

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
FRIDAY, 18 MAY 2018**

SESSION TWO

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 1.01pm

Dr KEIRON BRADLEY

Clinical Lead, WA Cancer and Palliative Care Network, Department of Health, examined:

Ms AMANDA JANE BOLLETER

Program Manager, WA Cancer and Palliative Care Network, Department of Health, examined:

Clinical Professor DAVID FORBES

Acting Chief Medical Officer, Department of Health, examined:

Mrs MARION ANNE SLATTERY

Director, Nursing and Midwifery, WA Country Health Service, Department of Health, examined:

Mrs MARIE BERNADETTE BAXTER

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

The CHAIR: On behalf of the committee, I would like to thank you for agreeing to appear today to provide evidence in relation to the end-of-life choices inquiry. My name is Amber-Jade Sanderson; I am the Chair of the joint select committee. We have Simon Millman; Hon Dr Sally Talbot; Mr John McGrath; Mr Mathew Bates, our principal research officer; Hon Col Holt; Hon Nick Goiran; Mr Reece Whitby; and Hon Robin Chapple. The purpose of the hearing is to provide an opportunity for the department to respond to issues arising from the evidence gathered to date and to try to close any gaps in the evidence gathered in relation to the existing arrangements for end-of-life choices and the existing laws and resources in Western Australia. It is important that 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 might say outside today's proceedings. I advise that the proceedings of today's hearing will be broadcast live within Parliament House and via the internet. The audiovisual recording will be available on the committee's website following the hearing.

Do any of you have any questions about your appearance today?

The WITNESSES: No.

The CHAIR: Before we begin with our questions, do you want to make an opening statement?

The WITNESSES: No.

The CHAIR: We have provided some questions, but we had a few questions about some of the answers that we got from questions that we put in writing to you, so we might open it up to that. The first is in relation to the question around admission of palliative care type, which requires assessment by a palliative care specialist team. Essentially we are looking for an explanation as to how patients receiving care in hospitals without a specialist palliative care team are able to be admitted under the palliative care type. The response we have had talks about kind of care episodes and what palliative care is, but it does not actually that particular question. How are they able to access palliative care if they are not admitted by a specialist?

Ms BOLLETER: I will go back a step to talk about the two different ways that patients who are palliative in nature might be coded in the Department of Health dataset. The first way is what is

called a Z515 coding. That is a diagnostic coding. A patient might have a range of diagnoses as part of their coding, including Z515, which indicates that the patient is probably at a palliative stage of their illness. That coding is simply around the diagnosis; it does not mean that that patient is palliative care type or is necessarily receiving specialist palliative care. As we have said previously, and I think other witnesses have said as well, not everybody who is at a palliative stage of their diagnosis or illness necessarily needs specialist palliative care. That Z515 coding applies across all health services across Western Australia. Then there is the palliative care type. Only hospitals that have been designated by the Department of Health as meeting the necessary criteria to provide specialist palliative care can make that change of care type and report it to the department. We have a list of hospitals that are accredited to be able to make that data change. That is because we know that they employ specialist palliative care clinicians. That is usually a palliative care physician and also palliative care nurses. The situation in WACHS is slightly different so I might refer to my WACHS colleagues to talk about how that works in the WACHS setting in country health. But in metropolitan a patient cannot have their care type changed to palliative care, and have that reported to the department, unless the department has got that health service on a list of the providers that provide specialist palliative care. Does that answer the question or was there still something outstanding?

The CHAIR: Yes. We will go to WACHS, but do you have a list of those hospitals?

Ms BOLLETER: Yes, it is a list of 28 services currently. I think we have provided that to you before but we are certainly very happy to provide it again.

The CHAIR: Yes please.

Hon COLIN HOLT: What about the list of who are not on it; can you do that?

Ms BOLLETER: Yes, we can. Next Tuesday we will publicly release the 2018–28 end-of-life and palliative care strategy for Western Australia. That includes in it maps that show all the specialist palliative care providers across the state. Our expectation is that every health service across the state is able to provide end-of-life care recognise when a patient is at end of life, provide appropriate management and care for that patient and their family, and refer for specialist palliative care if and when that is needed, so that is how we structure that.

Mr J.E. McGRATH: So if any private hospital, such as the South Perth Community Hospital in my electorate, wanted to go into palliative care, could they make an application?

Ms BOLLETER: With that particular hospital we would expect that the patient would be able to receive end-of-life care there if that was their choosing and if the hospital was able to meet the patient's needs. If the patient's needs could not be met at that hospital, you would be looking at a referral to a specialist palliative care service; for example, Fiona Stanley Hospital in south metro or St John of God Murdoch Community Hospice, for example. It really depends on the patient's needs and whether they can be met by the health services where they are. In many cases they can be. It does not mean that everybody who dies needs to be referred to a specialist palliative care service.

Mr J.E. McGRATH: No, but if a hospital like South Perth wanted to put in the specialists and the people to run a very good palliative care service—today it is more day surgery and things like that—they could make that application to do that switch?

Ms BOLLETER: They could make that application to the department. They would need to demonstrate the appropriate level of staffing and contractual issues would need to be negotiated.

Hon ROBIN CHAPPLE: Two issues come from that. You talk about palliative stage of diagnosis. Can you expand on that? We are hearing about palliative care services, palliative care clinicians and

palliative care providers. Suddenly we now have a palliative stage of diagnosis. I would like to know what that is.

Ms BOLLETER: The terminology around this is confusing. I am sorry, I may have confused the terminology when I said that. It is really for somebody who has a life limiting condition. If it is recognised for that patient that treatment is unlikely to be successful, you would be looking at a patient who may require palliative care or who may be called at end of life. It is a pretty broad term and there is a lot of variation within that, so it can get confusing.

The CHAIR: Can we hear how this operates in the country setting?

Mrs BAXTER: As Amanda alluded, we have a different process for bed management and bed allocation in country health services. We have some of the regional resource centres who have specific beds for palliative care allocated to them. In the NPS and integrated health service areas we have beds at any time we can flex to a palliative care bed. Access to palliative care physicians is through the model that we have. Predominantly our patients are cared for by a GP, so it is a very different model. We do not say that of the 71 inpatient facilities that we have, with over 2 00 beds, 50 of those are definite palliative care. We have palliative care in the regional resource centres using the same codes because it is a national dataset, and then we have beds in the other facilities that we can flex according to patient need. Most of the access there for management is with the GP and through telehealth.

The CHAIR: Are there hospitals that are not able to adjust the code as in the metro area?

Mrs BAXTER: No.

The CHAIR: There is no regional hospital that is unable to accept specialist palliative care?

Mrs BAXTER: No.

The CHAIR: What are the requirements for a hospital to accept a patient as specialist palliative care?

Mrs BAXTER: Again, it would be the determination as to where they are in the patient journey and whether they have moved into what we call the palliative care phase. That would be dependent on what the relationship was with the GP, with the patient, with the family and with specialist services here in Perth.

The CHAIR: In Perth?

Mrs BAXTER: For metro.

The CHAIR: I am talking about in the country setting, in a country hospital someone is at a palliative stage and the hospital wants to admit them as a specialist palliative care patient.

Mrs BAXTER: They can.

The CHAIR: How?

Mrs BAXTER: It is usually with the GP.

The CHAIR: It just requires the GP to refer this person as a specialist palliative and then they can access palliative care funding?

Mrs BAXTER: Yes, palliative care services.

Hon Dr SALLY TALBOT: May I delve a little deeper into this. I have to stress from the beginning that we are not trying to catch anybody out, but we have heard an enormous amount of evidence and I just want to try to reconcile something that I had understood with what you have just said. If we take the general region around Albany, Denmark and Mt Barker, that triangle, what we were given to understand—at least what I was given to understand; I will speak for myself—was that in Albany,

and admittedly we have a blip at the moment because that contract is in the process of changing, we are planning for people to be able to access palliative care in their home, on a package, 24 hours a day, seven days a week. In Denmark, the available packages are only offering basically nine to five, five days a week. In Mt Barker, it is seven hours a week. If you could comment on that first.

The second thing I want to raise with you is that it was suggested to us that in Mt Barker hospital—I am not sure how many beds the hospital has—there are many times of the year when every single bed is occupied by a palliative care patient, but they are not classified as palliative care because they do not have access to a palliative care specialist.

Mrs BAXTER: I will have to do some further investigation on that process because I am not sure about this seven hours.

The CHAIR: That was in the home setting?

Hon Dr SALLY TALBOT: Yes, it is in the home setting.

Mrs SLATTERY: Packages are available. We tend to coordinate the palliative care. The patients are referred to our service within every region. The assessment is made for the patient and they are triaged. We coordinate the care but we actually refer out to other services to provide home support, such as Silver Chain or Red Cross. If necessary we will also go into the home. I am not sure what you mean by the package but I am wondering if that is the package that is available to support them at home and it is not necessarily the palliative component.

Hon Dr SALLY TALBOT: The Chair's questions are about that definition of a patient, for statistical data collection purposes and funding purposes—the admission of a patient into a palliative care service.

Mrs SLATTERY: Our palliative care service—that is how we admit them into our service. We have the specialist team that covers the whole region and all the referrals are referred to that team. That is where the triage and case coordination occurs. That is how it comes under the umbrella of a specialist palliative care service.

[1.15 pm]

Hon Dr SALLY TALBOT: Could it be, albeit hypothetically, that there might be a case where your data is showing you that somebody is receiving specialist palliative care services in a place like Mt Barker—I am only using it as an example of a community of that size—who you think is receiving specialist palliative services but, in fact, they are not?

Mrs SLATTERY: We have access to consultants, either through Perth or sometimes visiting consultants. GPs can liaise with specialist palliative care but, as Marie said, the GPs are providing the medical oversight, as do some of the medical consultants in some of the bigger hospitals who are physicians.

Hon Dr SALLY TALBOT: But a GP would not necessarily be a palliative care specialist, clearly. If they were a palliative care specialist, you could be a GP as well, but many of those GPs are not palliative care specialists. Is there a difference between a palliative care patient who is being treated by a GP and a palliative care patient who is under the care of a specialist palliative care practitioner?

Mrs SLATTERY: Yes. Not every patient, as Amanda said, requires a specialist level of care. It depends where they are in the disease process. Many do not need that specialist input. GPs are very experienced at managing patients.

Hon Dr SALLY TALBOT: What I am trying to get to is: if I am manager in a hospital in Boyup Brook or Mt Barker —

Mrs SLATTERY: Boyup Brook is one of mine.

Hon Dr SALLY TALBOT: Okay. Can I admit and get funding for a patient in palliative care if there is no palliative care specialist around?

Mrs SLATTERY: Yes, that is linking to our specialist palliative team. Because the referral has gone through our specialist team, the triage occurs there and the coordination and oversight of their treatment occurs there because it is our specialist team in each of the regions. We then work with the GPs and, if necessary, link to a specialist in Perth or a visiting consultant. It is because each region has a specialist team that they are under palliative care.

Hon Dr SALLY TALBOT: Could there be patients who do not come under that—they do not coincide with the team process?

Mrs SLATTERY: We receive all referrals and we report the data.

Mr J.E. McGRATH: So that person might have been referred to your team by the GP?

Mrs SLATTERY: Yes, the GPs refer them to our team.

Mr J.E. McGRATH: Then you will get back to that GP and that GP will continue to carry out —

Mrs BAXTER: Be involved in that care.

Hon COLIN HOLT: I wonder if I could put the question a slightly different way for my own sake. Is there any reason why an admitting GP to a country hospital would not put them in as a palliative care patient and then put them into the referral system? Would a doctor make that decision, that they are not going to refer them to you, if they are in the palliative care phase? No reason?

Mrs BAXTER: There is no reason not to.

Mrs SLATTERY: There is no reason because we provide a lot of support and ongoing care and facilitate the patient if, say, they had to be admitted for some symptom management or a crisis situation, into the local hospital. We would facilitate their early discharge back into the home and support them in the home.

Hon COLIN HOLT: So there is no real reason why a doctor would admit the patient but not refer them to palliative care? No reason at all?

Mrs BAXTER: No.

Mrs SLATTERY: No.

Hon ROBIN CHAPPLE: I might be asking a “please explain” question. Palliative care in the terms you are talking about is referring back to palliative care specialists. We have heard from doctors who have palliative care skills. They are not palliative care specialists. How do you delineate that on the ground? We heard this morning from the AMA that they believe palliative care principles should be embedded with all doctors. I am trying to get this whole idea of why we have palliative care specialists when there are on-ground doctors who have developed their own palliative care skill set. Is it mythology that there is this specialist group or are there other people who can administer palliative care in a very effective way because they are particularly well trained doctors?

Hon COLIN HOLT: You should ask the mythical beast.

Dr BRADLEY: In fact, I am a GP and a palliative care specialist. Definitely, the ideal is that the majority of doctors will manage the key end-of-life care or palliative care of patients without needing palliative care specialists. As a GP, I got trained in that. I worked in rural areas and provided the palliative care and end-of-life care for my patients as their GP. At that point I was not a mythical being; I was just a GP.

Hon ROBIN CHAPPLE: I am trying to make that delineation between this cohort of palliative care specialists when, in fact, we have heard from you yourself that you were a GP who practised good palliative care. I am trying to work out at what stage you say we need to refer you into that palliative care stream when you may have a GP who is doing damn good palliative care anyway.

Dr BRADLEY: From a specialist point of view, the majority of GPs, we would hope, would be able to manage the simple things. I think that when it gets to much more complicated symptom control, then my extra three years of specialist training stands me in good stead to be able to deal with those. That is not saying that some very qualified GPs or other specialists could not do that too, but it obviously is what I have focused on for three years of my training beyond my GP training. From the point of view of the specialist service, it is not really so much about the doctors, it is about the whole support that is offered to the GP and the team on the ground locally. That may be coordinating the care. That may be getting a specialist's support, if needed, but it may also be coordinating the home care package, making sure that the nurses are getting the support they need, giving help to the GP on things as well. If the patient, for some reason, needed a specialist test in Perth or something done, it would link then to the metro services as well. Does that make sense?

Hon ROBIN CHAPPLE: It is helping. Derby Hospital, up in my neck of the woods, the hospital staff there, without palliative care, organise home and community care, all of the facilities and stuff like that, which is part of what you are saying is palliative care. I am trying to work out at what stage there is some delineation between what a hospital or a doctor normally does. I understand the role of palliative care specialists in those cases of particular diseases or issues facing a patient, who might need some special medication management—that sort of stuff—but a lot of what seems to be being done is being done anyway by hospitals and GPs. I am really trying to explore that area.

Mrs SLATTERY: Yes, very much that is the case. GPs, generalists and nurses, we manage patients to a certain point but sometimes the patients become very complex and they require some extra symptom management that is above our generalist skill. That is when we call in the specialist. It does not mean the patient has to go anywhere, perhaps. We just need that information. Generally, we manage most patients.

Mrs BAXTER: It is a similar model to what we have in the country for maternity services on a shared model basis. We do not have obstetricians in every region. We have general practitioners with obstetric skills who work in partnership on a shared-care model with obstetricians in Perth. It is a similar approach.

Hon ROBIN CHAPPLE: I think that is really valuable. I really want to work on that whole basis that there is availability to provide palliative services without necessarily a palliative care specialist.

