosis of a life-threatening illness to have a discussion about their wishes as part of their advance care planning and document those wishes. Certainly, our policy position is that we encourage people at all ages and stages of life to undertake advance care planning.

Hon Dr SALLY TALBOT: My question was specifically about the engagement with palliative care providers.

Ms BOLLETER: In my experience, it is not something that tends to happen. We will talk a bit later about people who might volunteer with a palliative care service, but that is often if they have had a family member who has been cared for by that service or have an interest. Palliative care services are often community-based organisations and have that community support and engagement, so it certainly happens in that way. But, as we said earlier, I think the fear of death in the community more broadly perhaps limits people's willingness to engage with palliative care unless they or a family member are at a point whereby they actually need palliative care.

Hon Dr SALLY TALBOT: By which stage, by your own evidence, it is often too late to engage effectively with the services.

Ms BOLLETER: That is why the awareness-raising of the public about what is palliative care, what is available, and dispelling some of the myths about palliative care, is really important. We have a specific section in our upcoming strategy that talks about the myths around palliative care.

Hon Dr SALLY TALBOT: It is not something that you rolling out at the moment, but it is something that is aspirational?

Ms BOLLETER: Yes.

Mrs SLATTERY: We work very closely with primary carers and GP services. The GPs who are dealing with these patients have access to our service, and if they feel it is appropriate, they do refer early.

The CHAIR: I am going to move on.

Hon NICK GOIRAN: We had a question about suicide and the Victorian state coroner.

The CHAIR: We have asked that.

Hon NICK GOIRAN: Can I follow up on that?

The CHAIR: Yes.

Hon NICK GOIRAN: I am interested to know whether, if someone suicides in Western Australia, the department is notified?

Ms BOLLETER: I do not have that information to hand and I will need to take that on notice

Mrs BAXTER: It is through the Chief Psychiatrist. All suicides are notifiable to the Chief Psychiatrist.

Hon NICK GOIRAN: We are seeing him tomorrow.

The CHAIR: You have before you questions on palliated starvation. I understand that Dr Bradley is the appropriate witness to address this area, and I would appreciate it if you could address us on this topic, although your colleagues are, of course, welcome to comment. I note, too, that we have been given notice of some areas on which you have received some legal advice not to respond. For the purposes of the public record, for the committee, we ask that you indicate this in your address, in addition to the basis upon which you have been advised not to respond. Patients can refuse

hydration and nourishment that is not provided as a medical treatment. When is a patient allowed to refuse hydration and nourishment?

[12.40 pm]

Dr BRADLEY: That question has all been, on legal advice, that I am not to respond to.

The CHAIR: Have they given you the basis on what that advice is given?

Dr BRADLEY: No.

The CHAIR: When is a patient in an aged-care facility allowed to refuse hydration and nourishment?

Dr BRADLEY: Legal advice is that I am not to respond to that question as well.

The CHAIR: When is a patient receiving palliative care allowed to refuse hydration and nourishment?

Dr BRADLEY: Legal advice is that I am not to respond to that question.

The CHAIR: In what circumstances do substitute decision-makers refuse hydration and nourishment on the patient's behalf?

Dr BRADLEY: Legal advice is that I am not to respond to that one as well.

The CHAIR: Are there circumstances in which health professionals can decide to discontinue artificial hydration and nourishment on the patient's behalf?

Dr BRADLEY: Legal advice is that I am not to respond to that one.

The CHAIR: Is it correct that, generally, patients refusing nourishment and hydration whether artificial or not, are treated with pain relief until they die?

Dr BRADLEY: Legal advice is I am not to respond to that question.

The CHAIR: If so, what types of medications are prescribed and dispensed in those circumstances?

Dr BRADLEY: Legal advice advises that I am not to respond to that.

The CHAIR: Can health professionals decline to administer pain relief in these circumstances?

Dr BRADLEY: Legal advice is I am not to respond to that.

The CHAIR: When hydration and nourishment are being provided as a medical treatment, can you confirm that the person's wishes, if expressed through an advance healthcare directive, EPG or their treatment decision-makers are not relevant?

Dr BRADLEY: Legal advice is I am not to respond to that.

The CHAIR: What is the physical process and length of dying associated with the refusal of hydration and nourishment?

