

JOINT SELECT COMMITTEE ON END OF LIFE CHOICES

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



**TRANSCRIPT OF EVIDENCE
TAKEN AT PERTH
WEDNESDAY, 28 FEBRUARY 2018**

SESSION ONE

Members

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

Hearing commenced at 8.58 am**Ms NATALIE JOSEPH****Manager, Clinical Services, Catholic Homes, examined:****Ms BERNADETTE BRADY****Executive Manager, Mission, Catholic Homes WA, examined:****Mrs SUZANNE GREENWOOD****Chief Executive, Catholic Health Australia, examined:****Mr JOHN FOGARTY****Executive Director, St John of God Health Care, examined:****Dr ALISON PARR****Director Medical Services, St John of God Health Care; Palliative Medicine Consultant, examined:**

The CHAIR: Good morning, everyone. Thank you all for joining us this morning. 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. I will introduce the other committee members. We have Simon Millman; Hon Dr Sally Talbot; John McGrath; Dr Jeannine Purdy, our principal research officer; Hon Col Holt; Hon Nick Goiran; Reece Whitby; and Hon Robin Chapple.

The purpose of today's hearing is to discuss the current arrangements for end-of-life choices in Western Australia and to highlight any gaps that may exist. 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 of today's proceedings. I advise that the proceedings of this hearing will be broadcast live within Parliament House and via the internet. Do you have any questions about your attendance here today?

The WITNESSES: No.

The CHAIR: Before we move to our questions, do any of you want to make an opening statement?

Mrs GREENWOOD: Yes, thank you, we would like to.

Catholic Health Australia represents Australia's largest non-government grouping of health and aged-care services. Across the country, we actually opened a new hospital in Werribee in Victoria last week and we are opening a new one in Berwick next month that happens to be a St John of God hospital. We presently have 80 hospitals across the country. It puts us in a very unique position because 23 of those hospitals are public hospitals, and the rest are private hospitals. It gives us that unique perspective into what is happening in the public space and the private space. Catholic Health Australia, as it were, is a little bit like the I suppose peak body that sits over the Catholic providers. So not just the hospital providers, but also the aged-care providers. You will see in our submission the size of our scale across the country, but I did pull some statistics this morning about what we are doing in Western Australia because I thought that was probably more significant for you. Private hospital beds, nearly 1 500; public beds, about 350; aged-care beds, 1 400-odd; aged-care facilities, 28 Catholic aged-care facilities in Western Australia; and there is also an offering of 1 735 home-

care packages. Obviously, care in the home is very much what is perceived as the future of aged care particularly, and obviously a lot of healthcare services as well. We have 536 independent living units and 118 retirement units. I thought that might help put things in context a little more.

Our members in Western Australia include St John of God Health Care, Southern Cross Care, MercyCare and Catholic Homes. Catholic Health Australia members have always valued the delivery of what we call person-centred care that is founded on a respect for human dignity and life. We welcome the opportunity to offer a response to the inquiry into end-of-life choices, and we do so from the position that it is the medical profession's duty of care to preserve and protect life. Catholic Health Australia's view is that it is never permissible to purposefully end an individual's life through euthanasia or assisted suicide because we believe it compromises the inherent value of the person and erodes trust in the medical profession who must care for individuals at all points of their journey. Based on our experience, Catholic Health Australia believes high quality palliative care and end-of-life care is the best solution to allow freedom of choice, comfort, dignity and respect as a person nears their end of life, not just for the individual but also for the family, the carers and the community that surrounds them.

Quality palliative and end-of-life care is best practice. It is cost saving and highly effective at providing choice and ensuring a peaceful end of life. It is coordinated between the patient and the clinician and the necessary allied supports to address the physical, psychological, social and spiritual needs of the individual. Clinicians assist patients and their family in the progression of their condition to improve quality of life, relieve suffering, coordinate symptom relief and provide support for their comfort and wellbeing until their natural death. Palliative care practitioners are equipped to care for those individuals, to ease the fears and anxieties associated with death and dying for the individual, the family and the carers, whilst playing a key role to provide opportunities for individuals with advanced disease to make informed choices about treatments that are acceptable to them.

Patients who access palliative care are consistently shown to have fewer hospitalisations, shorter stays in hospital, reduced use of intensive care facilities and fewer admissions to emergency departments, amounting to significant savings in the health system. This is drawn from the data of Palliative Care Australia. There is also increasing evidence that appropriate end-of-life and palliative care reduces unnecessary testing and futile treatments. Currently in Australia almost two-thirds of terminally ill people for whom home or hospital palliative care would be appropriate though die in hospital, often receiving heroic interventions—as is the terminology in the sector—but often that is also frequently distressing and unnecessary. We therefore welcome the opportunity of this commission to be looking at what are the choices and how can we do those better.

Despite the proven benefits of quality palliative care, it remains chronically underfunded across Australia. It is inaccessible to much of the Australian population, particularly those in rural and remote communities. The Productivity Commission actually estimates that many—perhaps tens of thousands of people—cannot access desired support to die in their own home and are dying in hospital instead.

In conclusion, I wanted to say that Catholic Health Australia members are committed to providing the best possible evidence-based compassionate care to all members of society. We believe that quality end-of-life and palliative care is the best and most effective way to provide choice and ease suffering at the end of life, and all Western Australians should have access to affordable, high-quality and multidisciplinary palliative and end-of-life care before any alternatives are considered. Thank you. I would, however, also like to call on each of my colleagues from St John of God Health Care and Catholic Homes to make some brief introductory comments as well.

Dr PARR: St John of God Health Care is a not-for-profit private healthcare group delivering care across seven hospitals in WA: Subiaco, Murdoch hospital, Midland private and public, Mt Lawley, Bunbury and Geraldton. Four of those hospitals deliver specialist palliative care services, including providing a total of 40 specialist public and private inpatient beds, making St John of God Health Care one of WA's principal providers of palliative care.

In WA the majority of the palliative care-related hospitalisations occur in private hospitals, and in 2015–16 St John of God Health Care provided 31 per cent of this care. St John of God Health Care participates in the national Palliative Care Outcomes Collaboration and is committed to continuing to deliver high-quality palliative and end-of-life care. The organisation has identified some key areas which we believe the committee should consider carefully, including the lack of understanding of the terminology used in relation to palliative and end-of-life care and the associated fear experienced by some patients and their families; the need for public and professional education in relation to the benefits of palliative care, including early referral and the need to raise awareness of referral pathways; the need to build capacity for provision of appropriate care; the need to respect the choice of individuals and to promote advance care planning; the need to protect and care for the most vulnerable in society, including the elderly, the dying and their informal carers, and people with dementia; and the need to respect the dignity of individual clinicians and Catholic Health Care providers through provisions for conscientious objection should assisted dying be legalised. Thank you.

Ms BRADY: Our organisation, Catholic Homes WA, has provided quality aged-care services to the Western Australian community for over 50 years now. We provide a range of aged-care services: residential care, dementia-specific care, independent living retirement villages, and in the last two years we have ventured into the area of home care, providing packages across the Perth metro area, north and south.

We currently provide residential care for about 400 people across six sites in Perth and one in Bunbury, and we employ about the same number of staff. We are not the biggest provider and we are not the smallest, but we value our capacity to create communities of care in our facilities and try to honour our values of love, joy and hospitality to those we encounter.