Ms BOLLETER: The department does have a classification framework for this—the clinical services framework. The clinical services framework sits across all aspects of health, including palliative care. It clearly delineates stages 1 through 3 as being end-of-life care and then stages 4, 5 and 6 being what we would talk about here as being specialist palliative care. It articulates the type of clinicians who need to be employed in each of those stages to meet that definition for specialist palliative care. This is completely consistent with similar documents that have been developed at a national level by Palliative Care Australia. There is a pretty consistent framework, I think, across Western Australia and across Australia around how this is differentiated. We can certainly provide copies of those documents if that helps.

Prof. FORBES: We can break down lots of medical processes into small bits which many people could deliver. But when you synthesise them into an integrated package, you often need some oversight, some specialist knowledge to be able to advise. We are now talking about a fairly mature system in that we have pretty well established palliative care services, although they are not necessarily

equally distributed. That is a result of people who have dedicated their lives to this. They provide enormous specialist drive, insight and oversight to ensure that the services are available. They remain available for consultation and direction and team leadership. We hope that everyone can have palliative care services close to their home, but we will still need oversight of specialist services, to make sure that services are up to date, and to monitor the quality of services.

Hon ROBIN CHAPPLE: A hypothetical just on the end of that: if all doctors basically had palliative care training within a training regime—more than just the current week that they get—would that help the whole process?

Dr BRADLEY: That is an interesting thought. From a specialist point of view, we would be talking about quite a lot of extra training to make them have specialist level skills. I think it would be great if all doctors had more palliative care training than they get. I got none as a medical student. It has subsequently changed since I went to medical school in Western Australia. A week of palliative care experience is not a huge amount, considering that pretty much any area of medicine they go into, they are going to be dealing with end-of-life care and palliative care. I think you are not going to get—unless you are talking about years of training—that same level of specialist experience or expertise to deal with the really complex stuff. But you could certainly get a lot of doctors better trained than the time limits offer at the minute.

Mr J.E. McGRATH: Further to that question, coming back to the metropolitan area, from my experience, a lot of GPs probably would not have the time.

Dr BRADLEY: That is very true.

Mr J.E. McGRATH: They are very busy, and even if they did have the expertise, they might not have the time to devote to palliative care.

Dr BRADLEY: Absolutely—yes. And the interest as well. Not all doctors find that area of care something that feels right or comfortable for them. We all find our area in whatever field we work in—an area we feel comfortable in and we probably have a natural skill set in as well.

Mr S.A. MILLMAN: There would be a hierarchy, though. There would be people who have studied the elective at uni. They have done the specialist training after they have graduated and it is their area of expertise. Then there would be other people who would take a professional interest in it and they read the journal articles that come through—all those sorts of things. Then there would be GPs who would have very limited experience but know of the rudimentary stuff.

Dr BRADLEY: All hospital doctors.

Mr S.A. MILLMAN: In terms of the distribution of doctors in WA at the moment, should we do anything to change the spread of people who fit into those different categories? Should we encourage people to develop a passion for palliative care? Is there something we can do in that direction?

Dr BRADLEY: I am incredibly biased. I would love everyone to have a passion for palliative care. Some people just are not going to be interested, no matter what opportunities are available to them. Certainly, making it easier to get experience and time in a palliative care setting would definitely be worthwhile. A lot of doctors would very much value that option. We have the PEPA placements, so GPs and other doctors—not just doctors—who want to get some more time, can come to Bethesda, where I work, and spend a day or two with us and really spend a bit more time hands-on seeing what we do. But it is difficult. There are things like diplomas in palliative care. GPs and specialists, potentially, could do a diploma in palliative care to upskill themselves that way as well.

[1.30 pm]

The CHAIR: This is probably more seeking your personal opinion, Dr Bradley. Is there a view in the medical profession that death is a failure of medicine?

Dr BRADLEY: It is my personal opinion. I suspect that, for a lot of doctors, that still is, in the more specialist fields. With GPs not so much, because I think they follow their patients a lot more through the whole life cycle, so to speak. But I think there is still a little bit of a feeling that death is a failure of medical care, because the majority of our medical training is about fixing people and making them better and helping them live as long as possible and all of those things. Palliative care still aims to do a lot of that too, but it is also acknowledging when, no matter what we do, death is going to happen soon.

The CHAIR: Ms Bolleter, you are probably the best person for this question. In our follow-up questions to you, we asked for the percentage breakdown of metropolitan and rural funding for palliative care for 2014 to 2016. I just want to confirm those figures. For those two years, the WACHS budget was 4.77 per cent.

Ms BOLLETER: That is what we have provided to you in the response. Appendix A provides more breakdown in terms of individual years of what that breakdown is. If you refer to, I think, the last table in that appendix, it gives you a year-by-year breakdown across all health services, which I think is probably the clearest example of that information.

The CHAIR: Yes. But is it fair to say it is a very small percentage of the budget?

Ms BOLLETER: In this breakdown, if you look at 2016–17, you can see that the WACHS proportion for that year is 17.18 per cent of the total budget. I think it is important to consider that in terms of head of population, and also just to consider, with all of this funding information we have provided, that we have sourced this information directly from health service providers and it is absolutely the best information we were able to get to you at this time. Given that palliative care funding is not neatly allocated centrally, there is always a risk when you go to a range of providers and ask them to give you budget information that it may not be completely consistent across all those sites. For example, some sites may incorporate a greater proportion of on-costs to those positions than another site might. We have provided you the best information we can, but I would just encourage you to have some consideration of those factors when you are reviewing it.

The CHAIR: Yes. I acknowledge that and appreciate that it has been a lot of work to get the information to us. I am just trying to understand, and this is probably just because of my trouble with numbers. We have got the WACHS percentages for 2014–15, 2015–16 and 2016–17 and they all go between 16 and 18 per cent, but the overall figure for those three years is 4.77 per cent. Am I comparing the wrong figures?

Ms BOLLETER: I think it is a difference between a breakdown year on year and then the total figure breakdown. We are certainly happy to look at that again.

The CHAIR: But if this is the total of those three years and those three years run between 16 and 18 per cent, how do we get to 4.7 per cent?

Ms BOLLETER: I think the difference is also the incorporation of the community services for metropolitan. I would be happy to have a look at that breakdown between the 95.23 per cent and the 4.77 per cent and provide some further breakdown of that just to help.

The CHAIR: Would you mind? Yes, please. That is quite a key point for us to look at, because we have heard a lot of evidence about accessibility of palliative care for regional areas, so the funding is pretty critical to that. So, if you would not mind, that would good.

Hon COLIN HOLT: This might also be suspect because of rubbery figures, I suspect. We have got an answer to the question on notice of \$123 397 000 on palliative care for those couple of years. It is probably unfair of me to say that, out of a budget of \$8 billion or so each year, it seems like a very, very low figure on palliative care. Would I be accurate in saying that or is that unfair of me?

Ms BOLLETER: I think it is important to note that these figures relate to the provision of specialist palliative care. They are where we can really identify a palliative care physician and specialist palliative care nurses, and the in-home service that Silver Chain provides for palliative care in metropolitan Perth. This is the combined figure for those budgets. This does not in any way address much of what we have been talking about today in terms of the care at end of life that is provided right across health. That is a very different budget figure from what we have provided you here.

Hon COLIN HOLT: I know. That is very useful. That is why I posed it.

Ms BOLLETER: We have provided you just the figure for specialist palliative care.

The CHAIR: That goes to my question: given the intensity of medical activity around end of life and the interactions that people have with the health system, are you able to quantify that in the last 12 months?

Ms BOLLETER: We have been trying to recently.

The CHAIR: Let me make it a bit easier. Are you able to quantify the cost of end-of-life care for the last 12 months of someone's life, which would include palliative care?

Ms BOLLETER: Certainly. We are able to see the data around who is in a public hospital and who has that Z515 code that we talked about before, so we can do some analysis based on that. We can do some data linkage which shows where patients move in the system between community and acute and aged-care settings, which is another, of course, significant area of care that we have not talked about much today yet. To actually totally quantify the amount of activity is a very large undertaking.

The CHAIR: We have had evidence that we spend X, X and X, so a ballpark figure, if you like, is useful for us. We have certainly heard evidence that the last 12 months of end-of-life care is very expensive, if you like—very costly. It is useful for us to have as much information as possible.

Hon ROBIN CHAPPLE: Do you have a copy of those five codes?

The CHAIR: Are you able to provide those codes for the committee?

Ms BOLLETER: Yes.

Mr J.E. McGRATH: What would be a trigger to lead to the provision of more funding for palliative care? Would it require an extensive review by the department to unpick where the funding goes and where the needs are? We as a committee are all very supportive of the work that is being done, but it has been raised that there are places, especially in the regions, where it is difficult for some people. We have also been told that it sometimes depends on your postcode what sort of palliative care you can access. If we as a committee wanted to make some recommendation regarding funding for palliative care, where would it start and where would it end, because it is obviously a very complicated thing to unravel?

Prof. FORBES: It will never end if you open it. Most decisions about delivery of health services arise in response to recognition of need which, if we are lucky, will be recognised by health services. But it is frequently generated from the community, from you people, from your constituents, identifying difficulty in access. In my experience, that is the most important driver for delivery of any new services.

The CHAIR: Following on from that, if palliative care is delivered throughout the system and the need for next year's amount of palliative care, if you like, is assessed on previous years and people are not necessarily coded as "palliative" in the system, how are you able to accurately assess what the financial need is?

Prof. FORBES: I think the reality is that budget building is an imprecise science. It is based on historical trends and predictions based on epidemiology, clinical experience and feedback from consumers via politicians and other agencies.

The CHAIR: So help us, as people who do not work in the system, understand what would make budgeting easier. Is it an improvement in the codes?

Mrs BAXTER: Correct coding.

The CHAIR: Correct coding; that is what I am trying to get at. So tell us how incorrect coding impacts the system at the moment.

Mrs BAXTER: We have a series by which every patient who comes into hospital has their record of care and their episode of care coded. Funding is allocated according to the activity and the DRG or the Z code, whichever is applied to it. If they are incorrectly applied, your funding obviously is affected. The processes that we have in place for the activity-based funding are that we have put a lot of resources in health to accurately correct coding to reflect the activity that is done so that the financial payments follow. That is where we are in that process. It does come down to accurate coding.

The CHAIR: Do you think palliative care is well coded in the system?

Mrs SLATTERY: It is complex and difficult, because quite often the patient will present and their presenting symptom or diagnosis is not palliative. That is where a lot of work has to occur to ensure that if they are noted to be palliative or become palliative, the coding is either changed or at least added to. That has been a problem.

Mrs BAXTER: You might have had, for instance, a fractured neck femur. You have been through a whole process—you have broken your leg and you have been in and had an operation and that is it. Throughout that process, you might end up with a wound infection and you might end up with a chest infection. If you do not appropriately code that episode of care, the funding for that wound infection and that pneumonia will not come along with it. It is vitally important that we correctly code and manage that patient record so that, at the end, when the patient has been discharged, we can correctly assess associated funding with it.

Mrs SLATTERY: The other issue is funding for community services and occasions of service. I do not know if you want to speak to that, Amanda, because that is a work in progress. At the moment, palliative care patients are treated more like an outpatient occasion of service for a funding code. Obviously, quite often it is a lot more than that, because we would attend at their own house. It might be two or three times a day; it might be during the night. It would be a lot more than just an outpatient occasion of service. That has been recognised and it is a work in progress, but that is the shortfall currently.

Ms BOLLETER: That recognition is at a national level, so it is part of the activity-based funding framework, which is managed nationally. I know it has been flagged as an issue nationally that those classifications do not fully reflect what is required for community palliative care. We are also in the process at the moment in WA—we talked about this in our last presentation to you—of rolling out a dataset across specialist palliative care services to better enable them to collect all the data that is required to attract that full activity-based funding payment from the commonwealth to the state

for specialist palliative care, because we do have some services that are still not fully able to provide that data. That is a priority for the department to complete that rollout.

Hon ROBIN CHAPPLE: Hypothetically, we have a patient in hospital who is basically unwell—ill—and they reach a stage where they become palliative. Is there a code around that? How is that implemented? Is it implemented on the basis of a doctor's evaluation, or does the nurse practitioner say, "This person now has reached code X" and therefore they go onto that? How do we deal with that?

Mrs SLATTERY: There are episodes of care and we have those episodes-of-care changes. It is the same as if a patient is acute and then they become subacute or rehabilitation. Then they have a care-type change. But for palliative, that would not necessarily occur. It is the fact that they have been seen by a specialist person, be it a nurse or a doctor, and that is recorded in the notes.

Hon ROBIN CHAPPLE: So it is only if they have been seen by a doctor who has determined that they are palliative?

[1.45 pm]

Mrs SLATTERY: No, it can be for a referral if they are complex and need a specialist referral.

Mrs BAXTER: I think what you are saying is if I am the patient in hospital and I have gone in with a chronic condition and the decision has been made that it is now time to move into the palliative phase, then that code is changed on the patient information system.

Hon ROBIN CHAPPLE: Okay.

Mrs SLATTERY: That is the care-type change.

Hon ROBIN CHAPPLE: Does that depend on the hospital or hospice where you are?

Mrs BAXTER: On the discussion with the family and with the team, with the patient, and with what information is there in front of you as to whether that patient now needs to move into a palliative phase.

Ms BOLLETER: It must be informed by the care of a specialist palliative care team. In the metropolitan service, that is likely to be a review and assessment by the palliative care team in the hospital. In WACHS, as we have talked about, it may be the regional palliative care team in consultation with the patient's GP. But our policy states that there must be care that is informed and a decision that is informed by the palliative care team to make that care-type change.

Dr BRADLEY: Which has implications if you do not have a specialist palliative care team in the hospital.

Hon ROBIN CHAPPLE: I go back to my colleague —

Hon Dr SALLY TALBOT: That is the Mt Barker question.

Hon ROBIN CHAPPLE: Yes, that is the Mt Barker question.

Ms BOLLETER: In a regional area, that is covered by a regional palliative care team, which can make that decision to change the care type.

Hon Dr SALLY TALBOT: Does the regional palliative care team travel around?

Ms BOLLETER: Yes.

Hon Dr SALLY TALBOT: How long might they have to wait in Mt Barker, for example?

Mrs BAXTER: They do not have to travel around; they can do it through telehealth. We can have that meeting and discussion —

Hon Dr SALLY TALBOT: They do not have to see the patient in person?

Mrs BAXTER: They can see on the screen. We have telehealth in 70 facilities.

Mrs SLATTERY: And the GP.

Mrs BAXTER: And with the GP, yes.

Dr BRADLEY: But if you are in, say, St John of God Midland that does not have a specialist palliative care team, then you would not have that option.

Ms BOLLETER: No, you could not change care type then.

Hon COLIN HOLT: Can you just say that again?

Dr BRADLEY: I used that as an example and I do not mean anything derogatory about it but as an example of a hospital that does not have specialist palliative care team. If you are a patient in that hospital and you went in for some reason and became a palliative patient or went into the palliative phase during your stay, they do not have a specialist palliative care team in that hospital so you cannot change the phase.