Dr BRADLEY: This is a very complex process which is influenced by a large number of factors. Death by dehydration is likely to occur before death by starvation. Symptoms of dehydration may include dry mouth, thirst, drowsiness, decreased urine output, low blood pressure, irritability, confusion, seizure and coma. However, these symptoms may not occur and some can be easily relieved by other means and some may actually be seen as positive, so a decrease in urine output for a patient's comfort can actually be a positive thing. The length of dying by dehydration varies depending on many factors, which I imagine you can imagine as well, but that would include how unwell a patient is at the time, how much oedema they have—so how much fluid they have in their system already—any other medical conditions they may have, including the primary diagnosis. It may be from days to a small number of weeks.

The CHAIR: Is starvation or dehydration recorded as the cause of death on the death certificate?

Dr BRADLEY: Medical practitioners have a legal duty to complete a death certificate accurately based on their understanding of the cause of death.

The CHAIR: Are the arrangements relating to palliated starvation well understood and respected consistently in WA?

Dr BRADLEY: From a definition point of view, voluntary palliated starvation is the process which occurs when a competent individual chooses to stop eating and drinking and receives palliative care to address pain, suffering and symptoms that may be experienced by that individual as she or he approaches death. Again, it is an incredibly complex topic with complex legal and ethical considerations. I am not actually in a position to comment on whether the arrangements relating to palliated starvation are well understood and respected consistently in WA. I think an accurate and comprehensive answer to that question would require a survey of all medical practitioners in WA about their understanding of palliated starvation.

The CHAIR: How is it distinguished from conduct which might be viewed otherwise as a suicide attempt?

Dr BRADLEY: From that point of view, clinicians would need to seek legal advice on a case-by-case basis.

The CHAIR: How is the administration of pain relief in these circumstances distinguished from conduct that might otherwise be assisting a suicide?

Dr BRADLEY: In my personal experience, any medical care provided in this situation would be with the intent of relieving suffering due to pain and other reasons, and the need to provide that appropriate care and assessment. That would be how you would make that decision to treat. Clinicians again should seek psychiatric and legal advice on a case-by-case basis though.

The CHAIR: Does permitting palliated starvation or dehydration compromise efforts to reduce suicide generally in the community?

Dr BRADLEY: I am afraid I do not have any data on that.

The CHAIR: Is the relationship between health professionals and patients compromised by permitting palliated starvation or dehydration?

Dr BRADLEY: I think an accurate picture again, as I mentioned earlier, would be best answered by collecting a survey and getting information from medical practitioners in WA about that—and patients and families obviously as well.

The CHAIR: You do not have a view?

Dr BRADLEY: No.

The CHAIR: Does the department monitor and report incidents when nourishment and hydration are refused?

Dr BRADLEY: No.

The CHAIR: There is no data collected on that at all?

Dr BRADLEY: No.

The CHAIR: Does the department evaluate the medical management of incidents where nourishment and hydration are refused?

Dr BRADLEY: No.

The CHAIR: Does the department keep statistical data of incidents where nourishment and hydration are refused?

Dr BRADLEY: No.

The CHAIR: Are there any concerns that vulnerable people are being influenced or coerced into refusing nourishment and hydration?

Dr BRADLEY: I do not have any data to provide comment on that.

The CHAIR: Are there any concerns that substitute decision-makers for vulnerable people are being influenced to refuse nourishment and hydration on behalf of those for whom they feel responsible?

Dr BRADLEY: I do not have any data on that either.

The CHAIR: How does the department assure patient safety in these cases?

Dr BRADLEY: This is a similar answer to what we have given previously, that we have in place a mandatory policy requiring health service providers to undertake review of death to ensure that the quality of care provided was appropriate and to help identify where we could do better. Hospitals may establish their local processes for facilitating this. That is typically through department level mortality and morbidity meetings.

Hon Dr SALLY TALBOT: You referred almost all the time I think, if not entirely consistently, in your comments about having received legal advice not to respond to that series of questions by saying that clinicians would have to seek legal advice, or your standard response to that is that clinicians would have to require legal advice on any legal issues involved. Then you referred to that a couple of times in your answer to subsequent questions. How many times do clinicians ask for legal advice about palliated starvation and dehydration?

Dr BRADLEY: I do not actually know the answer to that question.

Hon Dr SALLY TALBOT: Why would you not be collecting data on that? You also referred in relation to the Chair's questions about the fact that you do not collect the general data.

Dr BRADLEY: I do not know.

Ms BOLLETER: Can I add a clarification around the role of the Department of Health and health service providers?

Hon Dr SALLY TALBOT: Yes.