Catholic Homes can offer a contribution to this inquiry by way of contributing to the conversation and the question of how may we best assist those at the end of their lives and their loved ones to make decisions; to have their wishes heard; to have suffering and pain, both physical and psychological and spiritual, alleviated as far as possible; and to die with dignity. Sometimes this conversation is what is missing in the debate in the public arena. It often gets reduced to simply a question as to whether one opposes or agrees with assisted dying. The issue is far more complex in our experience and cannot simply be reduced to a legal dilemma. There are moral, social and ethical considerations in caring for people at the end of their lives and those making important decisions at that time. Catholic Homes holds the hope that government, on whatever side of politics, will develop an understanding of the needs of those at the end of life. We are passionate about our care for people and we are very happy to contribute to this inquiry to help develop that understanding in the broader community context as well. There is much already being done to assist people to make informed decisions and we can always do better at that. Catholic Homes has been reflecting on how we provide care to those at the end of life and we are very excited about our model and our way of caring for those people, which we will allude to during this hearing. Thank you very much for the opportunity.

[9.10 am]

The CHAIR: This is a question probably for Ms Greenwood. We have obviously had a figure from St John of God that they provide around 31 per cent of palliative care in WA. Have you got the total amount of palliative care in WA that is provided by your members?

Mrs GREENWOOD: Unfortunately, it is a difficult figure to land on very tightly because what is defined as being palliative care can differ so broadly. It is probably more in the vicinity of about 42 per cent. Actually, Palliative Care Australia on Tuesday of this week released their new national standards, and one of the main impetuses for them reviewing their standards was terminology used in this space. So we do have a very fresh document that will assist us in that regard, but, unfortunately, it has not really yet been fed into our presentations today.

The CHAIR: Regarding your submission, you referenced an article by Hudson where the intention of palliative care is to neither hasten nor postpone death. There was a comment on the notion that palliative care is highly effective as a life-preserving intervention. Can you just expand on that for us?

Mrs GREENWOOD: Yes, certainly. Probably the term “life-preserving” was really meant to distinguish from the term “a life-extinguishing measure”; that is, palliative care does allow a person to reach the end of their life as naturally and as comfortably as their condition is going to allow and life is not ended by direct and intentional interventions. Certainly, there is evidence around matters—Alison may wish to add to this—that effective pain relief can actually prolong life by ensuring that patients are not dying from the exhaustion associated with uncontrolled pain. But it is certainly not really the intention that it is to bring about the early or the late passing.

The CHAIR: Are you able to clarify the distinction between specialist palliative care and palliative care?

Mrs GREENWOOD: I might defer to Alison with this, but our definition really does follow the World Health Organization definition and so it very much is that palliative care, to a degree, is provided—all aged-care facilities would really need to answer that call to an extent. But specialist palliative care very much is in accordance with the World Health Organization definition, which really is around all those aspects that I mentioned earlier—the social, the psychological, the spiritual. But perhaps Alison, being a palliative care specialist, might like to —

Dr PARR: The World Health Organization defines palliative care as an approach that is a holistic approach and involves teamwork, and really that applies across the board, whether it is being delivered by aged-care facilities, general practitioners or hospital practitioners in general. Specialist palliative care is different in that the people delivering that care are specialist teams who have specific training in palliative care who are able to deal with the most complex of those problems, whether those are physical symptoms, psychological needs, complex social circumstances or spiritual needs, and to look at that holistic assessment with a specialist eye and be able to pick up on the challenges and involve appropriate members of the multidisciplinary team and, if necessary, external providers, to ensure quality of life for the patient and the family.

The CHAIR: Do you think there are enough specialist palliative care providers in Western Australia to meet demand?

Dr PARR: I think there are gaps, definitely. Over the four years that I have been in Australia and working with St John of God Health Care, there have certainly been an increasing number of specialists. We have got increasing numbers of doctors in training in palliative care. Certainly, the provision has improved over that period of time, but I think we have still got significant gaps, within the multidisciplinary team context as well—not just doctors, but also specialist nurses and allied health professionals with that expertise as well. Particularly, as you say, there are groups of people

that have very poor access to those specialist services in rural areas and certain groups of people. For example, within our own unit at Murdoch Community Hospice, the Aboriginal and Torres Strait Islander people are only represented in less than three per cent of our admissions to the hospice there. The question then is whether or not those needs are being met in alternative settings, and my suspicion is that we are not good at reaching out to those groups that perhaps need a different approach.

Hon ROBIN CHAPPLE: Thank you very much indeed. Just as a subset to that question, how many specialist palliative care providers do you have across your service?

Mrs GREENWOOD: That is not actually a statistic I drilled into. I can tell you from the Australian Institute of Health and Welfare statistics the number across all of Western Australia. Across all of Western Australia, we are sitting at about 0.8 of one full-time equivalent per 100 000 people in the population. I think at present it is about 42 or 43 specialists in the state.

Dr PARR: Not quite that many.

Mrs GREENWOOD: Not quite that many; okay. It was only about 20. The statistics from the Australian Institute of Health and Welfare is that between 2012 and 2015, there was a 43.9 per cent increase in the number of employed specialist palliative care physicians in the state. So we have had some rapid growth in recent history, but we would certainly contend it is not sufficient to address the need.

Hon ROBIN CHAPPLE: The second part of that question on specialist palliative care providers is: how many other providers of palliative care do you have across your organisation?

Dr PARR: In terms of specialist palliative care —

Hon ROBIN CHAPPLE: No, not specialists.

Dr PARR: Because you could argue that anybody is a provider of palliative care if they are caring for people with progressive illness.

Hon ROBIN CHAPPLE: That is fine. So just about everybody provides ordinary —

Dr PARR: With varying levels of skill, and I think that is the concern.

Mrs GREENWOOD: Yes, and therein lies the dilemma.

Hon ROBIN CHAPPLE: In terms of the regions, and I am a regional member, do you, as an organisation or organisations, provide care beyond the twenty-sixth parallel—that is, the north of the state?

Mr FOGARTY: No. We have a palliative care service at Geraldton that services the midwest region—public and private—and at Bunbury in the south, but beyond Geraldton we do not provide anything further north than that.

Hon NICK GOIRAN: Whatever the number of palliative care specialists there are in Western Australia, whether it is 40 or a lesser figure, Dr Parr, are you one of them?

Dr PARR: Yes.

Hon NICK GOIRAN: Yesterday we heard from a group, the WA Palliative Medicine Specialist Group, and I recall them saying they had about 20 specialists as part of that group. Are you one of them?

Dr PARR: I am.

The CHAIR: We have heard quite consistent evidence that early access to palliative care services provides a better end-of-life experience for patients. In your experience, does that hold true?

Dr PARR: Definitely.

The CHAIR: Why might that be?

Dr PARR: I think the evidence is there in research. I think you may have heard evidence already in regard to Australia having a palliative care outcomes collaboration which people can voluntarily contribute to as specialist services. The data from the palliative care outcomes collaboration does show that over the last few years, certainly through pulling together and looking at where services are achieving better outcomes and sharing that information, we have been able to improve symptom control across Australia through contribution to that collaboration. There is also good research evidence that shows that early intervention with palliative care improves quality of life for patients and families, reduces treatment toxicity and, ultimately, results in better bereavement outcomes. In some cases, it can even deliver improvements in prognosis equivalent to some forms of chemotherapy.

[9.20 am]

The CHAIR: According to the Australian Institute of Health and Welfare, Western Australia was the only state in which private hospitals deliver the majority of palliative care compared to the national figure where 84 per cent of palliative care is provided in public hospitals. Do you have any comments on why that is so different in Western Australia?

Dr PARR: I think that is about the contracting for public palliative care services. In Western Australia, the public system has chosen to contract with private hospitals to provide those services. So in a hospital, for example at Murdoch Community Hospice, we are funded for 10 public beds but we also have 10 private beds.

Mrs GREENWOOD: If I could possibly add to that, I think too it is that the Catholic services are prepared to invest in the provision of palliative care. It is one of those things that is an important area of care for us. It is fair to say that one of the Catholic traditions is that we will look for opportunities to care for those in the margins—to care for those disadvantaged. Often people at their end of life will fall into being a class of person who is in need of care and particularly if the public system is not adequately servicing them, then the Catholic providers will attempt, as far as they are able to, to step in to that need.