Hon COLIN HOLT: You cannot change the code?

The CHAIR: Could you not even access MPaCCS, for example?

Ms BOLLETER: MPaCCS, which is the Metropolitan Palliative Care Consultancy Service, their remit is in residential facilities; it is not in hospitals. So we would expect in a service like St John of God Midland that they would be able to provide good end-of-life care from their existing staff with their experience and skills. But if a patient required specialist palliative care, then the decision would have to be made about referring them to another service for that hospital.

Hon COLIN HOLT: You would have to shift them—really? Does that seem like a gap to you? Can you just say that?

Dr BRADLEY: That was a yes; sorry, no nodding allowed.

Hon ROBIN CHAPPLE: For the record, Hansard, that was a yes.

Hon Dr SALLY TALBOT: To do a quick follow-up on Hon Robin Chapple's question, first of all, when the code changes, what are the practical implications of that?

Ms BOLLETER: The practical implications, if we use an example perhaps of a patient who is at Sir Charles Gairdner Hospital in Perth who might have been admitted with a chronic condition and then the determination is made in consultation with the palliative care team at Sir Charles Gairdner that this patient is now a palliative patient and that their care will primarily be from the specialist palliative care consultancy service, as it is at Sir Charles Gairdner, then the patient still remains under the primary treatment team, under whom they were admitted. In addition to that, their care is managed and informed by the specialist palliative care team so they would have regular assessment and review by a palliative care physician and care and input from specialist palliative care nurses and also access to specialist palliative care social work input. In a service like Sir Charles Gairdner, and also Royal Perth and Fiona Stanley have the same model in the metro, the patient will remain where they are in the hospital, in the same bed that they were admitted to, most likely, but they will now have the additional care of the specialist palliative care team, who work right across the hospital to provide that consultancy. I think it is a model that enables the care to come to the patient, which has a lot of advantages.

Hon Dr SALLY TALBOT: What about outside the metropolitan area?

Ms BOLLETER: Outside the metropolitan area, there are similar principles, but I would refer to my colleagues.

Mrs BAXTER: The same principles, yes.

Hon Dr SALLY TALBOT: To go back to Mt Barker, if you are admitted under scenario A and then there is a code change, what actually happens on the ground because there is no visiting palliative care specialist?

Mrs SLATTERY: That would be the referral through to the specialist palliative care nurse. We actually have nurses in each of our areas that come under the remit of the specialist palliative care nurse for the regions, but it is not just one. There is one nurse that coordinates, but we have specialists in each of our sites as well.

Hon Dr SALLY TALBOT: How is their time divvied up between the regional centres that they might serve? Are we getting closer now —

Mrs SLATTERY: It depends on the need.

Hon Dr SALLY TALBOT: Are we getting closer now to the answer to the question I asked earlier in the session about the 24/7 care in Albany; nine to five, five days a week in Denmark; and seven hours a week in Mt Barker? Could that be the specialist palliative care nurse?

Mrs SLATTERY: No. The specialist palliative care is a consultancy service from the nursing perspective. We develop the skills of the nurses in each of the hospital sites and then sometimes we visit, particularly if there is a particularly complex patient, but we can VC-in and we can telephone in. Obviously the patients are under the care of the GP and the GP can access specialist medical advice as well.

Hon Dr SALLY TALBOT: We did hear some very enthusiastic reports about the telehealth. I do not think we have heard a criticism of that service, but how often is it used?

Mrs SLATTERY: We have actually just—do you want to speak to the nurse of the year?

Mrs BAXTER: Yes. This year's winner is one of my nurse managers who is a palliative care nurse manager. He established a pilot program to put telehealth in the home of palliative care patients, so all palliative care patients were given an iPad and access to specialist nursing services and access to GP and specialist services as and when they felt it was needed. It means that you do not have to visit every day because you can telehealth-in. So, if anything, they are probably getting more access to a specialist nursing service through this model of care. It has been very successful in the wheatbelt and we are putting it in the south west and great southern.

Hon Dr SALLY TALBOT: Is this in-home palliative care?

Mrs BAXTER: Yes, well we can keep the patients at home for much longer than what we previously would have.

Hon Dr SALLY TALBOT: So is that slightly different to the service you were referring to just now? You were talking about the GP and the nurses at, for instance, Mt Barker hospital, being able to access the specialist via telehealth.

Mrs BAXTER: Yes.

Hon Dr SALLY TALBOT: How often does that happen?

Mrs BAXTER: As and when it is needed.

Mrs SLATTERY: When it is needed.

Hon Dr SALLY TALBOT: Would it happen —

Mrs BAXTER: I am not going to say 24/7 because it is not there 24/7.

Mrs SLATTERY: We have a telephone advice line 24 —

Hon Dr SALLY TALBOT: So it is not there 24/7?

Mrs SLATTERY: We have —

Mrs BAXTER: We have the advice line 24/7.

Hon Dr SALLY TALBOT: If I am a GP in Mt Barker and I have a palliative care patient in the hospital, what hours of the week is that telehealth expertise available to me?

Mrs SLATTERY: Telehealth is working hours.

Dr BRADLEY: Telehealth would be business hours.

Mrs SLATTERY: Yes, business hours.

Dr BRADLEY: But they have a 24-hour number directly to a specialist palliative care consultant.

Hon Dr SALLY TALBOT: Is the 24-hour number a videoconference?

Dr BRADLEY: No, at this point it is not; it is just a telephone.

Hon Dr SALLY TALBOT: So they can phone a friend?

Mrs SLATTERY: An expert.

Dr BRADLEY: Yes, exactly. Hopefully we are friendly, too.

Hon Dr SALLY TALBOT: In-home, you are talking about this new service where patients at home can access services but I will go back to my original question, which is about the difference in the services that you receive from the health department if you live in Mt Barker compared to Albany. Albany is going back to 24/7, so they can have access to a specialist palliative care service—a nurse—24/7. What access do they have to a service in Mt Barker?

Mrs SLATTERY: It is exactly the same.

Mrs BAXTER: They are exactly the same.

Hon Dr SALLY TALBOT: Is it 24/7?

Mrs SLATTERY: Yes.

Hon Dr SALLY TALBOT: Somebody to come to their house?

Mrs BAXTER: No, but they will have access to specialist consultation.

Hon Dr SALLY TALBOT: So this is the patient ringing from home?

Mrs BAXTER: Into the 24-hour service in Albany.

Hon Dr SALLY TALBOT: Right, so that is a 24/7 phone service?

Mrs BAXTER: It is similar to a hub and spoke —

Hon Dr SALLY TALBOT: Yes.

The CHAIR: If someone needed treatment or very immediate addressing of pain issues, how would you do that?

Mrs BAXTER: It is the GP.

The CHAIR: You then contact the GP who would try and get out to see that patient or get that patient in to them. Alternatively, would they have to bring them into a regional hospital?

Mrs BAXTER: Yes.

Hon Dr SALLY TALBOT: Who does that contact? Is it the specialist service that then says, “Look, you just stay there and manage as best you can; we’ll send somebody to help”?

Mrs SLATTERY: It depends where the patient is on their journey. If they are at the terminal phase, we are aware of that so we would have a nurse on call. Then the nurse would either give telephone advice or would visit as needed, or would advise for the patient to come in. We do not provide an on-call service for every palliative patient throughout every night. We provided for when they are complex and when they are end-of-life. Some patients are beyond our ability to manage at home and sometimes it is the tyranny of distance if they live on a farm or somewhere. But then we offer that service in our local hospital so, as close to home as possible. It is pretty rare that we cannot manage them there and sometimes they have to go to the regional resource centre, but that would be perhaps for symptom management or if they were particularly complex or in a crisis. Then we would still hope to step them back down to their local hospital or even to home.

Hon Dr SALLY TALBOT: My final question is: how many beds there are in Mt Barker? I do not think it is very many.

Mrs BAXTER: I think it is 12.

Hon Dr SALLY TALBOT: If there are 12 beds, do you know how many of those would be occupied by palliative care patients?

Mrs BAXTER: It could be any on any given day. We would have to find that out.

Hon Dr SALLY TALBOT: Would you have that information you could give us? Choose a period of time; I do not want to create work for you.

Mrs SLATTERY: I would doubt it would be all 12 beds, but it could be any number.

Hon Dr SALLY TALBOT: Say over the last 12 months, what is the average bed occupancy for somebody who has a palliative care code?

Mrs BAXTER: Yes.

Hon ROBIN CHAPPLE: I have a very simple question: how many doctors are there in Western Australia?

Dr BRADLEY: I do not know, I am afraid.

Ms BOLLETER: In terms of specialist palliative care positions?

Hon ROBIN CHAPPLE: No, just doctors.

The CHAIR: Do you mean practising doctors?

Hon ROBIN CHAPPLE: I mean practising general practitioners and hospital doctors.

Mrs BAXTER: We have just done just over 800 medical services agreements for doctors for WA Country Health Service and that is not all of them.

Prof. FORBES: We need to take that question on notice.

Hon ROBIN CHAPPLE: Yes, that is fine.

The CHAIR: I assume there is a registration?

Dr BRADLEY: Yes. AHPRA would know.

Hon ROBIN CHAPPLE: Yes. We have an idea that if the AMA represents 50 per cent of doctors and they have a membership of around about 5 000 to 5 500 people, that assumes there is somewhere between 10 000 and 11 000 doctors in Western Australia.

Prof. FORBES: I have a figure of 9 500 in my head, but I would need to confirm that.

The CHAIR: I think we can probably get that information from the practitioners registration board.

Hon ROBIN CHAPPLE: No worries.

Mrs BAXTER: They do not all work full time.

Hon ROBIN CHAPPLE: Yes, I understand that. I think it is about registered doctors, actually; that is the issue.

The CHAIR: I will now move to some of the questions that we did not get to last time and some of the newer ones that were sent through. I am going to go through the questions that were declined to be answered because of legal advice. I will run through them and hopefully we will have responses.

The refusal of medical treatment can include refusing artificial hydration and nourishment, as in the Rossiter case. In your experience, is this issue now clear for medical professionals, patients and treatment decision-makers?

Prof. FORBES: The decision of the court is quite clear and practitioners will include this in their decision-making. It is important to remember, however, that the medical establishment is not static. It changes. There are people coming into WA all the time, many of whom will have never heard of the Rossiter case. I also believe that there will be some practitioners who will be very uncomfortable with the ramifications of the Rossiter case and will be confronted by not intervening, and will have to work through that issue.

I am not aware that it is an issue. It is certainly not an issue that has been raised with my office that doctors are unaware of or struggling with this.

The CHAIR: In your experience, is the practice implemented appropriately in Western Australia where it does occur?

Prof. FORBES: Yes, it is. As I said, I have had no indication that it is not being implemented.

The CHAIR: Patients can refuse hydration and nourishment that is not provided as a medical treatment. When is a patient permitted to refuse hydration and nourishment?

Prof. FORBES: The issue here is of competence to decide. If an adult is competent to decide and they decide not to eat or drink, then we need to respect that. In my own practice as a paediatrician, I have worked with lots of adolescents who had eating disorders and indicated that they did not want to eat and drink, that they wanted to die. Clearly, we intervened because they were deemed not competent because of their malnutrition and the underlying disease. But if someone is competent or if they made an advance care directive regarding this, that would be respected.

[2.00 pm]

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

Prof. FORBES: Exactly the same right is there. If they are competent or if they have made an advance care directive when they are competent, their views need to be respected.

The CHAIR: Again, when a patient is receiving palliative care, are they allowed to refuse hydration and nourishment?

Prof. FORBES: Again, exactly the same answers. It comes down to competence, or an advance care directive when they were made competently.

Hon ROBIN CHAPPLE: Who determines competency?

Prof. FORBES: That will be a clinical decision which will be made by the various practitioners—it could be nurses, it could be doctors.

Hon ROBIN CHAPPLE: It could be nurses?

Prof. FORBES: It could be nurses, who know people and are often in the best place to know when there has been a change in mental functioning.

Hon ROBIN CHAPPLE: Okay, so doctors determine competency?

Prof. FORBES: No, with respect, I said it can be nurses, it can be doctors—it will be a team. Doctors may take advice on this and may make the decision. Sometimes a process will be well established and a nursing team who will be looking after a patient may make the decision. I would anticipate that most would consult with the GP if they were in an aged-care facility.

Hon ROBIN CHAPPLE: So it will be a discussion between the nurses and the doctors around competency?

Prof. FORBES: And usually the family. Very few of these decisions are made unilaterally. It is only really when people have no next of kin; if they have made a declaration in advance and they deteriorate, their requests will be followed. My experience is that whenever there is a family involved, they will be consulted in these processes.

The CHAIR: If a patient was receiving palliative care and opted to refuse hydration and nutrition, would you require a psychiatric assessment to assess competency?

Dr BRADLEY: Not necessarily, no. I think if the team felt comfortable making a decision of their competence, then we would not, and accessing a psychiatric assessment is very difficult because of availability of psychiatric time. From my personal experience in a stand-alone unit, it can be very difficult for us to get psychiatric—someone to come and visit to do that assessment, so it may make it impractical.

Prof. FORBES: Most GPs are quite well trained in determining competency. They are trained to do mini-mental health exams. And if they already know the patient, they can recognise deterioration.

Hon COLIN HOLT: I think you also said that they follow an advance healthcare directive that is in place. I assume that that is made and signed off when there is a level competency.

Prof. FORBES: Yes.

Hon COLIN HOLT: So that competency that you have at the time of filling out your advance healthcare directive carries on?

Prof. FORBES: Yes. The decision that is made when you are competent persists.

Mr S.A. MILLMAN: Is the exercise of the medical treatment under that advance health directive ever conditioned by other factors or is it adhered to? Is there ever the situation in which I make an advance health directive that I will refuse food and water—that is my decision, I have done it, I have prepared it with the doctor and a lawyer and I have signed it and all the rest of it. My family comes in and says, “No, what he really wanted was to have food and water.” Is it ever the case that those considerations are taken into account or is it always the case that the advance health directive is followed?

Prof. FORBES: Here we are talking hypotheticals. I can envisage a situation in which you have done all of that and you are at an advanced stage of illness, but something happens to cloud your consciousness for a period. Everyone else thinks, “This is it, he’s about to die”, and I make a judgement that minor treatment to renal function or something could in fact change the situation completely. Under those circumstances, I would discuss that with the family and say that I do not think this is terminal.

Mr S.A. MILLMAN: How does that sit with patient autonomy?

Prof. FORBES: Patient autonomy is always a balance between respecting the individual and doing no harm. If someone has made it very clear that under no circumstances do they want any intervention should they deteriorate, and I have known people who have done this, I think most doctors would respect that.

Mr S.A. MILLMAN: Are you aware of circumstances where it has not been?

Prof. FORBES: No.

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

Prof. FORBES: This would require the substitute decision-maker to have been appointed with an enduring power of guardianship so that they were legally entitled to make such a decision and —

The CHAIR: Would that be the only circumstance that you could envision?

Prof. FORBES: My understanding is that the State Administrative Tribunal could appoint somebody who had not been previously appointed, and could make that decision.