Ms BOLLETER: The role of the Department of Health as system manager is that we provide the overall framework and policies for health service provision in WA. The delivery of care is the responsibility of health service providers and non-government organisations who have been contracted by the department. Queries about the number of times that clinicians might seek legal advice may be more appropriately directed to those health service providers and NGOs who may keep that data at that level. But apart from the mandatory policy that we have around review of death at the Department of Health, there are not separate collections held separately by the Department of Health because that is a responsibility of health service providers.

Hon Dr SALLY TALBOT: Individual service providers might be collecting that data. Is that the same as every other type of treatment provided to patients in the health system? For example, do you collect data on the number of cancer patients receiving types of chemotherapy?

Ms BOLLETER: There is a centralised cancer registry, which is held by the department, but I think how that data is captured, according to different types of treatment or different types of illnesses, is beyond the scope of my knowledge to present to you today.

Hon Dr SALLY TALBOT: Do you play a role in the training of the providers of palliative care services? I think you do, do you not?

Ms BOLLETER: Yes.

Hon Dr SALLY TALBOT: Does the topic of palliated starvation and dehydration arise during the training of those health professionals?

Ms BOLLETER: The Department of Health, as such, does not directly provide training, but as we discussed before, we do contract organisations such as the Palliative and Supportive Care Education service to provide some training. I would need to check specifically with them about palliated starvation, whether that is on the curriculum or whether it is brought up. That is not information that we have to hand.

Hon Dr SALLY TALBOT: Could you take that on notice?

Ms BOLLETER: We can take that on notice. We would also say that it is a responsibility of health professionals as part of their registration to ensure that they know the laws relevant to their practice and follow those laws. It is also an individual responsibility of health professionals to ensure that they know and follow the relevant laws.

Hon Dr SALLY TALBOT: It is likely it is included, I would imagine, and that would be your expectation.

Ms BOLLETER: Yes, and once again, this is not our area of jurisdiction but these questions could also be directed to tertiary institutions in terms of the undergraduate training that is provided to medical and other health professionals.

[12.50 pm]

Hon ROBIN CHAPPLE: Dr Keiron Bradley, in relation to your answers in 9—I understand it is difficult—you have been involved, as you say yourself, for 15 years dealing with this. Does the department monitor or report incidents where—no, they do not. But from your experience of 15 years, what would be the percentage of people who have or are permitted palliative starvation or dehydration anecdotally from your experience?

Dr BRADLEY: From my clinical experience, I think it is actually a very small number that I see.

Hon ROBIN CHAPPLE: One per cent?

Dr BRADLEY: I would find it very difficult to put a percentage on it, but I would say one per cent or less. It may be something that community-based organisations face more than I would clinically because I work in an inpatient setting. But certainly from my clinical practice in the last five years in Western Australia, I probably could count on one hand how many patients have decided to stop eating and drinking with the aim of shortening their life.

Hon NICK GOIRAN: The whole range of questions revolves around the topic of palliated starvation. Can you advise the committee what is palliated starvation?

Dr BRADLEY: I gave that definition but I am very happy to repeat it. In a paper by White, Willmott and—I cannot pronounce the surname—Savulescu, voluntary palliated starvation is defined as the process which occurs when a competent individual chooses to stop eating and drinking and receives palliative care to address pain, suffering and symptoms that may be experienced by the individual as he or she approaches death.

Hon NICK GOIRAN: Your evidence to the committee is that, more often than not, it is dehydration rather than lack of nourishment that results in the death of the individual.

Dr BRADLEY: My experience from that is based on clinical experience and that is not actually in a voluntary palliated starvation setting; it is actually in an end-of-life setting when people are in the terminal phase of their illness and stop eating and drinking naturally as part of that process rather than as a voluntary decision.

Hon NICK GOIRAN: So they are two different things.

Dr BRADLEY: Yes.

Hon NICK GOIRAN: Do you want to explain that a little bit more?

Dr BRADLEY: Yes; I am happy to try. For all terminal situations, which is where people are very close to the end of their life—so, if I look at some time probably within the last couple of weeks of someone's life—it would be universal in that chronic situation. I am not talking about someone obviously in a car accident or something acute. But in that chronic situation, it would be very, very common that people would lose their appetite altogether and that they would stop eating and drinking. That happens for a variety of reasons; one is a lack of appetite but the second is lack of energy, lack of thirst and being unwell generally that they are no longer eating and drinking, and the body shuts down those desires for food and fluid.

Hon NICK GOIRAN: So that is normal.