The CHAIR: We heard evidence yesterday from some of the WA palliative care specialists that palliative care was originally included in the contract for Midland Health Campus and then was removed. Have you got any views as to why it was taken out of that contract?

Mr FOGARTY: My view would be that possibly it was related to the service at Kalamunda. There is a service in the East Metropolitan Health Service at Kalamunda, which we refer patients from Midland to if they need inpatient palliative care. So we do provide palliative care consulting, if you like, at the hospital for inpatients, but I think it was withdrawn mainly not for any specific reason other than there was an existing service that was to be preserved.

The CHAIR: On the PCOC data, which you referred to and St John of God contributes to, it demonstrates disproportionate access to inpatient palliative care services by those with the highest socioeconomic status. Is that reflective of your data, St John of God?

Dr PARR: I think that is reflective of our data too, yes.

The CHAIR: And Catholic Health, generally?

Mrs GREENWOOD: Think I would just comment that those with private health insurance therefore might be more able to avail themselves of some of these services, so, yes.

Mr J.E. McGRATH: Would this be a reason why there is such demand for palliative care out there in the community and so many people are saying that they have not got access to it?

Mrs GREENWOOD: Look, entirely. Really, those people in a lower socioeconomic area and we also talk in terms of the social determinants of health: your education, your housing circumstances, your employment. All those factors can feed into your health and wellness. So, unfortunately, the statistics are that the health disparities exist for those that are living in the lower socioeconomic areas. If anything, is probably a greater unmet need amongst those communities, yes.

Mr J.E. McGRATH: In other states where more palliative care is provided by the public sector, maybe that would not be the case?

Mrs GREENWOOD: Certainly, there are varying levels at which public palliative care is offered and it is at a higher percentage in some states. I would argue that the level of palliative care offered right across Australia is inadequate—at an inadequate level.

Hon COLIN HOLT: I have a couple of questions. Do you have any figures around the percentage of people who would like to die in their own homes versus what actually occurs? Can you grasp anything?

Mrs GREENWOOD: Speaking off the top of my head, because I did not think to actually bring that sort of data with me, I would say anecdotally that the vast majority of people want to die at home. Why would anyone say, “Gee, I hope I’m in a hospital at my end of life”? That is something we would probably like to talk a little bit about with some of the later questions when we are talking about advance health directives and advance care plans. That is one of the reasons why we are very strong advocates of advance care plans because it does help to have that conversation with individuals about what they want their end-of-life care to look like—what they want that stage of their life to look like. It is that opportunity to open those conversations around what care they want. Most people will say that they do not want highly burdensome or futile treatments at their end of life. They would like to be left in peace as far as possible, but having their pain managed.

Hon COLIN HOLT: I know it is a bit of an unfair question, I understand, because it is pretty hard, but are you aware of any research that would be beneficial that you could point us to?

Dr PARR: My understanding is that around 70 per cent of people will express a wish to die at home but many fewer do—less than 50 per cent of them probably do. There are many reasons for that. Some of that is about people actually being faced with the reality of a situation and the reality of the support that is available in a community, and actually making a different choice when push comes to shove. Whilst people may plan ahead, we have always got to be prepared to review those decisions with patients to see what fits at that point in time with the circumstances they have got. In regard to research, some research was published towards the end of last year by Kathy Eagar and a group of physicians looking at the data from PCOC, which actually showed that in terms of symptom control, that is better achieved in an inpatient setting, so the compromise you make if you die at home is that you are less likely to have your symptoms well controlled.

Hon COLIN HOLT: Thank you. I have one further question. In your opening statement, Mrs Greenwood, you talked about erosion of trust—this may also be a question for Dr Parr. We have heard that in some submissions. Can you explain why that would occur? If laws of voluntary assisted dying were to be introduced, why would they be an erosion of trust? That was a statement we heard.

Mrs GREENWOOD: Look, I would actually like to answer that from a couple of aspects. I am a lawyer by profession. I am an admitted solicitor in the state of Queensland and I am admitted to the High Court of Australia. To me, laws are there to protect those who are more vulnerable in our community. I have a very deep concern around how do we protect the vulnerable from laws such as what we are seeing come in in the state of Victoria. We see many episodes of elder abuse, of

older persons being thought of as a burden on our society and our community, so I think safeguards are something that they do very strongly need to turn their minds to in Victoria. On to the question of clinical erosion, it is very much that the role of the clinician is to assist and help a person. To come to the conclusion that assisting and helping a person to remove their pain is to remove the person is just something that is not palatable to us. I think possibly Dr Parr might have some views as well.

Dr PARR: I think one of the big challenges with palliative care is the fear. When people initially hear about a referral to palliative care, for example, we spend a lot of time with those first contacts with patients and families just actually providing reassurance about what we are there to do. For some people, there is a fear that actually what we are there to do is end their life. To be able to currently say to them, “Look, we’re here and we’re all about living, actually. Until you die, it is not about assisting you to die and we’re not about to do anything that is likely to shorten your life” often helps to build trust and allows people to open up in their most vulnerable times and talk very openly about their thoughts and fears. I guess there is potential in that situation to not be able to offer that level of reassurance and for people then to be even more wary of accessing services that might help them. That would potentially be a concern.

Hon COLIN HOLT: Do you think that if these laws are introduced, your conversation would be different with those patients?

Dr PARR: My conversation would have to be different. If the law existed and that was an option, then we would still want to broach people’s fears and understand really what was underlying their worries at that point in time. That is part of holistic assessment. In terms of our role as a palliative care physician, it is about promoting choice and autonomy and therefore if there are other choices, it becomes a different conversation. Still, the key thing is to understand that if somebody were to request or want to explore assisted dying in any way, shape or form, then our first response would be, “Tell me why” and the need to understand actually what it was that had brought somebody to want to explore that option. Often, we can work with people to work through those things and actually there are often interventions we can offer that put a whole different perspective on a situation. If somebody is in severe pain, it can be unbearable. We deal with their pain. Equally, we deal with psychological distress or we look at options in terms of social support and integration back into the community; we look at building somebody’s role so that they have a meaning and purpose despite the situation that they are in. All of those things can actually change people’s minds about what they want.

[9.30 am]

Hon Dr SALLY TALBOT: Ms Greenwood, in your answer to the question asked by Hon Colin Holt, you mentioned the Victorian legislation. You have obviously had a chance to have a look at that, because this is clearly an area of interest for people in your profession. Are you of a view that there are missing safeguards for vulnerable people in the Victorian laws?

Mrs GREENWOOD: Look, it is very difficult, I suppose, to tell at this early stage, because we have not had the opportunity yet to see how things will play out at a practical level. Catholic Health Australia members are actually holding a workshop tomorrow in Victoria, and one of the things that we are wanting to discuss there is, how might this look like for people who are coming into our facilities; how do we support them; how do we support our staff in addressing some of these questions? How do we address questions, as Dr Parr pointed out, of the fear of those who feel that, “I’m here because you’re going to bring about my death.” There are a lot of complexities in that conversation that we are yet to work out. I think one of the concerns with the legislation in Victoria is that there is not the ability for an institution or body to consciously object to providing the service. It is very much in the hands of the doctors, and in talking to some of the clinicians, as individuals—

in the hands of the doctors as individuals—and in talking with some of the clinicians, they feel it a significant burden that they are being isolated to have to make those kinds of decisions when they are not in agreement with the legislation. Certainly, I suppose, one thing I would like to see in the Victorian legislation is an ability for the institution—the hospital, as it were—to be able to conscientiously object to the provision of voluntary assisted dying.

Hon Dr SALLY TALBOT: One further question on that subject: do you take people in your facilities who are not Catholics?