Hon NICK GOIRAN: I take it, however, that what we are talking about here is a circumstance in which a patient does not have capacity, hence there is somebody else who is making a substitute decision for that person, and here the question that has been posed to you is about the refusal of hydration and nourishment. If that patient does not have capacity and yet demonstrates signs to the carers that they would like food or hydration, that would be provided to them. I cannot imagine there would be a circumstance in Western Australia in which a patient would be sitting there and gasping or begging for water and the health carers would say, "Sorry, we're not going to give that to you because your substitute decision-maker has said there is to be no hydration or nourishment."

Prof. FORBES: Absolutely, I agree with you. That would never happen.

Dr BRADLEY: And that would then be communicated carefully with those substitute decision-makers to try to work out why they are saying something that does not seem to fit with what the patient's wishes are.

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

Dr BRADLEY: I think certainly if a patient's prior wishes are known, then absolutely—so if they have expressed their wishes, whether that is in an advance health directive or whether it is just by discussing it with her family, we would respect that. I think also we, as medical professionals, and certainly my experience would be that if I felt that artificial nutrition or hydration was no longer in the patient's best interests, I would be discussing that with the patient and their family or carers to talk it through with them and really express my concerns about what harm might be done by doing it versus the benefit. We would hope in an ideal circumstance, and certainly in my experience, we always reach an agreement on the right way to go forward. Sometimes that may be the family or the patient saying very strongly, "I really want to keep this going for a little bit longer. I feel like I might get better", or we meet in the middle or we see what works best at the time.

The CHAIR: Is it the case generally that patients who refuse nourishment and hydration are treated with pain relief until they die?

Dr BRADLEY: It depends on if they have pain. If they do not have pain, they will not necessarily receive pain relief.

The CHAIR: If that is the case, what kind of medication do they usually use in those circumstances?

Dr BRADLEY: It would depend on the assessment of what the pain was from. Not having food and fluid does not tend to cause pain. It is not a painful process as such, but they may have a lot of other medical conditions going on that cause pain and then it would be choosing the appropriate medication, which may well be opioid-based medications if that is the appropriate one for what they need. There may be other circumstances where they have pain because their bladder is really full of wee—they cannot wee because they are deteriorating—and a catheter going in would cure that pain, or they are immobile in bed and they are comfortable and pressure care will cure that discomfort or that pain. We look beyond just medicine to treat the pain.

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

Dr BRADLEY: Not if the person has pain, no—it would be inappropriate. If there were any circumstance or some reason that the doctor did not want to administer pain relief, I think they would really need to review what was going on and if that was the case, I would ideally suggest that another doctor then became involved if, for some reason, that doctor had a personal concern about it, but it would need to be explored with the team as well.

Mr J.E. McGRATH: Just further to that, do you find that many people request to have no nourishment or hydration?

Dr BRADLEY: In my clinical experience of working in palliative care, I have worked in palliative care now for 16 years, I have not had anyone do it.

Mr J.E. McGRATH: No-one?

Dr BRADLEY: No-one. They may do it without necessarily making it obvious to the healthcare team, so I would not know necessarily, but I have not had any suspicion that that is what has happened. I know other specialists have had that experience of patients doing it. I have had that experience of patients talking about it and starting it and then deciding that they actually do not want to do that.

Mr J.E. McGRATH: We are told that sometimes patients at that stage of their lives lose their appetites anyway.

Dr BRADLEY: That is very different, absolutely. At the end of life, basically 100 per cent of patients will lose their appetite and lose either the ability to safely swallow or just the interest in doing so. I would say for 99 per cent of my patients that that would be the case, that they lose that intake. That is not a conscious decision to stop eating and drinking, that is just no longer having that desire there.

Prof. FORBES: Can I just pick up the point that Dr Bradley made?

The CHAIR: Yes.

Prof. FORBES: Sometimes family may perceive that a patient has pain and it could be something like a full bladder or it could be some agitation for some other reason. I am aware that sometimes there is conflict in hospitals about not delivering pain relief, but it is about a perception of what is going on and that should lead to a discussion between the care team and the family, firstly, to understand what is the cause of the distress and, secondly, to take steps to alleviate it.

The CHAIR: Are there circumstances in which health professionals could decide to administer sedation on a patient's behalf at the very terminal phase—so, without explicit consent, if you like, from the patient?

Prof. FORBES: There is inevitably an indication for an intervention, so if a patient is in pain and that has been indicated, that pain should be alleviated. If they are distressed because of their hunger, because they having struggles breathing, an opiate might alleviate that. Is there an indication to provide sedation just because someone is near death? I would struggle to see that.

Dr BRADLEY: It is only if they appear distressed, yes.

The CHAIR: How would the doctor come to that conclusion, I guess? Let me give you another example where a patient feels their pain is being unmanaged.

Dr BRADLEY: I suppose there are sort of the two things. When a patient can tell us what is going on, that is incredibly helpful. If they feel their pain is not being well managed, we should absolutely be listening to them feeling that and exploring what is going on for them to feel that, and working out whether it is a physical pain that requires opioids, is it a discomfort for another reason or what else is going on and provide the appropriate management. It gets more difficult when patients are no longer able to have that discussion with you so you cannot get that information from them. As David said, if they look unsettled, it can be very difficult to work out whether it is because they have pain or they are just feeling distressed for other reasons; what else is going on. Sometimes it is impossible to know whether it is pain versus some other cause of distress. In that case, we would often do a trial and see what medicine works best in that circumstance and work out whether it is pain relief or sedation that works best. Does not make sense?

The CHAIR: Yes, it does.

I want to touch on the Criminal Code and end-of-life practice. There is already quite a different standard for criminal liability for medical professionals in administering end-of-life treatment, in particular terminal sedation, and the reliance of double effect, and it really centres around the intent of the medical professional. We have also heard evidence that for medical professionals to be part of voluntary assisted dying, that it is not a huge departure from that. Do you have a view on that?

Prof. FORBES: I do. I think the intent is the key here. If the intent is to hasten death, that is a serious departure. I reject completely that it is very close to what we would do because the intent is everything. If the intent is to relieve suffering and there is a possibly anticipated but undesirable consequence of hastening death, that can be considered and maybe acceptable. If the only intent is to hasten death, that is not acceptable. The question has been asked: why is the intent different? If we do not take account of the intent, I find it very difficult to differentiate between any therapeutic misadventure, if you like, and a criminal act. They can look exactly the same so all we can judge is the intent, so it is crucial to all this discussion.

Mr J.E. McGRATH: Further to that, do you think the public have a misconception about this? When I speak to people about the subject we are talking about now, they say, "Oh, the doctors do it now anyway." In fact, the doctors do not do it, and you are telling us they do not do it but the public believe they do.

Dr BRADLEY: I get that every single day at work. The families go, "Oh, you're going to set up the pump." It is kind of done in inverted commas, almost, as if they assume that because we are talking about providing appropriate levels of pain relief for the patient, sedation if they need it, that that is us as doctors ending their life. We spend a lot of our time on a day-to-day basis explaining that that is not at all what we are doing, that we are not hastening death.

Mr J.E. McGRATH: Professor, what do you think?

Prof. FORBES: I absolutely agree with you that the public does have a misperception here. I actually think it is a very dangerous misperception because it devalues life. It devalues the relationship with the physician as healer. If we lose that, we find it very difficult to do our work. Every therapeutic complication will end up being adjudicated by lawyers and destroy the medical system as we know it, let alone the relationship between patients and doctors.

Hon NICK GOIRAN: Further to that, it is a good question from my colleague there with regard to the misperception within the community. Is it the view of WA Health that some of that misperception is also contained within the medical community itself?

Prof. FORBES: I do not think the department can have a view on that. My personal view is that the medical profession reflects the rest of the community in so many ways. You can find a range of views in the medical profession, as you can in the rest of the community.

Dr BRADLEY: I agree.

Hon COLIN HOLT: It sounds like Parliament!

The CHAIR: Do you think that there is the risk of underdosing or undermanaging pain for fear of this misconception—what you have characterised as misconception?

Dr BRADLEY: I think that from the point of view of anyone who is working in palliative care and has experience in end-of-life care, no, I do not think that we underdose in pain. I think we very carefully assess the risk of side effects and the risk of benefits and adjust the dose in line with those. I do think, in line with what we have just as our personal opinion—other medical practitioners have concerns particularly about opioid medications, but potentially sedative medications as well—my experience is that when we see some patients, they are not getting adequate doses because the doctors are worried about increasing the levels. We see that all the time. Our patients will often be on very high doses of medication, as their background level. That is what maintains their pain well at home. If they end up in an acute hospital setting, for example, they get given a tiny, tiny little breakthrough dose if they have pain when they get there, and their system is used to and requiring a very large dose, and that does nothing but the doctors are too concerned about the risks to then give the appropriate dose, even if they may have that dose information provided by the patient or the family when they go in.

The CHAIR: That is certainly the evidence that we have heard.

Prof. FORBES: This reinforces the discussion we had around the very first question about the relationship between specialist palliative care services and community level expertise. The specialist services frequently provide advice to GPs and others who provide palliative care about dosing, about adjustments, about safety and about drug interactions.

[2.20 pm]

The CHAIR: Is there a danger—I think this follows on from your point, Dr Bradley—that someone gets put on the pump and this concept of slow titration up to a particular dose could leave that person in quite significant pain for some period of time whilst we go through this slow titration process?

Dr BRADLEY: Ideally not. From an inpatient unit where I work, we would know straight away so it gets treated by the peacock thing: if the nurses have given three breakthrough medications within a shift, they would automatically, within Bethesda, need to call the doctor on call or find us in the building and tell us that what is happening is not working, that the patient's pain is not being managed and we would therefore change the background pain medicine, whether it be the pump or tablets or whatever they are receiving.

The CHAIR: That is in a hospital setting. What about a home setting?

Dr BRADLEY: I think it is then more difficult because it is obviously getting access, someone coming out and adjusting that medication. They can advise on breakthrough doses so hopefully they would get them advice to increase the breakthrough dose, which is the acute acting medicine that they take for the pain. That would then hopefully kick in. The problem would be if a patient cannot

swallow, the family cannot necessarily give a subcutaneous injection; they would need to wait for the community service to come and give that injection.

Prof. FORBES: That could trigger a transfer to a hospital too, if symptoms are not being adequately managed.

Dr BRADLEY: Depending on the patient's wishes and the family's wishes. That is right.

Hon COLIN HOLT: Again, that comes back to resourcing to be able to get to the home, where they potentially might want to see out their days rather than being bundled in the back of the car or ambo and taken off.

Dr BRADLEY: Exactly.

Mrs SLATTERY: We often have regimes written up for the family and the nurses can visit up to three times a day and we can ring the GP and get a verbal order for a change in medication. We can respond quite quickly.

Hon COLIN HOLT: It is pretty interesting, given the size and remoteness of Western Australia, how we manage that with people's wishes of being able to die in their home or their country, as we heard up in the Kimberley. There are some big challenges there.

Dr BRADLEY: I think a lot of patients, when I speak to them about going home, say if they have been an inpatient and they want to go home, it is acknowledging that the responsiveness is good but it is not necessarily as good as an inpatient setting, whether that be a hospital or a hospice, and the patient accepting that risk. I am not saying that is ideal but that is the nature of it.

Hon COLIN HOLT: That is where we are at.

Hon NICK GOIRAN: The committee would like to know whether the current protections in the Criminal Code are sufficient. We just heard from the AMA earlier this afternoon on this point. I will just refer back to my notes. I am pretty sure that the response from the AMA was that they do consider the current protections for practitioners in the Criminal Code sufficient. In fact, my colleague asked whether there is a fear by medical practitioners. The response was that there is emphatically not a fear. What is the position of WA Health on that?

Ms BOLLETER: We do not have specific legal advice on that so I do not think we can give you a legal opinion around what is in the Criminal Code and whether that is applicable. There is further legislation. The legislation that established advance health directives protects clinicians who follow a patient's advance health directive from criminal implications for their actions so long as they are following what is articulated in the patient's advance health directive. It is not just the Criminal Code; there are protections in other WA legislation for clinicians as well.

Hon NICK GOIRAN: Professor Forbes, you can consult from time to time with medical practitioners in WA?

Prof. FORBES: Yes.

Hon NICK GOIRAN: Do any of them express to you a concern that the Criminal Code provisions are insufficient?

Prof. FORBES: They have not to date.

Hon NICK GOIRAN: Dr Bradley, do you have any concern about the Criminal Code provisions?

Dr BRADLEY: No.

The CHAIR: I wanted to ask about death certificates. We had evidence from the UWA medical school that the Department of Health is responsible for teaching pre-internship med students about issuing death certificates. Is that correct?

Prof. FORBES: Yes, that is correct.

The CHAIR: Is it the case that when someone has died following refusal to consent to treatment, refusing nutrition, hydration, terminal sedation and when medication could potentially have brought forward that person's death that none of those are listed on the death certificate—that it is the underlying disease? Is that right?

Prof. FORBES: That is my understanding and belief, yes.

The CHAIR: So the practice of, say, terminal sedation is not listed on a death certificate?

Prof. FORBES: No.

Dr BRADLEY: No, because the patient is dying anyway. It is just the medicine that is provided to help them be comfortable while they are dying.

The CHAIR: We will go to palliative care for the moment. What are the palliative options available for the neurodegenerative patients?

Ms BOLLETER: The palliative options for people who have a neurodegenerative condition are really the same as for people with any other diagnosis of a life-limiting illness. People may also choose to access support and advice from disease-specific groups like the Motor Neurone Disease Association of WA or Multiple Sclerosis WA, which, despite its name, provides care for over 30 different neurodegenerative conditions. There are also three specialised motor neurone disease clinics in Western Australia, and these are based at Sir Charles Gairdner Hospital, Fiona Stanley Hospital and St John of God Murdoch. The palliative options, the palliative care that is available for somebody with a neurodegenerative condition, are the same options that are available for anybody with a life-limiting illness so there is care available across metropolitan and rural Western Australia, in inpatient settings like Bethesda, in consultancy teams like the one I talked about at Sir Charles Gairdner Hospital, or community care like that provided by Silver Chain. Those options are all available for people with neurodegenerative conditions. All palliative care services are expected to be able to assess and meet the needs of people with neurodegenerative conditions as part of their care. There are no services currently in WA that are specifically set up for the purpose of providing specialist palliative care for somebody with a neurodegenerative condition because their needs are met by existing service providers. We have a motor neurone disease model of care for Western Australia. This is very clear around the importance of relief of symptoms and anxiety, how that might sometimes require a complex medication regime and the need for that real 24-hour attention, so hydration, hygiene, catheters, medication, possible ventilation and other general nursing measures. For people who have a neurodegenerative condition, it is also important to look at the use of equipment, for example, for safely lifting a patient, and also to assist around communication, if someone has lost the ability to speak verbally, how else clinicians communicate with that person. Of course, support for families is always important in palliative care and I think it is particularly important in neurodegenerative conditions partly because of some of those difficulties around communication. I do not know whether Dr Bradley would like to add anything further from her clinical experience.

Dr BRADLEY: No, I think that sums it up very well.

The CHAIR: We have heard some evidence—I am interested to get your feedback—that people with neurodegenerative diseases are too hard, I guess, for community-based care and even hospice care. We have had some evidence of people being turned away from hospice care. You have said it is

available and we ensure services provide that. That is the experience that we have had in this committee.