Dr BRADLEY: Yes, very normal, and that is very different from someone who is not in the last, say, couple of weeks of life who chooses to stop eating and drinking.

Hon NICK GOIRAN: We will distinguish those two groups then. If it is normal for a large proportion, or it is very common—I will not go in that area. Let us look at this other group who are not in the final stages of death, it is possible—you are not going to answer that. Does this practice of palliated starvation occur in Western Australia?

Dr BRADLEY: People certainly consider it. We had a patient recently on the ward who was talking about whether they wanted to do it or not. In the end, he chose not to. I do not know that people will always talk to their health care provider about it. It may be a decision that they choose to take without discussing it with their health care providers, so it makes it difficult for me to —

Hon NICK GOIRAN: But it is a choice that exists in Western Australia.

Dr BRADLEY: Yes.

Hon NICK GOIRAN: Who would the committee be best placed to talk to about instances where this has happened in our state?

Dr BRADLEY: I actually do not know the answer to that.

Hon NICK GOIRAN: Is that something that the department could take on notice?

Ms BOLLETER: We could do. I wonder if it may be relevant to the Chief Psychiatrist, but I am happy to take that on notice.

Hon NICK GOIRAN: I think we have the Chief Medical Officer coming soon. He might be able to help us.

The CHAIR: Yes, after lunch.

Mr HAYS: It may also be part of the coroner's information.

The CHAIR: Before we move onto the next topic, I am conscious that we are breaking for 30 minutes at one o'clock. We still have quite a few questions to go through that I know we are keen to get to. Are witnesses able to stay to address those questions? We have Professor Geelhoed due at 1.30 pm. We are happy to get to you first, sir, if that would suit and then we can come back to the department.

The WITNESSES: Yes.

The CHAIR: Are committee members happy with that? Yes, all right. We will keep going through until one o'clock.

You have before you our questions on terminal sedation. I understand that you, Dr Bradley, will be the appropriate witness to address this area to. I would appreciate it if you could address us on this topic, although your colleagues of course are also welcome to comment. I note, too, that we have been given notice of some areas in relation to which you have received legal advice not to respond. For the purposes of the public record, the committee would ask that you indicate this in your address, in addition to the basis on which you have been advised not to respond.

What is terminal sedation? Is artificial nutrition and hydration provided or withdrawn during the period of sedation leading up to death?

Dr BRADLEY: Palliative or terminal sedation is the use of medication to induce decreased or absent awareness in order to relieve otherwise intractable suffering at the end of life. In those situations, decisions about artificial nutrition and hydration during the period of sedation would be made on an individual patient basis and would depend on their symptoms and the clinical situation. Mostly, they would not be used, as they are unlikely to relieve suffering in that situation.

The CHAIR: Who is eligible for terminal sedation?

Dr BRADLEY: Terminal sedation would be available for patients who are at the end of their life and have intractable suffering that is not relieved by other means. It would be for patients or their surrogate decision makers who have given informed consent and ideally when consensus among patients, family and staff exist that this is the appropriate course of action.

The CHAIR: Is it just for the relief of physical symptoms or also the relief of psychological or existential suffering?

Dr BRADLEY: The suffering may be due to physical or psychological issues.

The CHAIR: Is the consent of the patient or the person authorised to consent on their behalf required?

Dr BRADLEY: Legal advice is that I am not to respond to that question.

Hon NICK GOIRAN: Can I take that up? You just indicated earlier in your response that there would be some—did you not say that on a clinical basis, on a case-by-case basis, in consultation with the patient and what their wishes and requests were, so that would be their consent.

Dr BRADLEY: Yes.

Hon NICK GOIRAN: I think you used the word “surrogate” decision maker. Is the consent of the patient or the person authorised to consent on their behalf required? Clearly, the answer is yes.

Dr BRADLEY: Certainly, that was my answer to the previous question when I discussed it.

The CHAIR: Are there circumstances in which health professionals can decide to administer sedation of this kind on the patient’s behalf?

Dr BRADLEY: Legal advice is that I am not to respond to this question.

The CHAIR: Are the arrangements relating to terminal sedation well understood and respected consistently in WA?

Dr BRADLEY: This would be my personal opinion. I am not in a position to comment other than from my own personal opinion, in which case I believe that the places I have worked do consistently understand and respect the use of terminal sedation.

[1.00 pm]

The CHAIR: Does the practice of terminal sedation hasten a patient’s death?

Dr BRADLEY: My personal opinion is that as it only occurs in patients at the end of their life, it does not hasten their death as death is already occurring due to the underlying medical condition and there is research evidence to support this.