Mrs GREENWOOD: Certainly; absolutely—you do not have to be Catholic to work for us; you do not have to be Catholic to be cared for by us, and there is absolutely no discrimination on any grounds. Actually, just thinking further on safeguards, I think there are a lot of challenges in that space that still need to be played out in Victoria, because they have not yet confirmed what the drug of choice will be. I am very concerned, from a medico-legal perspective. We talk about the management of schedule 8 drugs. Schedule 8 drugs, in layman's terms, are those drugs listed in schedule 8 to the legislation as being those able to, I suppose, bring about death—very burdensome on an individual, particularly if mismanaged. At the moment, those kinds of drugs must be kept under lock and key and registered, and two people at a time sign them out, what is used in operation, and then whatever is left over, two people sign it back in and register it. We are talking about a drug that is potentially even more lethal than many drugs on that list, but that may just be placed into the hands of an individual to then take back to their home and possibly administer. I have seen also the clinical procedure for, I think, Oregon in the United States, where it is death by lethal injection, and in that circumstance it is a course of three different types of drugs injected over a period of time. It is extremely distressing, actually, just to read the clinical procedure, because it is things like, if there are any carers in the room for the individual, warn them that after this injection the individual may be gasping for breath, may suffer a cardiac arrest. It also contemplates that the timing of death may be up to 24 hours. It is very difficult to kill a human being; there is not a nice easy one-size-fits-all approach, and so one of the big areas of concern I have, to answer your question about safeguards, is how are they going to safely manage those drugs—a drug that will have a massive value on the black market; a drug that will not be administered under lock and key in the hospital context, as other drugs of that ilk would be.

Hon NICK GOIRAN: Ms Greenwood, my colleague has just asked you about the Victorian safeguards, and in effect whether you think they are adequate, or something else needs to be added. Can you advise the committee why you say safeguards are needed in the first place?

Mrs GREENWOOD: Because every human being is important, and I do not want to see anyone get killed who does not want that to happen.

Hon NICK GOIRAN: So that could happen without the safeguards?

Mrs GREENWOOD: Well, that is what I fear. It is terrible to think about the what ifs, but if they settle on a particular drug that the individual is able to take home with them, and that individual decides, “I don't want to do this today, but I may want to do this”, and leaves it on their bookshelf, there is just no control over the security of that drug. What about persons visiting? What about the grandchild who might be visiting grandma, and seeing what looks like a mint sitting on her shelf? They are terrible examples I am extrapolating out there, but I do think control and management around the drug, and whatever the drug is, are critical questions, and we are certainly not seeing any clarity coming out of discussions in Victoria that assure us of any safety in that regard. Hopefully it will come, for that state.

Hon NICK GOIRAN: Is your concern that the patient may be coerced into this practice?

Mrs GREENWOOD: Look, I do not think I am the only one who would have that concern. There was even that recent movie—I cannot think what the name of it was—that was done out of the New South Wales film commission, where the elderly parents were sitting on fantastically valuable real estate in Sydney, so the children thought that euthanasia would be a good option, because then they will get their inheritance faster. There are all sorts of concerns, I think, around elder abuse and that sort of thing.

Hon NICK GOIRAN: That is around coercion. You indicated earlier that you are a practising solicitor, an admitted solicitor, and you did talk about medico-legal issues. Do you have any concerns about the possibility of a mistake or negligence by the practitioners in this field?

Mrs GREENWOOD: Look, Australia has some of the most excellent clinicians in all of the world. I would not at all be actively suspecting any of them of negligence or untoward behaviour.

Hon NICK GOIRAN: So medical practice is negligence-free in Australia at the moment?

Mrs GREENWOOD: I do not think anything is negligence-free, but I do not think people are actively wanting to harm others when they enter into a profession such as the medical profession.

Mr R.R. WHITBY: My question is, perhaps, to Mr Fogarty, but others might like to add their views. Yesterday we had evidence from a representative of Braemar Presbyterian Care, who said that although they were not supportive of the change to voluntary assisted dying, nevertheless their view is that it is inevitable, either on this occasion or in the future. I would like to ask you your view on that, and also, if you do believe that this is a change that is inevitable or even possible, how would your institutions respond?

[9.40 am]

Mr FOGARTY: My initial response would be, given the Victorian situation I suspect it is inevitable, whether it is now or in the future. Our organisation would seek to be able to conscientiously object to the delivery of voluntary assisted dying in our institutions, and we hope that that would be enacted in any legislation in Western Australia, so that we have that right, and our clinicians indeed have that right.

On the private hospital side, we, effectively, provide services for clinicians to admit their private patients. The relationship we have with the clinicians is not one of employer and employee, it is actually an associate type—not really a contractor relationship, but an associate. We would have to also work with our accredited clinicians—medical practitioners around our view. If they were of the view that they wanted to support that procedure, we would have to advise they would not be able to undertake it in our hospitals.

Mr R.R. WHITBY: From a practical logistical sense you would have to have the removal of patients who are sometimes in an advanced and serious state of terminal illness to be removed from your institution to go somewhere else where they could undertake that service?

Mr FOGARTY: Yes. I imagine that is the way it would play out.

Dr PARR: And sometimes people may be too unwell to move.

The CHAIR: Can I confirm that you receive commonwealth and state funding?

Mr FOGARTY: Yes.

The CHAIR: And are there existing restricted services in Catholic institutions?

Mr FOGARTY: Yes. There are a number of services which we in Catholic hospitals do not provide. We do not participate in IVF, we do not participate in the termination of pregnancy and we do not participate in procedures that effectively render people infertile, so sterilisation procedures.

The CHAIR: Does that include the provision of contraceptives?

Mr FOGARTY: Yes.

Hon ROBIN CHAPPLE: You said earlier on you have got 60 non-government hospitals and 23 government hospitals. Do these decisions apply to both of those hospitals?

Mr FOGARTY: Yes. I guess the live example for us is in the Midland Public Hospital here in Western Australia, where we have a services agreement with the state government to provide public hospital services on their behalf. It is a 307-bed public hospital and we have some private beds there as well. We are funded to provide services that we contract directly with the state on. During the process of the negotiation of that contract, in our bid to government we said there are services we will not provide, and our bid was successful and the government of the day acknowledged that those services would not be provided by us and so they funded a separate entity which is close to Midland to provide services that we do not provide.

Hon ROBIN CHAPPLE: I have a supplementary question to that. If you have a patient in your public hospital and there is a need for a service which you do not supply, how is that dealt with in a good way; that is, transfer and that sort of thing? Do you have a system?

Mr FOGARTY: We assist them to be comfortably transferred if they are unable to transfer themselves. Probably the services that we do not provide currently that are legal services elsewhere would not require a patient—usually the patients who access those services are quite physically well so the need for transfer is probably less—something that we assist; they would be discharged from our care and they would make their own arrangements. It is probably less likely in that situation to be a transfer.

The CHAIR: Would you provide them with a referral to those services, because they do require a referral?

Mr FOGARTY: It is not our role as an organisation to provide referrals; it is a medical requirement. Again, in a private hospital sense it is the role of the practitioner to decide whether to provide that referral based on their view. It is probably more so that a general practitioner would provide that referral. We do not employ general practitioners.

The CHAIR: Are potential residents and patients fully informed of these restrictions before entering into either a care home or hospital?

Ms BRADY: Catholic Homes does not have any restrictions really. Some of the restrictions that the hospitals have are not relevant to aged care, such as contraception. Other than that, we do not have any restrictions that we need to notify anyone of.

Mrs GREENWOOD: Not to cut you off there, but if I could just offer: we have what we call our “Code of Ethical Standards for Catholic Health and Aged Care Services in Australia”. That is a document that is available on our website—cha.org.au. It does outline our position on those kinds of matters. It is a publicly available document and freely available.