Ms BOLLETER: I want to ensure that the information we provide to you is evidence-based and we do not have information that has been provided to the department around care not being provided. Certainly, if that information was provided to the department, we would investigate it thoroughly in terms of why that occurred because it is not consistent with the model of care that the department has set. That would be something that we would investigate thoroughly. As I said, the model of care itself acknowledges that care needs are complex and they are 24-hour needs so these are patients and families who have very significant care needs, but we expect that the services that are available can meet those needs; or, if for some reason on an individual basis they are not able to, to appropriately refer that patient in a really timely way to ensure that the patient's needs are met. There is no exception in terms of the models of care around providing care for some conditions and not for others.

[2.30 pm]

The CHAIR: I want to explore this notion of palliative care as being not just physical pain, but spiritual and psychological. We are just about to release the end-of-life specialist palliative care strategy, which cites the goal of end-of-life care is to prevent or treat as early as possible psychological, social and spiritual problems relating to life-limiting illnesses. Who would assess psychological, social or spiritual problems?

Dr BRADLEY: Any member of the health care team can do that assessment, and it would depend on where the patient is being cared for—whether that is as inpatient or out in the community. If they are in the community, it will be their usual GP, plus or minus nursing staff who are involved in that patient's care. In my experience, in an inpatient setting, it can be any member of the team. Our team involves nurses, doctors, chaplains or social workers—so anybody could assess it. It would depend on whether the patient wants those concerns assessed and who is best placed practically to do that assessment, and also the comfort level and skill level of the practitioner to do the assessment. Usually what would happen is that as someone comes into a service or while they are within a service, if there is a highlight of a concern, then it is about looking within that service at whether the people involved are able to meet that need; and, if not, to look at referring outwards if that need is not able to be met.

The CHAIR: Where somebody is assessed as having psychological, social or spiritual problems, who would treat them, and what training and qualifications would they have?

Dr BRADLEY: In my clinical experience, often just by talking about what is going on for the patient—that may well be psychological issues—it often helps them, with their own skills, resilience and resources, to come to a solution for the problem or at least some resolution of the distress they are experiencing. Often it does not need treatment from a medicine point of view or a proper therapy. Certainly, if it is highlighted that they need more treatment, then, again, it would depend on whether the patient wants it treated and what phase of their illness they are in. If they are very end of life, it could be very difficult to fully explore the issues. But it certainly would be whichever member of the team worked best with that patient, or if the patient felt comfortable to be involved with them providing that care, and who felt they had those skills. From a doctor point of view, we, obviously as part of our training, get assessed in assessing psychological distress, particularly in looking for severe psychological stress—if you are thinking about risk of harm to the patient or to others, then that is obviously a really important assessment that needs to be done. Nurses also get that as part of their training. We would also look at whether they need a psychological assessment by a clinical psychological or whether they need a psychiatric assessment as well.

From a practical point of view, at Bethesda, we do not have ready access to a clinical psychologist, so we could not get that that assessment in-house even if we wanted to because we do not have the funding available to get that service. If patients are well enough—for our inpatients—they would have to go outside of our service to access that, which they can do through their GP, with a mental health plan, getting Medicare rebated access to a clinical psychology service. They can also do it privately, paying for it or being reimbursed through their medical fund.

The CHAIR: So if funding is not available for psychological, social or spiritual problems, why is it part of the strategy?

Dr BRADLEY: It is available; it is not widely not available—it depends. There are some differences in availability depending on where the patients are, and that is more from my personal experience rather than necessarily from the department. But certainly from the Bethesda point of view, that is not available to us, and so it is using what resources you have available at the time. We do have a chaplaincy service at Bethesda, so we would call our chaplain, but it is not nine to five, five days a week, or even, necessarily, over the weekend. If there is an emergency and we require a chaplain, we can always get someone to come in—but not always. It depends on what is going on.

That is the same from a psychiatric point of view. We certainly can, at Bethesda, occasionally get a psychiatrist in; but, otherwise, it would be accessing services through the hospital system. There is the WA Psycho-Oncology Service—a WACOSS service—that is run through Sir Charles Gairdner and Fiona Stanley Hospital. That is available from an outpatient point of view for our patients; but, also, if they are an inpatient within the hospital system, it is available. There is a waiting time for that, and that then comes into the practicalities for our patient group of having potentially a four-week wait to be seen or of how much time our patients have to be able to deal with significant psychological issues.

The CHAIR: Focussing on the concept of spiritual problems, which is in the strategy, is there a potential professional ethical conflict if someone holds particular religious views to try to treat those spiritual problems?

Dr BRADLEY: I think from the point of view of spiritual problems, they are not necessarily religious. Spiritual concerns can be more existential distress or other distress about meaning of life and general spiritual issues rather than just religion. So from the point of view of anybody addressing their concerns or starting to explore it, I do not think it matters whether that practitioner has religious beliefs or not. I would hope that any practitioner would know their religious beliefs or know their own beliefs and hold them at bay while they listen to the patient experience. I do not think there is an ethical concern so long as you are aware of the impact of your own beliefs on patient care. That is the same not only for spiritual concerns, but also personal experience and all sorts of things. As practitioners, we need to be aware of what the impact of our care is based on our own personal experiences.

The CHAIR: Do you think there is a good understanding from practitioners of how their own beliefs impact on patient care or patient choices?

Dr BRADLEY: That is a good question.

Prof. FORBES: I think, just like everything else in society, some people are very sensitive and aware, and some people less so. My experience is that people working in the area are generally highly tuned to their perceptions of other people and other people's needs. One of the benefits of working in teams is that you do not have to take everything on yourself; you can recognise the strengths of another team member who might be able to deal better with the spiritual aspects of a patient's journey while you deal with pain relief or fluids or something like that.

Dr BRADLEY: Absolutely.

The CHAIR: I understand the strategy also outlines bereavement support. Who assesses patient and family needs for bereavement support and how is that provided? Is it also provided for people who die suddenly, for example—unexpectedly?

Ms BOLLETER: I will take the first question first, about who assesses. This is really setting-specific. But, as Professor Forbes was just saying, it really is a team responsibility. So it would be a member of the multidisciplinary team—that might be a doctor, it might be a nurse or it might be an allied health professional such as a social worker. A member of the team would identify that the family is in need of bereavement support. There are a range of bereavement assessment tools that are commonly in use across Western Australia and Australia—and then would refer, as appropriate, for assessment and treatment. As Dr Bradley was saying, sometimes those needs can be met by having a conversation within the team. The identification of needs does not necessarily lead to a formal referral for ongoing counselling. Bereavement is included in the strategy, as you have noted, and also in our existing palliative care model of care it is one of the domains that should be addressed as part of holistic palliative care. This is consistent with national documents like the recently revised national standards for palliative care, which has a specific standard around grief, so our model is consistent with other models nationally.

In terms of who actually provides that bereavement support, as I said, usually it would be a member of the multidisciplinary team. Ideally, if a team employs a palliative care social worker, they will have particular skills in the area. That does not mean they are the only member of the team who can help to address those needs. As I said, sometimes if it is clear that the needs are complex and cannot be met by the team, then a referral will be made to a psychologist or another counsellor for counselling and support.

I think that it is really important when we are talking about bereavement to note that it really varies very much according to the individual and the family. It varies in terms of some people, who might be described as particularly resilient, may only really experience acute symptoms of grief for a relatively short period of time. For most people we would expect that experience of grief to subside over time. But for a subgroup of people—and estimates vary quite a bit; I have heard some estimates in international research around five per cent, estimates around 10 to 15 per cent of people—might experience some complex needs that really do need some specialist intervention. But the vast majority of bereaved people will have their needs met from within their existing families and friends and community—perhaps an input from their GP or a community health service, or the patient's treating team or palliative care service. Not everybody who is bereaved, whether they are bereaved through an expected death or unexpected death, necessarily needs specialist bereavement support.

The CHAIR: We will take a break now for about half an hour.

Proceedings suspended from 2.40 to 3.07 pm

The CHAIR: I will pick up where we left off. We are still really exploring this sort of ethical boundary or the ethical views of medical practitioners. I think I will just get straight to the question, which is, essentially: is a patient entitled to know whether a doctor's decision is a clinical judgement or a decision of conscience?

Prof. FORBES: I absolutely believe they are entitled to know that, and I believe a doctor should, and most practitioners would, make that very clear. They should advise when their conscience is impinging upon any decisions. I believe that happens.

The CHAIR: Are there practices or medications that are used in palliative care practice that would lead to a doctor having a conscientious objection to using them?

Dr BRADLEY: Currently, not that I can think specifically think of. So long as they are used appropriately, then, no, and I think we tend to discuss with our patients the risks and benefits of medications, and that is including all sorts of medicines whether that be pain relief, sedation, but also antibiotics and things that may prolong life, and a patient may not want that to happen. So we go through all of those medications. I had someone who came in the other day who is on a lot of heart medicines. He came in and said, “I want to die.” In actual fact when we explored it, he had not ever realised that he could stop this whole host of heart medicines that he was on, including intravenous medicines and subcutaneous. So when he realised that, when we talked it through with him, it was this huge relief to him that he could stop them.

[3.10 pm]

The CHAIR: De-prescribe.

Dr BRADLEY: Yes, exactly.

Mr J.E. McGRATH: So was he given bad advice or —

Dr BRADLEY: I do not know that he had felt comfortable enough to express that feeling that his life was not worth living; that he felt that his symptoms were overwhelming and that he was not able to enjoy his life. He was continually being attached to various things and given various medications. But I think it is a mindset as well. Because he came into an inpatient setting, coming from an acute hospital where it is almost expected that you get all of that treatment, he probably did not question it either, and it was not until he came to a different setting that he said to us, “This isn’t living”, and actually then when we stopped things, he has been kept comfortable, he is not on all of those medications. So I think the conscience can sometimes—coming back to your original question—be which medicines are appropriate to give and which are not, and going through with the patient what they want.

Prof. FORBES: I was going to say I think it is important to be very clear that conscientious objection is never in my experience to relief of suffering. Conscientious objection is to any intent to end life as a primary objective.

The CHAIR: Would terminal sedation as a practice be a practice that some practitioners would be uncomfortable with —

Dr BRADLEY: I think if you are not —

The CHAIR: — and not make available to patients in their care?

Dr BRADLEY: Sedation at the end of life, if someone is within a few hours or days of death and they are given sedating medication, which would be called terminal sedation, then certainly not in my working experience that would be something that anyone would have a conscientious objection to if the patient is distressed and it is meeting that distress. So it is really saying, “This patient is dying; they are not settled; they are not comfortable.” You can tell by body language, by frowning, by movement that they are not comfortable, and then you use the appropriate medication to manage that situation.

Hon ROBIN CHAPPLE: If I may, following on from that, that is obviously from a palliative care perspective. Obviously, a lot of people are in hospitals going through the end-of-life process. So we are looking at general medical professionals, and there might be all sorts of reasons why that medical professional, from an ethnic background, from a religious background, might be very concerned—I am using my words—about providing medication that may hasten death. It might be

very difficult, but do you know if those sorts of situations exist, and what happens if they do? Is that professional taken off that patient and somebody else provided?

Dr BRADLEY: I think part of the problem can sometimes also be diagnosing dying, and some doctors are not comfortable or confident in diagnosing dying and knowing when dying is occurring in a short period of time. You do not want to be giving sedation to a patient who is not dying if it is going to affect their ability to enjoy the life that they have. So that certainly would play a part, but I think definitely people's backgrounds play a part in how comfortable they are with medications. That is true of any medications.

Hon ROBIN CHAPPLE: What would happen in a situation like that, where a particular medical professional has said, "I just don't want to deal with this"? Would you be passing it on to another medical professional?

Dr BRADLEY: It would depend on the setting really and where the patient is as well. Obviously, there may not be too many medical professionals to hand it on to, depending on where they are. But certainly, yes, I think if it is within an acute hospital setting, then you might refer to the palliative care team to get their input, if it is looking at someone who is at the end of life or a palliative care patient, so you can get their team's input. That gives a new —

Hon ROBIN CHAPPLE: I am working on the assumption that we might not be able to.

Dr BRADLEY: Access that? Fair enough.

Hon ROBIN CHAPPLE: Access that. So we are talking about general medical professionals.

Prof. FORBES: If you as a patient are asking me, "Please give me some medicine to kill me", and I am uncomfortable with that, I would make it very clear that I would not be prepared to do that and I would be prepared to discuss it with my colleagues to seek a second opinion to see if my judgement was sound or not. I would not assume that any of my colleagues would be keen or willing, nor would I ask them, to do something that I felt was not justified, and that is deliberately taking life. If you are asking am I frightened of hastening death in relieving suffering and I was uncertain about that, I would certainly ask a second opinion and would negotiate with the colleague around that. My experience is in well-run hospitals—most of our hospitals are well run—it is not necessary for administrators to intervene and remove patients from an individual's care. Most of these things are done in a consultative process.

Mr S.A. MILLMAN: I have a supplementary to that. Professor Forbes, that was a fantastic answer. The way you described how clearly you would have that conversation with the patient was excellent. I just wonder what can the department do or what can we do as a society or as a Parliament to encourage doctors—because obviously the doctor–patient relationship is built on trust, and so there is a reciprocity that exists there. How do we encourage other medical practitioners to respond to that situation in exactly the way that you have just articulated?

Prof. FORBES: Well, we have to demonstrate it. I think demonstration is the most important method of teaching young doctors. I think we all have role models and mentors, and I think it is ensuring that this is part of junior doctors' training. I think it is much more than it ever used to be, and I think Keiron can comment on that. But my training was always in acute-care hospitals and I had fantastic role models who taught me this. I also think it is penetrating into the community. My own father died in February of this year; it was expected. A year before that, he went into a nursing home and they presented me with a form. It was basically to prepare an advance care directive with him. They were very comfortable it had happened, I was very comfortable; in fact, he was very comfortable with it. So, it is not actually that difficult if we overcome our fears, and I think it is the demonstration in clinical training and practice which is so important.

The CHAIR: I want to go to Catholic Health. Catholic Health is one of the largest providers of palliative care, but also other health care. In evidence to the committee, Catholic Health Australia told us that patients are informed of their policies and procedures by their code of conduct, which is published on their website. Given that there is probably a number of policies and procedures and restricted procedures that would not be accessible that are legal from Catholic Health, do you think that is sufficient information for patients entering into a Catholic institution?

Ms BOLLETER: Public patients in private providers, whether that is one provided by Catholic Health or another private provider, have exactly the same right to information about limitations to services as public patients in public hospitals. So the way in which that model is structured in Western Australia, there should be no difference whether that service is provided for public patients by a private provider or by a health service provider through the Department of Health. This is stipulated in WA government agreements with the commonwealth and in WA government policy. That is a clearly established position. The policy in WA Health which is relevant to this is the consent to treatment policy. That outlines the minimum mandatory requirements for health professionals in obtaining a patient's consent to treatment—just noting that is a mandatory policy, so all health services providers, including any Catholic Health Australia providers, must follow that policy. The policy applies to all health professionals who provide treatment on behalf of WA Health, who admit patients to a public hospital from his or her private rooms, irrespective of whether the patient is to be admitted as a public or private patient. So I think we have really clearly established that those people have exactly the same rights. Catholic Health Australia has that code on their website, but I think the consent to treatment policy is in addition to that. So I do not think it is a yes–no; I think both options are important to have covered.