The CHAIR: How is terminal sedation distinguished from conduct that might otherwise be an offence under the Criminal Code?

Dr BRADLEY: In my clinical experience, terminal sedation occurs only in patients who are assessed by the palliative team as already being close to death and with the aim of relieving their suffering, not hastening their death, and it would be done with the consent of the patient or the person authorised to do so. I am not in a position to comment any further on this because I do not have any legal training.

Hon ROBIN CHAPPLE: You have talked previously about the end of their life and now we are talking about what is close to their death. Is there a time line?

Dr BRADLEY: I think it is impossible to put a very specific time line on this.

Hon ROBIN CHAPPLE: Several days, hours?

Dr BRADLEY: Are you talking about terminal sedation itself and when it could occur, do you mean?

Hon ROBIN CHAPPLE: Yes. There is a decision made at some point that we can move into terminal sedation and I am trying to work on a time line.

Dr BRADLEY: It is impossible to be very specific but I would be thinking days rather than hours. I think if there are hours to go, we would often be able to manage the symptoms without the official¹ —

Hon ROBIN CHAPPLE: I am going to investigate this a bit further. Is “days” one day, two days, a week?

Dr BRADLEY: The trouble is that it is impossible to know because obviously they are dying and we do not know exactly when they are going to die so it is actually impossible to know.

Mrs SLATTERY: We do have the end-of-life care pathway, which guides the symptoms and when to introduce new treatments. Is that part of the package?

Ms BOLLETER: I do not think it is but it is publicly available and we could provide it to the committee.

The CHAIR: Thank you. Is the relationship between health professionals and patients compromised by the facilitation of terminal sedation?

Dr BRADLEY: If carried out appropriately, I do not believe that it would compromise this relationship. I believe that the skills required to explore and discuss this issue may positively affect the relationship.

Hon ROBIN CHAPPLE: Could I just ask one more question on that point. Going back to what Hon Nick Goiran mentioned before, you have a person who might be five days from the end of their life and terminal sedation is being decided as a process. Is that terminal sedation always justified by request of the patient or do we then leave that up to family, staff, the medical profession?

Dr BRADLEY: From my personal experience, often towards the end of someone’s life, they are not able to consent directly because they may well have a delirium which would affect their ability or their capacity to consent to something. In that case, it would be their surrogate decision-makers who would.

¹ Correspondence from the witness clarifying this part of the transcript can be accessed on the committee webpage.

Hon ROBIN CHAPPLE: Is that just down to medical professionals or is that associated with close relatives?

Dr BRADLEY: Yes, absolutely close relatives would be very much involved in any of these discussions.

Hon ROBIN CHAPPLE: So close relatives are making a decision about terminal sedation of patients?

Dr BRADLEY: Any end-of-life issues, if the patient does not have the capacity, we would be looking at relieving their symptoms and relieving suffering and that would be terminal sedation, but any other management of their symptoms at the end of life, the loved ones would be very intimately involved in the decision-making unless they did not have close family members.

The CHAIR: For the purposes of Hansard, Hon Colin Holt from Albany has joined us.

Just continuing this line of questioning, does the department monitor and report incidents when terminal sedation is administered?

Dr BRADLEY: No.

The CHAIR: Does the department evaluate the medical management of incidents when terminal sedation is administered?

Dr BRADLEY: No.

The CHAIR: Does the department keep statistical data of incidents when terminal sedation is administered?

Dr BRADLEY: No.

The CHAIR: Are there any concerns that vulnerable people are being influenced or coerced into accepting terminal sedation?

Dr BRADLEY: I have no data to answer that.

The CHAIR: Are there any concerns that substitute decision-makers for vulnerable people are being influenced to request terminal sedation or are exploiting their position in their own interests?

Dr BRADLEY: I have no data to answer that.

The CHAIR: How does the department assure patient safety in these cases?

Dr BRADLEY: Exactly as my answer to this question for other areas, but the Department of Health has in place a mandatory policy requiring healthcare service providers to undertake review of death to ensure quality of care provided was appropriate and to help identify where we could improve or do better. Hospitals may establish their local processes for facilitating this, typically through departmental mortality and morbidity meetings.

Hon NICK GOIRAN: As the chair of the committee, you provide advice to whom? The committee that you chair provides advice to whom—to the department or to the minister?

Ms BOLLETER: Primarily, the role of the palliative care advisory committee is to provide advice to the palliative care program within the department.