The CHAIR: Thank you. In the instance of Catholic Health—this is probably more relevant for Catholic Homes or St John of God hospices—do you support a patient at the end of life requesting palliated starvation and dehydration?

Dr PARR: In my experience, people very, very rarely would request that in its own right. What we see is that as people become less well, they gradually lessen the amount they drink, and towards the end of life it is not uncommon for people to be unable to eat and drink because physically they are too weak and they cannot coordinate to swallow, and we look at mouth care and comfort measures. That is the usual circumstance that we see. I have very, very rarely in 22 years of being a

palliative care physician had somebody ask me about starving to death. I can only actually in all that time think of one patient who even discussed it, and actually after discussing it their choice was different and we looked at what we could do to help them in their situation. I do not think this is a common scenario. I think it is important for you to understand that this is not something that people ask for commonly. We would address that in the same way currently that we would with any person who was wanting to explore options to hasten their death in that our response would be, “Just tell me why. Let’s look at what your reasons are for requesting that and let’s see whether we can look at options that actually make life more bearable at the moment. How can we assist you to live well until you die, or as well as is possible in the circumstances?”

The CHAIR: Is it same for the aged care?

Ms BRADY: Yes, I would agree with those comments. We would always support the decision of a competent person. The Catholic position is fairly consistent. If the provision of nutrition or hydration prolongs or enhances the person’s suffering or it can only be given by means that are too burdensome for the person to consider bearable, in consultation with everyone involved in their care I think that decision would be made after all those things are taken into consideration. Our code of ethical standards says the refusal of treatment is a moral right that healthcare providers must not override if a person is competent and mentally stable. We would also look at if a person were seeking to end their life by not eating or drinking—almost suicidal or depressed—then we would address their distress or their mental health issues as best as we could and support them and their family to make informed decisions.

Hon NICK GOIRAN: I am constantly intrigued about this topic of palliated starvation and dehydration. The committee has had a lot of hearings and invested a lot of its time around this topic. It is good to talk to practitioners who are actually there on the front line, rather than advocates and academics. The evidence from actual practitioners there on the front line seems to consistently be that this is incredibly rare. I am interested in the one case that you had. What was going on for that patient that brought them to that request and how did you handle it?

Dr PARR: That was many years ago —

Hon NICK GOIRAN: As best as you can recall.

[9.50 am]

Dr PARR: And I guess you also have to realise that over the course of 22 years of practice, our options for palliating symptoms have increased. We have more things that we are able to offer these days than we did early in my career. For that particular patient it was somebody who had advanced cancer, who had reached the end of active treatment, who was very distressed at the news that there were no further options for chemotherapy to prolong life, and it was at that stage where it was almost that hopelessness and, “This is my only option now; let’s just try and accelerate death.”

When we started to talk more about what we could do to support someone at that stage, that, “Actually that doesn’t mean there’s nothing we can do. There is lots we can do and we will be here. We’re staying alongside. These are the things we might come across further down the line. This is how we can help you. We are here to support your family as well. Let’s look at what we can put in place. Let’s think ahead and plan so that we don’t reach these crises, or have less of a chance of reaching a crisis”, then actually once we had worked through all of that, that person chose a different route.

Hon NICK GOIRAN: We have heard a little bit about this concept of demoralisation. I understand that that is somewhat of a new—I do not know what the right phrase to use is, but perhaps —

Dr PARR: Terminology?

Hon NICK GOIRAN: Yes, a new terminology, so perhaps it was not around in this case you are talking about. But this sense of hopelessness that someone feels when there is seemingly no other options available, is that what we are talking about when we are talking about demoralisation?

Dr PARR: Absolutely. Often once you explain what options still exist, people feel more able to cope and feel supported. In practice, I do not recall a single patient having taken the option to actively choose to starve to death. We would also talk to someone where they were expressing that wish. We talk about the reality of what that looks like. It does not happen instantly. It is something that would happen over a period of weeks. When they understand the reality of what they are asking for, again sometimes their choices change.

The CHAIR: Do Catholic Health facilities support a patient at the very, very end of their life in intractable pain and suffering seeking terminal sedation?

Dr PARR: Again, the evidence is that that is rare. It is uncommon for us to see people who are that severely distressed at the end of life that sedation is the only option. Certainly, we would be looking to optimise any symptoms that were causing that severe distress that might mean that our only option was sedation, so we would have to have exhausted all the options we have for symptom control, psychological support and so on. So that we have tried what we can and either it has not worked or it is not tolerated by the patient; and that they are still very distressed. As we are getting towards the end of those options, we would usually be talking to a patient about sedation possibly being an option further down the line if things were not working as well as we had hoped. Actually, we would want to gauge for them as an individual if they were the sort of person who would want to be more alert at all costs and for us to support them through the distress, or would they be someone for whom sedation might be an option they would want to consider. Again, we are talking about somebody in the very last stages of life with hours or days to live where this may be something we would consider. In that circumstance ANZSPM, our overarching body as palliative care specialists, has issued guidance on the use of palliative sedation. I would draw your attention as well to questions of terminology around palliative sedation and terminal sedation, and even in specialist fields people do not always refer to exactly the same thing when using those terms. So we need to be very clear about what we are talking about.

Mrs GREENWOOD: I think as Catholic providers, we would say that terminal sedation is really the administration of sedative medications in such a dose as a route to cause—to bring about—the patient's death where death is the goal. So, of course, in that sense terminal sedation is not part of the practice of palliative medicine for Catholic providers of care. Certainly palliative sedation, though, is.

Ms BRADY: I agree with that too. If the clear goal of sedation is to cause the patient's death, then, no, that would be clear. But then you have another whole pile of conversations to be undertaken with those responsible for their care and involved in the care as to how to accompany that person and not abandon them to their decision. We would have lots of conversations around the continuing care of that person and how to manage their symptoms. I do not know whether you have any comments about that.

Ms JOSEPH: I think the role of sedation at end of life really is to alleviate suffering. From the care we give in Catholic Homes, if someone shows symptoms that require a sedating-type drug, it is usually given in combination in increments with painkillers until their suffering is relieved. It is very much end of life. We are talking usually the last 24 to 48 hours. At that time, all their systems are shutting down. We look at alleviating suffering. It does not result in death but it will give the same result; it will result in death because they are no longer eating, drinking, that type of thing.

Dr PARR: They are dying.

Mrs GREENWOOD: Actively dying.

Dr PARR: They are actively dying at the time. Sedation is offered during the process of dying to alleviate symptoms. That is the difference. So it is not given with the intent of bringing about death.

Mr J.E. McGRATH: So you could guarantee to this committee that the practice of terminal sedation has never happened in a Catholic hospital?

Dr PARR: Again, I would like to qualify what you mean by terminal sedation because some people would use the phrase to mean sedation that may bring about death but also brings about alleviation of suffering. Others would say that terminal sedation is sedation offered during the dying phase that brings about relief of distress and does not bring about death itself.

Mr J.E. McGRATH: I am referring to the former.

Dr PARR: I do not believe that terminal sedation, meaning bringing about death, ever happens in a specialist palliative care unit.

Mr J.E. McGRATH: Not even if a specialist might be the person looking after the patient and unbeknown to the hospital this might have happened?

Dr PARR: I believe that in a specialist palliative care unit where you have experts using sedation appropriately, what we are giving is palliative sedation and not any sedation that is bringing about death. A study was done by Maltoni a few years back that looked at a hospice inpatient setting. It was an observational study; they looked at a group of patients who were receiving palliative sedation and a group of patients who were having standard hospice care. When they looked at that, it showed no difference in terms of survival between the two groups so the conclusion from that was that palliative sedation was not hastening death in any form.