As I said before, WA health hospitals and health services must adopt this policy. We would expect that that would happen. In discussion with colleagues, one of the comments around this is that there is normally a discussion around the limitation of services to be provided. You would expect that there would be a clinical discussion around the time of admission, because that will vary significantly from individual to individual. Some limitations on service provision may have absolutely no relevance and other limitations may be absolutely very relevant for that individual, depending on their situation, so it also needs to be a discussion with the clinical treating team.

[3.20 pm]

The CHAIR: In relation to end of life, the code of conduct states that patients have the moral right to refuse any treatment that they judge to be futile, overburdensome or morally unacceptable and such refusals must be respected. Given that it is actually the legal right to refuse treatment, and that is not limited in any way, do you think that is clear enough for patients who enter into Catholic institutions? And is that consistent with public health?

Ms BOLLETER: I think it is clear because, as I referred to before, the consent to treatment policy and the associated legislation is in place. Our assessment is that that code is consistent with the consent to treatment policy, but the consent to treatment policy is really the overriding document that you would be referring to if you were looking at provision of information or rights of patients to refuse treatment.

The CHAIR: We have heard from Catholic Health Australia, who run aged-care facilities, that they do not promote advance health directives. Given the evidence we previously heard from the professor around the importance of advance health directives and that they are legally binding, do you have a response to that or an opinion on that?

Ms BOLLETER: I think that is a question for Catholic Health, with respect. I think the Department of Health's policy is clear around consent to treatment and the use of advance health directives, but

I think that is primarily a question for Catholic Health. The legislation and the policy around this is very clear. As I said in relation to another matter that you raised earlier, if a concern was raised with the department around this, we would address it, but that concern has not been specifically raised with the department.

The CHAIR: I suppose I bring it to your attention as in many instances a significant funder of those institutions.

Hon NICK GOIRAN: Did you say aged care?

The CHAIR: On that one, yes, but there are hospitals as well.

Hon NICK GOIRAN: We have had evidence that in Catholic hospitals they do not promote advance health directives.

The CHAIR: In the aged-care facility.

Hon NICK GOIRAN: Because they are not funded by the Department of Health.

The CHAIR: No, they are not.

Prof. FORBES: Again I would ask the question: is there evidence of a problem? Is there life being sustained against their will? Are they accumulating lots of patients who do not want to be there? As Amanda said, this is not an issue that has been raised with the department that people are being treated against their wishes in those circumstances.

Hon ROBIN CHAPPLE: Through the Chair, I thought we had some evidence that when they said the contracts that had been established with them, that the contracts were written by the government in a way that they did not have to deal with this issue, and they put the responsibility back on the contract writers as opposed to themselves. You most probably need to go back through previous transcripts and have a look at that.

Hon NICK GOIRAN: It might assist the honourable member if I remind him that that session was with the LJ Goody Bioethics Centre and the question that was posed at the time was by the Chair and had to do with the termination of pregnancy. There is a dialogue between the Chair and that member with regard to contracts, but of course that is not with respect to what we are talking about here with end-of-life matters.

Hon ROBIN CHAPPLE: With respect to the member, I thought we had another session with the hospitals themselves when they indicated that that was the case.

Hon COLIN HOLT: I think it is an interesting point that Professor Forbes makes: Is there a problem? Is there an issue? It seems to me that we do not know if there is an issue, because we do not know. If people are not filling out an advance healthcare directive because no-one has taken it to them and asked if they would like to fill one out, then we do not know. We have not documented their wishes so we do not know if we are going against their wishes. That seems to me to be a bit of a complicating factor. I do not know.

Prof. FORBES: I take your point. I am not aware whether advance health directives are not being supported in those institutions, but equally, we have clinical issues drawn to our attention all the time. We are not having clinical issues drawn to our attention here.

Hon COLIN HOLT: I understand.

Prof. FORBES: They are not the same thing, I agree.

Hon COLIN HOLT: It may be that how people report those incongruous situations may not be clear, so there may not be a reporting mechanism.

Ms BOLLETER: Just as a point of clarification, I would say that advance health directives are one method of documenting a patient's wishes around their future treatment. It is a very valid and effective method and it is the statutory method in WA, but it is not the only method. In a situation like you have described, we would want to look at what else is happening around discussions with those patients, around common law, around enduring power of guardianship, and all the other mechanisms that are there. Advance health directives are part of a suite of mechanisms; they are not the only one.

The CHAIR: In relation to the Silver Chain hospice service that provides the 24/7 helpline and emergency assistance, as referred to in question 21, we have had lots of evidence about the quality of the service. The committee went on a visit with home hospice and it was incredibly enlightening—really useful. I think it is fair to say that it is a really good service. Putting aside Albany, which is going through the process, is there any action to ensure that people who at least live in the more populous regions would have access to this type of service?

Mrs SLATTERY: We do provide a very similar service, certainly across all of WACHS and particularly the more major regional centres. We have a community palliative care team and a community palliative care service in Albany, Geraldton, Kalgoorlie, Broome and across the south west.

The CHAIR: So a Silver Chain-type medical service?

Mrs SLATTERY: We provide the same service but not a medical, well —

Ms BOLLETER: There is medical input.

Mrs SLATTERY: There is medical input, very much as we were describing earlier.

The CHAIR: Can you describe the service for me?

Mrs SLATTERY: The patient is referred into the service and, as I said, then they are triaged and assessed to their care needs. They then have a regular contact with the palliative care team. It might be a weekly phone call or it might be two visits a week. As their condition deteriorates, their level of care is increased, depending on their need, to the point where we may be visiting three times a day and have an on-call service to assist them during the night.

The CHAIR: In every major regional centre?

Mrs SLATTERY: Yes.

The CHAIR: Including Broome?

Mrs SLATTERY: Yes, I have spoken to Broome today.

The CHAIR: So that is not a consultancy service; that is an actual service in the home?

Mrs SLATTERY: That is an actual service. This is different to the regional consultancy service. This is a local service, a community service, which comes under the auspices of the regional service, so that is where that higher governance is given.

Mr J.E. McGRATH: Further to that, what about Silver Chain in the metropolitan area? The population of Perth is growing rapidly. Do you believe they are under any more stress or do you think they are able to cope with the needs?

Mrs SLATTERY: I cannot respond for Silver Chain in the metropolitan area, I am sorry.

Ms BOLLETER: I would hesitate to give too much of a detailed response because we do not have that detailed evidence. But certainly we hear the same reports that you have around the quality of that service. If you look at the death at home rate for patients with Silver Chain in metropolitan Perth, it is sitting at just over 70 per cent currently, which is significantly higher than the national

average. That indicates that that service is really meeting patients' needs and preferences to be cared for at home.

All services in health have to prioritise their resources, have to triage referrals very carefully, and have to have a very strong focus on ensuring that their resources are absolutely being used where they are most needed. That is not just true of palliative care; that is true right across health, and I think people would say that is true of Silver Chain as well.

[3.30 pm]

The CHAIR: We have had a lot of evidence regionally that people are not able to die at home or on country when they need palliative care, if you like. That is very much their preference, or the culture, if you like. People are being brought into hospitals or regional centres, or sometimes even down to Perth, particularly the Aboriginal community. Has any cost–benefit analysis been conducted to show whether savings in terms of reduced hospitalisation or patient transport would make any major reforms viable? If someone gets RFDS from Broome to Perth, and they are palliative or in final kidney failure, and the cost of that and the cost of the system—has there been any work done on that?

Mrs SLATTERY: No specific cost–benefit analysis has been conducted for this purpose in WA. Research shows that very little work has been done in the area of cost–benefit analysis for palliative care internationally. Bickel and Ozan, in a paper that we can refer you to, from 2017, note that there are challenges to undertaking these types of analyses in palliative and end-of-life care, in terms of attempting to quantify the value of human life and balancing tensions between societal good and individual healthcare goals. Any future analysis of this type in WA would need to be undertaken with awareness of these risks and tensions.

Hon COLIN HOLT: An interesting dilemma, I reckon, in terms of futility of treatment versus patient's wishes, and let us explore it to the end. How do you have that conversation, and where do you draw the line? Potentially, there is patient transport from the Kimberley to Perth through patient's wishes for potentially futile treatment.

Ms BOLLETER: There is more evidence around futile treatment and the costs associated with that that possibly can be efficiencies that are made across the health system. I think that is different to looking at options for palliative care, where we are not talking about futile treatment; we are talking about where is the most appropriate place to provide care for this person. That is more ethically challenging in some ways, or ethically different to a discussion around futile treatment.

Hon ROBIN CHAPPLE: We had a case recently where an Aboriginal man who was receiving dialysis determined not to continue receiving dialysis, and went back to Jigalong to die. That was his wish; that was his really happy wish, and that is quite often what we get. There needs to be some way to be able to factor that in, in dealing with people in remote locations, where being on country is far more edifying to them than the fact that they are going to die.

Dr BRADLEY: It is being comfortable having those conversations with the patients and opening up the options, so the patients do understand.

Hon ROBIN CHAPPLE: Could you speak up?

Dr BRADLEY: I have such a quiet voice, sorry.

The CHAIR: Hansard needs to be able to hear you.

Dr BRADLEY: I think those conversations are really important, and I think it is incredibly important for health professionals to be comfortable with having those conversations to discuss the options that are available for patients. They do not have to continue with the treatment if their place of care is not consistent with where that treatment can be provided.

Ms BOLLETER: For most patients who are with the rural palliative care teams, they either have care at end of life close to home or at home, so I think in the last year they cared for well over 1 000 patients, and only 30 of those patients died in Perth. The vast majority of patients are able to be cared for at home or close to home, if they are with the regional palliative care teams.

Hon COLIN HOLT: Would you say it is your experience that generally patients' wishes around exploring all available options kind of outweigh the futility bit, in terms of, "I really want to have this treatment. We think it is probably not worth it, but I really want to have this treatment"? Does it end up to be much more weighted towards the patient's goals, in your experience?

Prof. FORBES: It is a journey; it is not a single point, and a decision I made today might be fuelled by my anxiety about a whole lot of things, and it might be very different to the decision I make in a week's time, when I understand the process. Good clinical services deal with this all the time, and they do help patients make those judgements. Sometimes people are not ready to give up a futile treatment because they are not ready to face death, but in a week's time they may be. These debates and discussions are constantly going on between doctors and patients and treating teams, and they are weighed up differently.

Hon COLIN HOLT: We have been to some site visits where the doctors basically said to us, "These patients are actually in denial; they are at an advanced stage, they are in denial and they still want to receive treatment, and they get it."

Prof. FORBES: The beauty of our system is that we can respect patients' wishes, and we continue to pay for it because we respect the patient and we respect their wishes.

The CHAIR: The PCOC data—we have also had other evidence—suggest a huge disparity between socioeconomic status and access to palliative care. Is the department doing any work to address this issue?

Ms BOLLETER: Yes we are, and we went back and checked with PCOC and absolutely that is their data that we are seeing with access to palliative care for different socioeconomic groups, and so this is information that we take very seriously, and I guess this has informed the inclusion of a range of different population groups in our upcoming strategy who we know may not have equitable access to palliative care for a whole range of different reasons, and advocacy groups have talked about it. It is also around Aboriginal people, people who have culturally and linguistically diverse backgrounds, people who might be homeless or might be refugees, and also people from the lesbian, gay, bisexual, transgender, intersexual and queer communities. We have quite deliberately put a specific priority around this in the upcoming 10-year strategy, because we know this is a really important area for focus over the next 10 years and probably beyond, I think. At this stage, the building blocks, as we are calling them, to realise these priorities are around culturally respectful and appropriate care, around health care and aged-care providers having a greater understanding around beliefs and values at end of life, and access to culturally appropriate information and for Aboriginal people working collaboratively with Aboriginal health workers. We need to do a lot more work and the implementation of this 10-year strategy around realising this. This is a strategy, it is not something that we have yet achieved, but we are also well aware of the needs. I would also point to some of the work that we are doing at the moment specifically around advance care planning and ensuring that we have got resources that are in community languages but also videos for people who have low literacy, so that they also have access to that same information around advance care planning. We have also been working recently with Aboriginal groups, particularly in the Kimberley, around developing advance care planning resources for Aboriginal people, so it has been an area that we are investing a lot of energy in at the moment.

In terms of socioeconomic status and access and location of palliative care services, the work that PCOC have referred to here is based on research by Professor David Currow, which shows across Australia that the location of palliative care services—they are often clustered in areas of high socioeconomic advantage, and much of that goes to the history of palliative care, especially community palliative care, where community groups or religious organisations grow up their own services where they are, and almost inevitably they tend to be clustered around areas of socioeconomic advantage. So it is a planning challenge, I think, for health and for palliative care across Australia, not just WA, to ensure that those services are equally located and available in outer metropolitan areas and rural areas. I think in WA we have a model in rural areas which works very effectively across vast geographical distance, but the maps that have already been released with the draft version of the strategy show the location of palliative care services, and you could map that to socioeconomic status, so it is a planning issue as well, and this is where it is really important to have that policy input to planning decisions around where services are located, so that we can address that over time.

The CHAIR: Are there any plans for hospice services in the northern suburbs?

Ms BOLLETER: We are informally advised that Joondalup hospital is currently establishing a palliative care consultancy service, so that is information that is being provided to the department. As I said, that is at early stages yet, but we are aware that they have advertised for the staff; therefore, in the maps and the strategy, we will note Joondalup as a service that is in development.

The CHAIR: And that will be a similar model to Charlies, where they would visit their patients on various wards, depending —

Ms BOLLETER: It is a consultancy service across the hospital, yes.

The CHAIR: But not a specific hospice as such?

Ms BOLLETER: I am not aware of that.

Hon NICK GOIRAN: It has been nearly six months since most of the witnesses were before us and, as I recall when you were last here, I think there were 14 of 22 service providers that were giving data to PCOC. Has there been any change in that?

Ms BOLLETER: I would need to double check, but I think that number is the same. It is a lengthy process to start reporting data through PCOC and to produce data that is sufficiently accurate that it is actually included in the PCOC report. So, it is not a quick process for services to start reporting data and to be included in the type of public reports, because PCOC needs to ensure the quality of the data being reported, so I would not expect to have seen a significant change in six months.

Hon NICK GOIRAN: Has there been dialogue between the department and those other eight service providers in the last five months and five days, since you were last before the committee?

Ms BOLLETER: The reporting of PCOC data is voluntary. Right across Australia, the reporting of that data is voluntary, and I think it is really important that it is not mandated by any Department of Health across Australia, because the purpose of PCOC is for services to be able to assess and review the quality of the care that they are providing, benchmark with other services and make improvements. The primary purpose of PCOC is not for state health departments to be reviewing the quality of services that are provided. There are other mechanisms, like accreditation, that are more appropriate for that. In WA, as I said earlier, the Department of Health is rolling out a dataset that will assist services who choose to report PCOC data to do that, so that will help to enable that, but again, that is not the primary purpose of that dataset so we are trying to enable that when we can, but we have not, and we would not seek to mandate that with services. I think it would defeat the purpose of the data collection.