Hon NICK GOIRAN: Does that advice come on a request basis or can the committee proactively provide advice?

Ms BOLLETER: The committee can proactively provide advice, so there is a set item on the agenda for that committee whereby members of the committee are asked to raise any issues or questions that they would like noted, usually as part of other business. The department also puts questions to the committee around key issues in relation to policy and planning.

Hon NICK GOIRAN: So those issues might include concerns by members of the committee?

Ms BOLLETER: They could do.

Hon NICK GOIRAN: Have there ever been any concerns raised that vulnerable people are being influenced or coerced into accepting terminal sedation?

Ms BOLLETER: I would need to check the minutes of the committee meetings since it was established in order to accurately answer that question.

Hon NICK GOIRAN: Would that be onerous?

Dr BRADLEY: Not really.

Hon NICK GOIRAN: So you would be happy to take it on notice?

Dr BRADLEY: Yes.

Hon Dr SALLY TALBOT: We call it terminal sedation. Do you call it terminal sedation within the service provision paradigm?

Dr BRADLEY: I think it falls within good palliative care as far as relieving symptoms and it is one of the options that we have available to us. It is a term that is recognised however, yes.

Hon Dr SALLY TALBOT: Is the answer no? If I am a patient, do you sit down with me as the provider of palliative care services and say, "By the way, one of your options will be terminal sedation"?

Dr BRADLEY: I can answer from a clinical point of view. Most certainly, if a patient is experiencing suffering that is not being relieved by other measures that we already have in place, then that would be part of my discussion with the person that that is available, yes.

Hon Dr SALLY TALBOT: Would you call it terminal sedation?

Dr BRADLEY: I may do, depending on the person. It depends on the individual patient and their family as to whether that would be an appropriate term for them or not.

Hon Dr SALLY TALBOT: Would you also raise palliative starvation and dehydration as options?

Dr BRADLEY: It would be an option to raise it but it is not something that I have clinically ever done. I think patients are aware in general that a number of patients, if they are looking at dealing with their own suffering and what they are going through, they will often have explored the options themselves.

Hon Dr SALLY TALBOT: Do they raise that with their clinicians?

Dr BRADLEY: Yes. I do not know if they always raise it. I think it is impossible for me to answer, but certainly it does get raised, yes.

Hon Dr SALLY TALBOT: Yet I think you have indicated that you do not have protocols set out for dealing with those questions.

Dr BRADLEY: The actual questions from the patient or family?

Hon Dr SALLY TALBOT: Yes.

Dr BRADLEY: I think it would be impossible to have protocols set out for every question that I got asked by family members or patients about their care.

Hon Dr SALLY TALBOT: Specifically, if the questions are about palliative starvation, dehydration or terminal sedation, those things are not mentioned in the protocols about how to answer patients' questions.

Dr BRADLEY: It depends on how you are using the term "palliative starvation". If you are meaning lack of appetite or lack of food and fluid intake at the end of life, that is certainly widely available in documentation for end-of-life care because it is such a normal part of the dying process.

Hon Dr SALLY TALBOT: I do not think that is what we are talking about, though.

Mr R.R. WHITBY: Refusal—I would suggest that the question here is where the patient is refusing food.

Dr BRADLEY: It is not part of our standard information giving, partly because I think it is not something that is discussed hugely frequently.

Hon NICK GOIRAN: My last question on this is: How do you distinguish between someone who you say has lost appetite and that is quite a normal and common thing and someone who says, “I refuse to eat that meal that you have provided to me or to drink a cup of water”? How do you distinguish between the two?

[1.10 pm]

Dr BRADLEY: Clinically, we would, obviously, ask the patient themselves why they are not eating or drinking. It would certainly be noticed by the healthcare professionals, particularly in an inpatient setting, which is where I work. Staff would notice if someone was not eating or drinking, and they would question why that is. I think that we would always be making sure that the person does not have nausea or some other reason that they are not eating. That can be quite a common reason that patients are not eating or drinking—because they feel sick. We have to manage that appropriately. I think we also use other clinical assessment to look at whether we believe clinically the person is at the end of their life in that last couple of weeks of life where it would be natural and normal for that intake to decrease as part of that process.

The CHAIR: I will close the session and have a chat with you about how we move through the remaining questions. 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 by 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 questions taken on notice during the hearing. In addition, we will include the proposed questions that we were unable to address due to time constraints. Thank you very much.

Hearing concluded at 1.11 pm