The CHAIR: We had some evidence late yesterday from a WA palliative medicine specialist group which I think you are a member of—it was Dr Tandon—and he said that he is not familiar with the term “palliated sedation”.

Dr PARR: Palliated sedation? Palliative sedation is a term that is recognised by ANZSPM, which is our overarching body—the Australian and New Zealand specialist palliative medicine group. They have issued guidance on the administration of palliative sedation.

Hon ROBIN CHAPPLE: You have referred to palliative sedation, terminal sedation within the palliative care area and your particular area. Are you aware of what we call “terminal sedation” or enhanced palliative sedation occurring outside of your organisation?

Dr PARR: I think certainly within an inpatient hospital setting where things are complex and people are thinking about using sedation, they tend to involve a specialist team because it is often outside people’s area of confidence and expertise. So certainly in an inpatient setting and in the community—many of these patients will be supported by hospice services in the community as well—I am not aware of any cases where sedation has been used inappropriately.

Hon ROBIN CHAPPLE: I have one question, going back if I may. In the Victorian legislation in division 2, I think it is section 47, it actually gives the provision for medication to be taken at home or away from a medical facility. Is that the particular one you are really concerned about?

Mrs GREENWOOD: Yes; that certainly touches on that whole question of medication management; of the security around the drug. I believe also in Victoria they are not going to be performing autopsies on anyone who passes away who has been prescribed with that medication, the result being that they will not know who has used and who has not. I am not advocating that people have to undergo an autopsy because it is a time of life for those people when all those around them will be in extreme distress and to add to that by saying, “Well, now we are going to subject the person

to an autopsy.” I am not saying that but I am saying that we are concerned that there will not be knowledge whether a particular drug has been used or not.

I think they are putting an obligation in the legislation around—I think they are going to flesh this out in the regulations a bit more—others having to return the drug. But others around the individual may not be supportive or happy that they have gone down this path, may not know where to find it—all those sorts of complexities—and in their own distress may not return it, so then we are left with what is potentially a very lethal drug being out in the community.

[10.00 am]

Hon ROBIN CHAPPLE: What I am really coming to is that if section 47 was not there, a lot of your concerns would be alleviated?

Mrs GREENWOOD: No; I cannot in any way, shape or form agree with euthanasia.

Hon COLIN HOLT: A quick clarification on the term “terminal sedation”, just to clarify for my mind and maybe the record, your understanding of terminal sedation really is sedation that occurs in the terminal phase of life rather than sedation that brings about a termination of life?

Dr PARR: Absolutely.

Hon COLIN HOLT: Is that right?

Ms BRADY: That would be our understanding.

Hon ROBIN CHAPPLE: You are the first organisation to manage that; well done.

Hon NICK GOIRAN: It is precisely the question I was going to ask, because once again the committee has invested a heavy amount of time on this issue, and the one thing that is clear is that the language is all over the shop, frankly. So when you said earlier, Dr Parr, that it is very uncommon, what I am understanding you to say by that is that sedation at the palliative phase is uncommon, whereas sedation to terminate a life does not happen?

Dr PARR: Absolutely, and again to qualify, palliative sedation to me means that you have got intractable symptoms, you have tried everything you can, you have explored with the patient or you have been through the hierarchy of decision-making that legally you have to go through, and you have arrived at a decision that actually sedation is a reasonable option for this patient. We are actually bringing about an altered level of consciousness. In other situations we may use very low doses of sedation that may relieve anxiety but do not alter consciousness. We do that more commonly.

Hon NICK GOIRAN: When an otherwise healthy person goes to the hospital and undertakes a procedure—I think sometimes at a lay level we refer to it as “being given the gas”—is that also a person being sedated, and to what extent is the level of sedation there different from the sedation you are talking about?

Dr PARR: Again, in both cases you are looking at appropriate doses of sedation for that individual patient. There is not a one-dose-fits-all in either scenario. For a procedure, you have usually got a clinician who is experienced with use of sedation in that kind of setting, who will look at the patient as an individual, look at their blood tests, look at their body weight and think about actually what is an appropriate use of sedation for this individual patient and will prescribe accordingly. In a palliative situation, again, we are looking at the individual patient, all of those parameters, and how they have responded to medication previously. We would usually start with low doses, and adjust if we needed to, to get to what was appropriate for that patient, whether that is relief of anxiety and maintaining consciousness or whether it is inducing some level of drowsiness.

Hon NICK GOIRAN: To follow up on this one, when you do that, this uncommon palliative sedation—sedation during the palliative phase—do people come in and out of consciousness during those last hours or days?

Dr PARR: This is where the phrase “terminal sedation”—I guess maybe the difference for me is that palliative sedation may be a little earlier and you may sometimes adjust your level of sedation and withdraw it. It may be about assisting someone to sleep overnight because they have not slept for several nights, and actually the following day you are going to reverse that sedation and allow it to wear off, whereas sedation at the very end of life, you sometimes are sure that when you give that level of sedation that patient probably is not going to rouse again. That is the difference for me.

Hon ROBIN CHAPPLE: Sorry, I think it was yourself, doctor, who talked about the activity of dying. Is there a definition of the activity of dying? When does it start and when does it become critical?

Dr PARR: If that was very easy to define, doctors would be so much better at it! There are a number of things that we can take into account to help us to identify the dying phase. But actually, doctors could be better at it than we are and it is uncertain and sometimes difficult to predict. What we do know is that as people get closer to death, we are better at predicting it. In those conversations that we have with patients and families about dying, sometimes we will say, “You know, this is a bit unpredictable.” Sometimes it will happen suddenly and we have not predicted it, but sometimes we see the signs. Certainly with families, we will be saying to them, if they have chosen to go home, that if we see any of these changes, we will be on the phone saying, “Would you like to make your way in?” Some of it is about the context—we have got somebody with advancing illness, we have seen the changes over a period of time, they have become less well, they are spending more time in bed, they are not eating and drinking as they were previously. But we begin to see in the actual dying phase, changes, for example, in circulation, and temperature regulation sometimes.

Hon ROBIN CHAPPLE: What I am trying to grasp, obviously the activity of dying can be from anything we have identified in the next hour or out to seven days ahead of that. Is that the sort of suite of time that we are looking at?

Dr PARR: In illnesses that are clearly progressing, we can often, certainly from days away from death, tell that we are in the final days of life. But in terms of being able to predict exactly when death is going to happen, that can be difficult. Sometimes we do not know if it is going to be hours or not. We can sometimes predict, if breathing changes have happened for example, that it might be in the next few minutes. But sometimes we might speak to a family at five o’clock because we are about to go off and say, “Look, things may or may not change overnight, and be prepared in case”, and we might come back the following morning and find the patient still alive, or they might have died an hour after we left. It can be very difficult to tell.

Ms BRADY: In aged care I guess we become familiar and sensitive to the signs of change that indicate a person is deteriorating, and we take steps to communicate with the carers and the multidisciplinary teams about what we are observing. There is an innate kind of wisdom that comes with that familiarity and constantly working around death and dying. I guess philosophically the activity of dying begins when we are born—all our cells live and die. But at end of life, because we develop that familiarity, we develop the confidence in our staff and our teams to have those conversations with others about what we are observing and what we then need to do about that.

The CHAIR: I want to just touch on the doctrine of double effect, particularly when using high levels of opioids. Do you think that for the doctrine of double effect there is adequate protection in the Criminal Code?

Dr PARR: Again, I think if you are using medications in a skilled way, actually the evidence from the literature is that the doctrine of double effect does not really come into play, because what we are doing is titrating medication according to need, and then we are bringing about relief of symptoms and relief of distress, and dying may happen alongside that.

The CHAIR: Do you think it is common that the doctrine is relied on in palliative care?

Dr PARR: No.

The CHAIR: Have you ever had patients or their substitute decision-makers request an increase in palliative medication, knowing the risk is to hasten death?