Hon NICK GOIRAN: Not to mandate, but perhaps encourage?

Ms BOLLETER: We are encouraging it in a facilitating kind of way.

The CHAIR: Describe to me why mandating would defeat the purpose.

Ms BOLLETER: There are two reasons. Part of it is that PCOC is a dataset that is funded by the Commonwealth of Australia but it sits with the University of Wollongong, and I think I have heard representatives from PCOC, like Professor Kathy Eagar, say that they would not seek to have this mandated, because the value of the dataset is that it is voluntary, and services do it because they know it is important to do. I guess it is: how do you kind of incentivise something? With PCOC, it works around the value that is provided to services in terms of being able to benchmark their care, rather than being mandated to do it and to provide it, and I think you probably get a higher quality of data because services see the value in it and choose to do it rather than doing it because it is mandated by any individual health department.

The CHAIR: So how do you assess the quality of care that people are getting, if it is not through a central data collection like PCOC?

Ms BOLLETER: As I said, there are other accreditation mechanisms in place and other quality mechanisms in place across health, which helps to establish the quality of care that is being provided. We certainly review the PCOC data reports in detail and take careful note of that, but it is not about—it does not serve the same purpose as—accreditation.

The CHAIR: A question about mouth care: we have had some evidence—I am interested in Dr Bradley's opinion on this—is it true that mouth care, at the end of life, when someone has refused hydration could potentially extend their life?

[3.45 pm]

Dr BRADLEY: No. Because it is such a tiny volume, very little would be ingested. Most of it just stays in the mouth cavity, so it would not add to their input.

The CHAIR: Is it possible that a competent patient could be mistaken about whether their pain or suffering is being adequately managed?

Dr BRADLEY: I think if a patient believes that they have pain and that they are suffering, I think we absolutely have to take them at their word for that. It goes without saying, really, that we have to listen to the patients and respond to what is affecting them. Sometimes it can be very difficult for patients to work out what the cause of that suffering might be, where it is a physical pain and exactly what the cause of that physical pain is, and that can be where that more careful assessment can help the patient work through the likely cause of it. Sometimes patients, particularly when they are very fatigued and are lacking energy, they feel bad, they feel terrible, but they cannot tell us why they feel terrible, and it is us trying to help lead them through that to get to an understanding of what is going on for them. But we would always take them at their word that something is not right and try to improve what they are feeling.

The CHAIR: I want to go back to the renal palliative care service. We have some information from them from our visit to the Kimberley. Is it your understanding that a large proportion of patients would initially decline dialysis?

Prof. FORBES: This is an issue which I believe is separate to the end-of-life issue. There are issues about access, which relate to a whole lot of other complex issues—we are talking about the socioeconomic distribution of palliative care services. Any indicator of health that you choose to look at in Australia is almost certainly distributed along socioeconomic lines, from childhood obesity to death from trauma, and renal disease is no different. Dialysis is complex, it is risky, and sometimes

it is difficult to have patients fit the requirements of a service, to be able to turn up three times a week, to maintain peritoneal catheters free of infection or the arterial venous cannula in a functional state. It is true that Aboriginal patients in particular have lower rates of dialysis than the rate of renal disease would predict. It is also true that Aboriginal patients are less likely to be accepted onto transplant programs. But we know that living related donors in these circumstances do much worse, so the donor is more likely to die. It is a very complex issue, and I do not think there are any simple answers. I am not sure I answered the question you asked!

The CHAIR: Sort of. We have had evidence that given the prevalence of chronic kidney disease, particularly in Aboriginal people—two out of five—often they initially decline dialysis, and that is viewed by medical professionals locally as declining medical treatment, which is a separate question to the one that I just asked you. Is support given by the Department of Health for those medical practitioners around decision-making about other treatments available to those people?

Prof. FORBES: Part of the answer to that is what is actually being intended in what you said. Much of our services in this day and age are so highly specialised that we end up only being capable of doing one thing, unlike people like Keiron who maintain very general skills. If you come to me with a kidney problem and I offer you dialysis and you say you do not want dialysis, then my response is, “I don’t think I can help you as I should in this situation. I can talk to other people who may be able to help you.” Sometimes that is said in a different way; sometimes it is interpreted as, “I’ve got nothing more to offer.” I do not think that is the right answer, and that should never be an accepted answer. From talking to my colleagues in WACHS, I do not believe that they would see that, “Go away; we’ve got nothing to offer you”, would be an acceptable answer either.

Mrs BAXTER: With the increasing number of chairs that we have got in the Pilbara, the goldfields and the Kimberley, and a new renal hostel being built, we are trying to take the service back to the areas where it is needed.

The CHAIR: We have certainly had evidence that patients end up being transferred to Perth for prolonged treatment. Is it also your understanding that that happens?

Mrs BAXTER: That is what I said—that is what we are now working to address. We have got increased chairs in Carnarvon, increased chairs in Pilbara, increased chairs in the goldfields, and increased chairs in the Kimberley with the building of a renal hostel.

The CHAIR: Are they all accessible now? Are they open and working?

Mrs BAXTER: The renal hostel is not finished yet in the Kimberley.

Hon ROBIN CHAPPLE: Just on that, because I come from that area: the dialysis unit that was at Jigalong, what has happened with that?

Mrs BAXTER: I would have to check.

Hon ROBIN CHAPPLE: It has not worked ever, yet!

Mrs BAXTER: I would have to check what is happening there.

Hon ROBIN CHAPPLE: Are you going to put one in the new hospital in Karratha?

Hon COLIN HOLT: That might be a question on notice for the health minister, Robin.

Mrs BAXTER: I will take that one on notice for the new facility, which is actually looking beautiful.

The CHAIR: There are no patients!

Are there any other questions on this?

Hon NICK GOIRAN: I want to ask about the 10-year plan—not the 10-year plan; the 10-year strategy—which I understand is to be released next week, presumably to coincide with National Palliative Care Week. What funding has been set aside to support the plan?

Ms BOLLETER: There are no specific funding announcements associated with the implementation of the plan. This is a very high level strategy, so I think any funding decisions would need to be made in terms of detailed implementation. I do not think we are in a position yet to provide advice or make a specific business case around the implementation of the priorities. This is the first step in what will be a long process.

Hon NICK GOIRAN: Does the 10-year plan itself identify which things ought to be done towards the front end of the 10-year period?

Ms BOLLETER: The 10 year strategy has six priorities and they are all evenly ranked, because the consultation we did with the sector was that these priorities were all equally important and it was very difficult to make a decision about whether support for families and carers should be ranked above equitable access to palliative care. They are almost impossible to separate out, I think. We will work with the palliative care and end-of-life sectors to do some more consultation with them about how we implement the strategy and what we implement first. I think that some of those decisions will just be pragmatic in terms of what are pieces of work that are already progressed that just need a little bit more work to get them finalised, versus something that really needs to be developed from the ground up that will take longer. The decisions around timing will be often pragmatic decisions rather than necessarily priority decisions. Does that answer your question?

Hon NICK GOIRAN: Yes, I think so. But of the six priorities, really it is up to the government of the day to determine which one or more of those it wishes to prioritise?

Ms BOLLETER: Yes.

Hon NICK GOIRAN: With the 10-year strategy, are you in a position to indicate to us who was consulted on the development of the strategy?

Ms BOLLETER: There were over 200 individuals who took part in the original consultations for the strategy in 2015, and we can provide you with their names. From that time, the work of developing the strategy was overseen by a working group and by our palliative care advisory committee, and again we can provide you with a list of their names. At the end of last year, the strategy was sent out for consultation, and we received a significant number of responses back to that consultation. We can provide you with the names of everybody who was contacted to provide feedback. I think much of the feedback was anonymous, so we cannot give you the exact names of who responded but we can certainly provide you with the names of those given an opportunity to respond.

Hon NICK GOIRAN: Does the strategy include a discrete component for rural palliative care?

Ms BOLLETER: Rural palliative care is really incorporated right throughout the strategy, so I think there is something in each priority that would relate to rural palliative care. There is a priority around equity of access, and of course that has particular relevance for rural areas, but as we mentioned before it may also be applicable for outer metropolitan areas, so it is not exclusively rural. We have really tried with the strategy to take a very incorporated approach, so rather than having a priority that is specifically about rural, to say in terms of all six priorities, how will they benefit people in rural areas, if that makes sense.

Hon NICK GOIRAN: When the Department of Health was last before the committee, on 13 December last year, a Dr Ransom appeared before the committee and talked about the need for more medium-term hospice beds. Is that issue addressed in the strategy?

Ms BOLLETER: I think it would be covered under the priority around equity of access and also around patient-centred care. The issue that Dr Ransom referred to around hospice beds—the implication if people are not able to have an extended stay in a hospice bed is often that they have a number of changes of location, and that is something that is quite specifically picked up in the program.

Hon NICK GOIRAN: Good. Does the strategy touch on dignity therapy?

Ms BOLLETER: Not specifically, no.

Hon NICK GOIRAN: And the provision for psycho-oncology services?

Ms BOLLETER: The importance of social, psychological and bereavement support is included as part of holistic care in the strategy. We have not specifically in the strategy—because it is a very high level document, we have not talked about individual services much at all because that is really the next step around the implementation phase. It may be that addressing social and psychological needs will translate to a need for more psycho-oncology services, but that is something that we would have to review the evidence for and make a decision on before we could put that in a strategy-type document.

Hon NICK GOIRAN: I think the question was asked earlier about bereavement support services, and that seems to be specifically mentioned, or it certainly was specifically mentioned in the draft. I take it that it is still there in the final, and that is good—bereavement support services should be mentioned. But specifically this problem with psycho-oncology services—I think someone mentioned earlier the four week waiting time, and I think we have only one specialist in that field—that is not specifically mentioned in the strategy?

Ms BOLLETER: That particular issue is not specifically mentioned but I think it is well covered by the priorities in terms of holistic care, care for patients and families. The strategy clearly acknowledges that palliative care is not just about managing physical symptoms; it is also about managing and supporting people's social, psychological and spiritual issues as well.

Hon NICK GOIRAN: Does the strategy include provision for improved training of medical students and/or professional development for health practitioners?

Ms BOLLETER: There is a priority that specifically relates to health professionals, around health professionals being ready to care or able to care, and undergraduate education is part of that.

Hon NICK GOIRAN: It sounds like a good strategy!

Ms BOLLETER: We think so!

Hon NICK GOIRAN: My last question on this is: is there some form of review mechanism or review period with respect to a plan as large as 10 years?

Ms BOLLETER: Yes, there is. From memory, we will review the strategy after three years to track progress and determine if there are any changes that need to be made, and if there is anything significant that has changed in any aspect of palliative and end-of-life care, then we would revise the strategy accordingly.

[4.00 pm]

The CHAIR: This is probably a question for Professor Forbes. Are there circumstances where Nembutal is prescribable in Western Australia currently?

Prof. FORBES: Yes, there are. Let me have a look.

Ms BOLLETER: Page 28.

Prof. FORBES: Nembutal, or pentobarbitone, is not available under the Therapeutic Goods Administration, but a practitioner may apply for individual access. As you can with lots of medications, a practitioner can apply via the commonwealth to gain access to the drug.

The CHAIR: What would be those circumstances?

Prof. FORBES: For Nembutal? They might want to use it or —

The CHAIR: For themselves or for a patient?

Prof. FORBES: If they thought there was a clinical indication, they would contact the commonwealth Department of Health and submit an application and then arrangements would have to be made for the payment of the drug, because special access scheme drugs are generally not covered under the Pharmaceutical Benefits Scheme.

The CHAIR: So it is what is called a special access scheme drug?

Prof. FORBES: Yes.

The CHAIR: I am trying to understand what clinical circumstances would lead a practitioner to —

Prof. FORBES: I do not think Nembutal has much of a place in routine medical care these days. It is not considered a very safe drug. I could only envisage someone who is looking at using it to hasten the end of life, and I do not know that it would be approved under those circumstances. But it has not been tested, to my knowledge.

Hon Dr SALLY TALBOT: What has it been used for in the past, professor? Was it used as a sedative or a pain reliever?

Prof. FORBES: When I was a boy, we used to use it as an oral medication to provide sedation to children for some procedures that were uncomfortable, but it was withdrawn because the window between its therapeutic effect and its side effects was too narrow, so it was difficult to manage.

The CHAIR: Thank you. I am going to skip a few because we have covered a lot of the ethics and relationship issues. If voluntary assisted dying legislation were introduced in Western Australia, do you have a view on whether legal medications to be administered should be regulated in the way that is currently being implemented in Victoria or whether physician discretion should be the standard?

Prof. FORBES: We have not yet established a view on this. We would need legal consultation once the legislation was enacted.

The CHAIR: Thank you. I want to ask you about advance health directives. Do you think there is a level of opposition for the binding nature of advance health directives from the medical profession?

Prof. FORBES: I do not believe so. It is not something I have encountered. Increasingly, this discussion is taking place and people are quite supportive of it. The department is putting quite a lot of work in encouraging the use of advance health directives. We have not had any pushback.

Mr S.A. MILLMAN: Just further to that, the answer to that question seems to be to advance health directives per se. I think the chair's question was more directed to their binding nature. This picks up a question that I asked before about: to what extent is it taken into the mix in terms of assessing what treatment is appropriate? There might be a loss of capacity or something on the way through, which means that if you have got a binding advance health directive and you, as a clinician, have a changed set of circumstances and you do not think that the prescription that is contained for in the advance health directive is appropriate, you might look for a way to arrive at a clinically more beneficial treatment. It is the binding nature of them that I think this question goes to.

Prof. FORBES: I do not see that as an issue. You talk about the prescription defined in the AHD. Most AHDs, I think, are more likely to relate to withdrawing medications.

Mr S.A. MILLMAN: Yes. I did not mean prescription in terms of prescribing medication; I meant prescription in terms of direction.

Prof. FORBES: I do not see that as an issue at all. I think in the twenty-first century, patient rights have a much greater respect in the medical profession and “Trust me; I’m a doctor”, does not work well anymore. I think more and more people are comfortable with it and are incorporating it into everyday practice.

Ms BOLLETER: If a clinician reviewed a patient’s AHD and felt that what was outlined in that directive was no longer valid or applicable, maybe because the patient’s condition had changed significantly since it was written or maybe there was a new treatment that had been introduced since the AHD was written, then if a clinician has concerns, they have the option to go to the State Administrative Tribunal and seek a review of that. Yes, it is binding and that is absolutely proper, but there are avenues that clinicians can take up if they have a query. The State Administrative Tribunal can respond very quickly, if necessary, to resolve a question around a patient’s advance health directive if a clinician has concerns about that.

Hon COLIN HOLT: Presumably, you would go to the family first, before you did that, if you have got concerns.

Ms BOLLETER: In the hierarchy of decision-makers, if a patient has a valid advance health directive, that is the first step on that hierarchy, so you would stay with that advance health directive unless SAT indicated that it was no longer valid.