Dr PARR: Yes. That has happened sometimes, and usually it is a reflection of levels of distress and a signal for us as a team to spend more time with patients and families and explore that distress, and often with intervention and time and the multidisciplinary approach, we are able to support people through that.

Ms BRADY: I would echo that, too. It is an opportunity for people to give families information around what is available as well. Often people are so distressed and they think medication is the only answer to that distress. There may be other interventions we can make to address psychological distress, spiritual distress, issues around meaning and family relationships that would be adding to that distress. It is a multidisciplinary conversation that needs to take place as well.

[10.10 am]

The CHAIR: I would like to, with indulgence, talk about advance health care directives, noting the time. Does Catholic Health Australia and its members also advise or assist patients with completing advance health directives?

Mrs GREENWOOD: As you are aware, there is different legislation around each of the states. I am aware that you are speaking with Professor Ben White from QUT also at some stage today. He is one of the leading authorities around Australia as far as bringing together the legislation and the differences between them. Catholic Health Australia, as you would have seen from our submission, has an advance care plan that we promote, and we have a website that supports that, which includes webinar materials and different sources of materials like that. The reason we promote this as a tool for people, and usually we encourage them to complete it before they turn their mind to an advance health directive, is that it is not as prescriptive, speaking generally, as all the advance health directives and forms like that around Australia. They are very cold, clinical documents. I sat down with my parents when their GP said that they needed to fill one of these out, and I could not get either of them to turn their mind to the document because it is very cold. It does ask questions around hydration and whether you want this to be stopped and this to be stopped. It is very affronting for an older person to be confronted with what is ostensibly a government form saying, "Please tick the box on how you want your life to end."

The advance care plans that we put out, as you would have seen from our submission, are a document that encourages the individual to think about: How do they want their end of life to look like? What will that time look like for them? Who do they want to have in the room? Do they want their pet brought into them if they are in an aged-care facility and their pet is being cared for by their son or daughter? Is there someone in their life that they want to meet with and say sorry to about something? Is there someone in their life that they have not told them they love them for a decade and they need that person to come in? It is very much a document that guides them through those sorts of questions. It does touch on basic care around food and water and what they would like that to look like, but it is more couched in terms of being kept comfortable, having effective pain relief. It is not: turn off my hydration or food supply.

It is a document that we, therefore, encourage people to complete. We find that it opens up those conversations before the advance health directives. I think it is fair to say that the number who have completed an advance health directive is much lower than is probably ideal, but, anecdotally—Dr Parr will probably tell you what it is at St John of God—it would be ambitious to think that we have hit five per cent of patients presenting at the hospitals on the eastern seaboard. I am not sure what the experience is here.

Dr PARR: I think that is reflected over here as well. It is very uncommon for people to have an advance health directive. I guess the concerns that we have around advance health directives are: How long ago was it completed? Who advised on the wording that went into it? Does that situation actually apply to the situation that we are facing now? How can we be sure that there was no coercion? Does it reflect the patient's current views even if there is a document that was completed a little while ago? It is never that straightforward. Our preference is certainly to focus not on whether or not there is a document that reflects that legally, but actually what is the patient's current view. So where patients have capacity to take part in those conversations, we would very much be revisiting that at regular intervals through an admission.

The CHAIR: Is Catholic Health Care bound by healthcare plans?

Mrs GREENWOOD: Advance health directives?

The CHAIR: No; healthcare plans?

Mrs GREENWOOD: It is not a prescriptive document, I suppose. Certainly, as Dr Parr has just pointed out, it is a document that is going to be a tool that will guide everyone. Often in cases this is not couched in terms of, "I want the hospital to do this," but, "This is what I want my end of life to look like," such that it is a tool that does support the carers around the individual who often may be called upon to make those decisions for the hospital about what may be happening, and consulting on the treatment.

Ms BRADY: At Catholic Homes our experience is that many people do not have advance health directives—I was at one site and there were three out of the 39.

Ms JOSEPH: And we do not promote them, because we do not find them helpful, because they are legally binding in this state, and we find nothing will take the place of good ongoing conversations with the doctor and family as things change along the whole palliative journey, as opposed to saying, "Yes, they've done that; let's tick that box. That's done. We don't have to worry about that anymore." It is not as cut and dried without palliative care. We do not promote them at all.

Ms BRADY: We do really have those conversations and document people's end-of-life wishes and thoughts, similar to that document. We have our own variation of that document that is constantly reviewed. Particularly when there is a change in the person's condition, we make sure that those sorts of documents are updated and that staff are aware of them. Yes, but that is the best way we think we can cope with that. We do ask people when they come in if they have enduring power of attorney and guardianship, whether they have their affairs in order or any other wishes, whether they have preparations for death or funeral arrangements. In those conversations you can engage people in starting to prepare for an end-of-life approach to care.

Hon COLIN HOLT: That is really interesting evidence you have just given, because it seem to me that you have raised a disconnect between the legislative approach of legislators and the boffins who write forms and what happens in life.

Ms JOSEPH: I think you will find most people who practise in that area will have a similar view.

Hon COLIN HOLT: It is a real red flag for me, that disconnect between what is trying to be achieved from a legislative approach around advance health care directives and what actually happens in reality. It seems as though we have a lot of work to do to gather your expertise to plug into that system to improve the system—absolutely. I do not know whether you have any comments on that or on how we might approach that improvement or that uptake?

Ms BRADY: If I may say, it is the bridge between the legal and moral and ethical areas. We are kind of dealing with the day-to-day realities of people's lives, which are about decision-making and ethics. They are not clear legal decisions often, and those documents are very legal. They are worded that way; they have legal implications. I think we are dealing with different things.

The CHAIR: Are they not legally dealing with a patient's wishes, essentially?

Ms JOSEPH: They are, but, for example, if an advance health directive is made when someone is relatively well and healthy, then of course they would be like, "Yes, I would like to be treated with IV antibiotics, for instance, if I get pneumonia." Maybe they will draw the line at CPR—not everybody, but a lot of people will want CPR. But five years down the track, if they have a lot of co-morbidities going on and advancing disease, they may have bounced in and out of hospital quite a few times, and they are like, "No, that's it. I don't want to go back to hospital. I don't want that." Their wishes completely change. It is not a conversation that you can have with them at that point when they made it, because until whatever their journey is—I mean, it is through their palliative journey—it changes along the way. The best way to support them in decision-making is ongoing discussions with people who can deliver the care and the doctors who are looking after them.

Mr J.E. McGRATH: I gather that a lot of people would be coming to palliative care not thinking that they are going to die or hoping that they might come good or their problem might be cured, or do they all come in with the inevitability, "I'm here and I'm not going to get out"?

Ms JOSEPH: I think in the initial stages, it depends on the person, but while there is hope and there are oncologists—if is a cancer diagnosis—offering active treatment, they are definitely not at the same point psychologically that they will be maybe a year down the track. That is a huge factor in determining what they want. When we say "palliative", we are talking end of life. Everyone who is admitted to aged care is essentially starting their palliative journey. It is a big difference again with the terminologies to what you are talking about.

<009> M/A [10:19:16 AM](#)

[10.20 am]

Mr J.E. McGRATH: But even though they are starting this journey, they still will not fill out the advance health directive?

Ms JOSEPH: Or, if they do, it is highly likely or highly probable that what they fill in then is going to be different in six months and then another six months.

The CHAIR: But they can be overridden orally?

Ms JOSEPH: Yes, they can. The reason we do not promote them is that because they are legally binding, if they do not get revisited along the way and they just get checked—tick, tick, that is done, that is in the file—then when it comes to the point maybe at end of life when it is looked at again, the person is maybe not as cognitive, particularly in aged care, as they were when they came in, but you know because of what they have said to the clinical staff that, no, they do not want to go back to hospital, and it is not documented, so it puts us in a bind if they have ticked, "Yes, go to hospital." It can result maybe in a traumatic ending to their life when at the eleventh hour we are ringing the ambulance and transferring them when really we know that is not what they want. But if there is a health directive that has not been updated, we have to do legally follow that. We have a similar

thing, an advance care plan, and that is continually updated as the conversations are ongoing throughout their illness.

Dr PARR: Just in terms of, again, the wording on advance health directives, sometimes it can be misleading and does not actually reflect the patient's wishes. Unless they have actually sought advice around the wording, sometimes what is written on their advance health directive does not match what they want. As an example, we had a lady who came in with end-stage neurological disease who did have an advance health directive. She had actually written on her advance health directive that the only intervention she would accept was pain relief. She was actually breathless, and what she meant was that the only interventions she would want were for comfort and she would not want active treatment of anything reversible. Fortunately, she still had capacity for us to tease that out with her and to determine that actually if she had other symptoms, we could treat those and we could manage her comfort. She was not limiting interventions only to pain relief. It is just that the wording sort of ties things down too tightly. So, it is important to get the wording right on advance health directives when they do exist.

Ms JOSEPH: Rather than simplifying things, they actually complicate matters.

Dr PARR: They can, and I think the key thing is that whether it is an advance health directive or an advance care plan, they do facilitate a starting point for the conversation. The conversation is the key thing.

Hon ROBIN CHAPPLE: I am going back to my perennial question. In your hospices or hospitals do you have the practice of DNR—do not resuscitate?

Dr PARR: What we are moving towards is a slightly different structure, if you like, around decision-making around resuscitation. So, yes, it is fair to say that we do still, and some hospitals have a form that is "refusal of cardiopulmonary resuscitation" or "not for resuscitation", with a discussion with the clinician. We are actually in the process of shifting towards what is becoming the WA model, which is to use a document called "Goals of patient care", which is more the discussion around the advance care plan, "What is important for you? Let's think about what interventions are still going to be appropriate, but what level of intervention are we going to stop at." There is then a whole range of things where through that discussion we can determine whether the care is going to remain ward-based, whether or not we are going to call the emergency team if, say, blood pressure drops or somebody develops observations that are outside of the range that we would find acceptable, or are we just going to focus on comfort? Are we going to offer resuscitation for this patient? Is it what they want? Is it medically futile? Have we had that discussion with them? The form provides a different framework for that decision-making, with the focus very much being around, "Let's think about where we are at and what our goals of care should be."

Hon ROBIN CHAPPLE: In that regard, could you provide us with your current form and also this proposed one? It is the first time I have heard of that, so that has been quite unique. Currently, if a medical professional who is providing services to a patient in your hospital says, "Do not resuscitate this person", does that go onto a particular form in your hospitals?

Dr PARR: Yes. The system that we are moving away from is a specific form just around resuscitation. There is space on it for free text where you can document the decisions about interventions that are appropriate or not for the individual patient, but the form is focused on resuscitation, and you fill it in if the patient is not for resuscitation, whereas the new form is much more generic and focused on the wishes of the patient and documents an appropriate level of escalation.

Mr FOGARTY: And one of those wishes might be not to be resuscitated.

Hon ROBIN CHAPPLE: If you can provide those forms, it would be very, very useful.

Ms BRADY: Can I just ask Natalie to comment on that—how we indicate people’s wishes around that at Catholic Homes.

Ms JOSEPH: It is a bit different in aged-care facilities. Obviously, we do not have an emergency team at our disposal for CPR. We do have one question in our advance care wishes that asks, “If your breathing or your heart stops, would you like St John Ambulance to perform CPR?” That is primarily in there for the ambulance, because that is what they want to know when they are called. Usually, if their breathing or heart has stopped, by the time the ambulance gets there it is already too late to do CPR, but that is why we ask the question.

Mrs GREENWOOD: Could I also add that our code of ethical standards, which gives a little bit of light of this as well, says —

The use of life-sustaining technologies needs to be evaluated in the light of Christian beliefs about life, suffering, death and resurrection. In so doing two extremes should be avoided: on the one hand, an insistence on futile and overly-burdensome treatments which merely obstruct death, on the other hand, the deliberate withdrawal of treatment in order to bring about death. Since good medicine treats a person rather than a condition, respect for persons requires that they neither be under-treated nor over-treated; rather, when people are dying they should have access to the care that is appropriate to their condition.

The code goes on to provide some grounds for decision-making around withdrawal or withholding of treatment and also goes on to how go about that decision-making process to provide quite a detailed framework for the decision-makers. Obviously, they can then work with the families on those decisions.

Hon ROBIN CHAPPLE: You just mentioned decision-making by the families. So, the families are involved in this decision-making about whether somebody should be resuscitated or not. What evaluation do you carry out of the issues of the family making that decision when they may stand to gain or lose by that decision?

Mrs GREENWOOD: I think it is a very multifaceted decision that has happened. I do not think any clinician would feel railroaded by a family saying this is the path we have got to go down if there is, say, other documentation such as the advance care plan or advance health directive that might be in place, or in fact the wishes of the individual person themselves. At the end of the day, it is the wishes of the individual that would be paramount, depending on how they have been able to articulate that. Often what is the case with a lot of family around the individual is we are all in denial that our loved one may be in those last days of life. We do not want them to be in that position. So it is difficult when we are talking about a situation in which people are acting in a very untoward fashion. I think it is the skills and experience of the team involved, probably, who would have an understanding of what was going on.

Dr PARR: And that comes back to holistic assessment.

Hon ROBIN CHAPPLE: We have heard a politician say that in conjunction with medical professionals, the family made a decision whether to continue the efforts of sustaining life or not. I am really concerned that that takes out of the individual’s control that ability to manage the end of their life.

Mrs GREENWOOD: I think it would only happen when we are at a stage where the individual no longer has the capacity to be articulating their wishes in that space. Would that be a fair comment?

Mr FOGARTY: Yes; I agree with that.

Dr PARR: Yes, absolutely. We would be following the framework of the hierarchy of decision-making in those sorts of situations in which a patient does not have capacity to contribute. Always when

you have got a competent person who is able to contribute to the decision-making, we respect their decision in that circumstance, when after a full discussion when they have got adequate information they have been able to weigh it up and so on. If you have got a patient in a situation where they are not able to contribute to that decision-making, we look at whether they have an advance health directive; if they have not, we look at whether they have an advance care plan that helps to guide us; and we would be approaching an enduring guardian, if they have got one, so somebody who they have authorised to make decisions for them.

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Dr PARR: In the absence of all of that we start down the hierarchy of the closest people to them. That is when family may be involved in the decision-making, but it is really a joint process. It is not their decision to make in isolation. It is done with the clinical team, not just with an individual. Because part of good palliative care is that holistic assessment where we understand the social circumstances, we have explored relationships within the family, we have some understanding of where there is potential for those kinds of situations, and ultimately, if we have concerns we can escalate through ethical and legal routes to obtain advice, but in practice we very rarely need to do that.

The CHAIR: Thank you for your evidence before the committee today. A transcript of this hearing will be forwarded to you for correction of minor errors. Any such corrections must be made and the transcript returned within 10 working days from the date of the email attached to the transcript. If the transcript is not returned within this period it will be deemed to be correct. New material cannot be added via these corrections and the sense of your evidence cannot be altered. 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.

Dr Parr, you mentioned the ANZSPM guidelines.

Dr PARR: I have already written it here. That was something I thought you might benefit from seeing.

The CHAIR: We will write to you requesting that and any questions that were outstanding that we were unable to address with time constraints. Thank you all very much for your time today. The committee really appreciates it.

Hearing concluded at 10.31 am