Hon COLIN HOLT: Would you go and have the first conversation with SAT around challenging the —

Ms BOLLETER: You would expect in good clinical practice—Dr Bradley would be more familiar with this than me—that there would be a conversation with the family. It would not be like it went to SAT with no discussion with the family, but that is the legal avenue that is available to clinicians.

Hon Dr SALLY TALBOT: What that discussion does not encompass is the situation where someone’s AHD says “Do not resuscitate” when there actually is not an opportunity to have a conversation with a family member or take it to SAT. We have heard some quite forceful evidence that the receiving doctor in an emergency department may well—we have heard evidence that this happens—take the approach that “That’s not what we do here.” So, somebody has not got capacity—they might be unconscious; I do not want to speculate on what the condition might be, but they are not in a position to say “Don’t do that to me”—and they have got a do not resuscitate order on them and the stretcher is followed by a family member saying, “Don’t forget so-and-so has a do not resuscitate” and the doctor is saying, “I’m sorry; we’re not interested in that here. That’s not what we do.”

Prof. FORBES: Emergency physicians do have a duty to respond to emergencies. They need to respond quickly and decisively, and in an emergency situation where a person is incapable of giving consent, treatment should be provided without the consent. Now, what you are describing is a situation that is very difficult because, equally, the emergency physician could be challenged later that they did not intervene if they had not assessed the AHD. It is the ability to provide that evidence and assess it in that situation, which becomes a pivotal point around which decisions are made. So, yes, emergency physicians may respond in the face of an advance health directive if they do not have clear evidence that that is exactly in place and legally binding.

Hon Dr SALLY TALBOT: That is a very reasonable response. I absolutely acknowledge that it is a complete minefield. I guess the thing that worries me slightly is that it occurs to me, and it has

occurred to me over the last few months as we have heard this evidence, that we have a system of AHDs but we do not really have a mechanism for dealing with them. If everybody in Western Australia took out an AHD this weekend and on Monday morning the health department was faced with two million AHDs, you are not going to be able to cope with them, are you? That was a rhetorical question.

Hon ROBIN CHAPPLE: I saw the shock and horror on your face then!

Hon Dr SALLY TALBOT: I have a specific question coming out of that.

The CHAIR: For the purpose of Hansard, that was a no!

Prof. FORBES: I take that as a statement.

Hon Dr SALLY TALBOT: Do you have a view about the applicability of the mandatory nature, the binding nature, of an AHD on paramedics? You did I think early in your evidence refer to—I am sorry it might have been the previous witnesses who talked about the someone being unconscious on the lounge room floor and the paramedics arriving and being presented with an AHD that said “Do not resuscitate”.

Prof. FORBES: We have been advised that St John Ambulance do adhere to AHDs and do not resuscitate directives if they are in place and they are aware of them. Again, like all emergency services, they may not be aware of them in a reasonable time. If in doubt, they will respond, treat the individual and then work out the details later. That is, I believe, their primary responsibility.

Hon Dr SALLY TALBOT: The AMA was suggesting that we as a state might want to look at identity bracelets.

Prof. FORBES: That is an interesting proposal.

Hon Dr SALLY TALBOT: I take it that is a Sir Humphrey “interesting”.

Ms BOLLETER: Could I provide some information to the committee about some of the mechanisms that are in place for identifying a patient who has an advance health directive because it is an area where I think we have made good progress in the last year.

Hon Dr SALLY TALBOT: We were impressed by Albany, I may add in parenthesis.

The CHAIR: Yes. Albany was outstanding as an outlier.

Ms BOLLETER: Yes, they do great work there. You might be aware of this already, but as part of the patient administration system, the PAS as it is affectionately known, if a patient has an advance health directive, then a clinical alert is placed on that patient administration system to let clinicians know that that patient has an AHD. This would apply if a patient was admitted to hospital and it was already known that they had an advance health directive. When they are admitted, a clinical alert will come up which will let the admitting team know that this patient has an AHD. It says that the patient has an AHD and it says where it is stored so that the clinicians can then access it if it is held at another hospital or where it is they can access it much more quickly. It is not an actual copy of the advance health directive on the patient’s record, but it is at least a clinical alert that says this exists and this is where it is. I do not have the data to hand, but we have seen an exponential increase—not quite, I think, two million—in the number of those clinical alerts that are being completed around the advance health directives. So we are seeing progress there, which is good.

The CHAIR: Is that PAS available to every hospital?

Ms BOLLETER: It is available to every public hospital.

The CHAIR: What about hospitals that are privately operated but publicly funded?

Ms BOLLETER: I would need to take that on notice to double-check.

Hon Dr SALLY TALBOT: Maybe we could have a look at the data if it is readily available.

Ms BOLLETER: Yes, we could provide you with a summary of that. As I said, it is preliminary because it has only been in operation for about 12 months, but we would be happy to provide that. The other mechanism worth noting is My Health Record, which is the Australia-wide initiative, which in the next couple of months becomes an opt-out electronic health record and people, not just patients, in the community can upload their advance health directive or any form of living will that they have as a PDF as part of their My Health Record.

The CHAIR: That was one of my questions. Would My Health be an appropriate repository for advance health directives?

Ms BOLLETER: Yes, it is and there has been a lot of work and discussion done around that.

Hon ROBIN CHAPPLE: Just in regard to an emergency response through an ambulance, are they in touch with the PAS?

Ms BOLLETER: No.

Hon ROBIN CHAPPLE: They are isolated. So, there is no ability currently or foreseen into the future for those people to get hold of what is either on the PAS or indeed what might be on an advance healthcare directive, so we have got a problem.

Hon NICK GOIRAN: What about My Health?

Hon ROBIN CHAPPLE: Would they have access in an ambulance to My Health?

Ms BOLLETER: We would need to take that on notice. I think they probably would, but I would want to confirm that.

The CHAIR: If I am from Albany, visiting Perth and I end up in hospital and a clinical alert comes up, is it a physical file that someone in Albany has to pull up? It is two o'clock in the morning in Perth. They have to wait—say it is a Saturday—for the clerk or the administration person to arrive on Monday to actually pull up a piece of paper?

Ms BOLLETER: Practices for storing them on patient medical records are going to vary according to whether that hospital has electronic medical records or not, but that is one possible scenario.

Dr BRADLEY: The patient may provide their advance health directive to their family members, so they may come with that.

The CHAIR: Is that common?

Dr BRADLEY: We certainly encourage them to give it to anyone—so, to their GP, to their family members, store one at home and have copies in multiple locations.

[4.15 pm]

Hon NICK GOIRAN: In an earlier session with the AMA, I took them through a few current end-of-life choices for Western Australians because this is actually our very first term of reference—the committee is to advise the Parliament, what are the current end-of-life choices for Western Australians. I summarise that session for you now by indicating that four current end-of-life choices were identified. The first is recommended medical treatment, and that could include palliative care and it could include terminal sedation. The second is refusal of medical treatment. The third is refusal of food or water and the fourth was suicide. I would just invite comment from any of the witnesses on whether you would agree with that list of current end-of-life choices, if you would seek for any to be deleted from the list, or if you would seek for anything to be added to the

list. Obviously, it is important that the committee get it right when we inform Parliament as to what are the current end-of-life choices available for Western Australians.

Dr BRADLEY: I need a few minutes to process those choices, just to think through.

Hon NICK GOIRAN: Sure. I am happy for it to be taken on notice.

Dr BRADLEY: Yes. I do not know whether anyone else has anything to say.

Prof. FORBES: I think that is a reasonable summary of the options that are available. Would we like to see any of them removed? What we would like to see is that every individual facing death is aware that their symptoms can be controlled and they can get access to good end-of-life services. We would like to see that up in big lights—that this is the standard that we aim for and we believe is achievable in Western Australia.

Hon NICK GOIRAN: Thank you. Those end-of-life choices for Western Australians have to be communicated in some fashion. It strikes me that those things can be communicated by way of written consent to treatment. They could also, I assume, verbally consent to treatment. Would that be the case; you would not necessarily always have to provide written consent for medical treatment?

Dr BRADLEY: No. You do not need to always provide written consent for treatment. It would depend on what the treatment was and how risky it was believed to be.

You do not always need to provide written consent for treatment. It is based on the degree of risk associated with the treatment involved, so all surgical procedures you obviously need written consent for, whereas offering a medication, you would not necessarily need written consent for.

Hon NICK GOIRAN: There has already been discussion earlier this afternoon about advance health directives. That is another method that a Western Australian can communicate their end-of-life choices on. We have not touched on it that much in this session, but certainly over the course of the 81 hearings, it has come up plenty of times that a person can have an advance care plan. That would be another way in which it can be communicated. Enduring powers of guardianship would be another mechanism available to a Western Australian to, I guess, communicate their end-of-life choice by delegating that authority to another person. I invite any comment about that.

Prof. FORBES: I will just say that that is really only applicable if they are not competent.

Hon NICK GOIRAN: Yes, indeed.

Prof. FORBES: Then they would need to have made some advance health directive to communicate their wishes to the guardian.

Hon NICK GOIRAN: If a person is competent and at that time they sign an enduring power of guardianship and at some later stage they become incompetent, the guardianship is triggered and the guardian then makes decisions on behalf of that person irrespective of whether there is an advance health directive.

Prof. FORBES: Yes.

Dr BRADLEY: Ideally, those conversations have taken place so that that guardian understands what the patient's wishes would have been.

Hon NICK GOIRAN: In accordance with the hierarchy, if an advance health directive is in place, that would effectively trump the views of that person.

Prof. FORBES: Yes.

Dr BRADLEY: That is correct.

Hon NICK GOIRAN: Can you tell us to what extent in the practice of medicine in Western Australia end-of-life choices is an enduring power of attorney relevant, or is it only the enduring power of guardianship that would be relevant.

Ms BOLLETER: Enduring power of attorney relates only to legal and financial matters. There is no jurisdiction in an enduring power of attorney over health or treatment or, I think, even lifestyle decisions; they are the remit of an enduring power of guardianship. They are commonly confused in the community and it is an area that needs more communication, I think.

Hon NICK GOIRAN: Good. Any other ways in which end-of-life choices would be communicated by Western Australians other than the ones we have just discussed?

Ms BOLLETER: Could I refer the committee to another initiative that has been piloted and will be rolled out shortly statewide, which is called Goals of Patient Care. This is similar to advance care planning and advance health directives, but it is in the jurisdiction of somebody who is usually in an inpatient facility, so it is really the decision that is happening and being documented in an inpatient facility. It is not necessarily only about end-of-life decisions; it is, really, as it says, around the goals of care for that patient. Does that patient want to receive all available treatment for their presenting condition? Do they want to receive only ward-based treatment but not, for example, to be admitted to ICU, or do they want to receive only palliative care and relief of pain and symptoms? There are four options that sit within that “Goals of patient care” form. I think we provided it to you at our last evidence, but we are happy to provide it again if necessary.

The CHAIR: That is okay; we have got it.

Ms BOLLETER: The “Goals of patient care” is intended to replace the “Do not resuscitate” form where it is used in hospitals. It provides a lot more information to clinicians around the patient’s wishes. It also has a section that enables it to be enacted in the community. If a patient completed “Goals of patient care” in hospital and was then transferred home, the patient’s doctor can sign that those goals also apply in the community for a period of time. It helps with that transition between hospital and home settings as well.

Hon NICK GOIRAN: Terrific. Can you just remind me where that trial of the Goals of Patient Care took place?

Ms BOLLETER: It has been piloted across all health services; so across WACHS, and then there are sites within south metro, north metro and east metro—not in CAHS, it is not appropriate for children, but amongst all the other health services that have been piloted there.

Hon NICK GOIRAN: Due to be rolled out when?

Ms BOLLETER: Rollout will be dependent on individual sites. It is a pretty complex process, as you can imagine. Some hospitals are using it already and we will work to rollout in the near future. It is a big project, so it is not one that can be rolled out quickly.

Hon NICK GOIRAN: Would it be particularly time consuming to provide the committee with information as to which hospital sites have already got that and which ones remain a work in process?

Ms BOLLETER: We can provide you with information about where it is being piloted and the status.

Hon NICK GOIRAN: That would be good. Can we take that on notice?

The CHAIR: Yes.

Hon NICK GOIRAN: On palliative care: has WA Health assessed the provision of palliative care in Western Australia by comparison to that in other countries?

Ms BOLLETER: We have not completed an analysis like that, no.

Hon NICK GOIRAN: Completed, as in one has not been started and is yet to be —

Ms BOLLETER: It has not been done.

Hon NICK GOIRAN: What about in comparison to other states in Australia?

Ms BOLLETER: There has been no formal analysis done around comparison. The different states and territories work quite closely together in terms of we have an informal working group, so there is good knowledge about systems and how they work. There is always that informal comparison, as you would expect, but there has been no formal work done in that regard.

Hon NICK GOIRAN: On advance health directives, has WA Health been consulted on any law reform in this area?

Ms BOLLETER: We were consulted around the review of the Guardianship and Administration Act and had input into that.

Hon NICK GOIRAN: That is quite some time now ago, is it not?

Ms BOLLETER: Yes.

Hon NICK GOIRAN: No recent consultation on that?

Ms BOLLETER: No.

Hon NICK GOIRAN: In that respect, that would also apply then to the enduring powers of guardianship?

Ms BOLLETER: I think that was covered as part of the same review, so we had input into that review.

Hon NICK GOIRAN: Has WA Health been consulted on the drafting of legislation for euthanasia or assisted suicide?

Ms BOLLETER: Not to my knowledge.

Prof. FORBES: No, not to my knowledge.

Hon NICK GOIRAN: It could be, but not in the knowledge of the current witnesses?

Prof. FORBES: Yes; it is possible that legal and legislative services have been consulted.

Hon NICK GOIRAN: Can we take that on notice?

Prof. FORBES: Yes.

Mr R.R. WHITBY: Professor Forbes, you, I take it, have contact with your counterparts in other states and even discussed contemporary issues?

Prof. FORBES: Some, yes.

Mr R.R. WHITBY: Can I ask you whether you have had any conversations with your Victorian counterpart and discussed or got any feedback on the implications and impact in Victoria of this change?

Prof. FORBES: I have not discussed this with the Chief Medical Officer in Victoria. I have discussed it with other colleagues in Victoria, yes. My impression is that they do not know what they do not know, having legislated. There are a lot of complex issues about management of people that are still to be resolved that legislation does not solve.

Mr R.R. WHITBY: What is your understanding of the way the health department over there is responding?

Prof. FORBES: I cannot give you any detailed comment, I am afraid. I am unaware. My discussion last week was with colleagues who are not directly engaged in the implementation but are practitioners working with patients.

The CHAIR: Thank you very much for your evidence before the committee today. A transcript of the hearing will be forwarded to you for correction of transcribing errors only. Any such corrections must be made and the transcript returned within 10 working days from the date of the email attached to the transcript. If the transcript is not returned within this period, it will be deemed to be correct. New material cannot be added via these corrections and the sense of your evidence cannot be altered. If you wish to provide clarifying information or elaborate on your evidence, please provide this in an email for consideration by the committee when you return your corrected transcript of evidence.

Thank you very much for your evidence this afternoon. We appreciate you all taking the time this afternoon—a very long time—to answer our many questions. We will write to you with those questions on notice and, again, thank you very much for your time.

Hearing concluded at 4.27 pm
