

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

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



**TRANSCRIPT OF EVIDENCE  
TAKEN AT PERTH  
WEDNESDAY, 13 December 2017**

**SESSION FIVE**

## **Members**

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

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**Hearing commenced at 4.43 pm****Mr KIM GREEVE****Project Officer, WA Cancer and Palliative Care Network, Department of Health, examined:****Ms AMANDA JANE BOLLETER****Program Manager, Palliative Care, Department of Health, examined:**

**The CHAIR:** I welcome Mr Kim Greeve from WA Cancer and Palliative Care Network and, back to the witness seat, Amanda Bolleter.

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 would like to introduce other members of the committee. We have Hon Dr Sally Talbot, MLC; John McGrath, MLA; Dr Jeannine Purdy, our principal research officer; Reece Whitby, MLA; Simon Millman, MLA; Hon Colin Holt, MLC; Hon Nick Goiran, MLC; and Hon Robin Chapple, MLC.

The purpose of today's hearing is to discuss the current arrangements for end-of-life choices in WA and to highlight any gaps that may exist. It is important you understand that any deliberate misleading of this committee may be regarded as a contempt of Parliament. Your evidence is protected by parliamentary privilege; however, this privilege does not apply to anything you might say outside today's proceeding. I advise that the proceedings of this hearing will be broadcast live within Parliament House and via the internet.

Please let us know if you have any questions about your attendance today.

**Mr GREEVE:** I have a background as a registered nurse and I am doing my masters in palliative care at the moment. My main role with the network is advance care planning.

**The CHAIR:** I understand you have a short PowerPoint for the committee.

**Mr GREEVE:** Yes. What I thought I would do is give a brief overview of advance care planning. It may answer a couple of the questions, but I thought it might also give a little bit of setting and cover some of the questions that have been covered before in terms of the hierarchy of decision-makers, so I thought I would particularly cover that as well. I normally use a clicker so somebody might be my clicker for me.

Advance care planning is essentially an ongoing conversation, if you will, for discussion. If we think about it from our own context, it is thinking about our worries our hopes, our fears our concerns around the care and treatment that may worry us in advance of the time when we may lose capacity. It is things, for example, that worry or concern us around our care; what treatment we may or may not want, particularly when we cannot consent or make decisions for ourselves; sharing that information, so, for example, not making the assumption that our family and loved ones will know this information by osmosis; we are going to share that information with them and, ideally, including our health professionals or people who are likely to make those decisions on our behalf, and a person responsible. We will look at the hierarchy later so they are aware of those decisions. Also part of that conversation can be fact finding. For example, if I have a disease trajectory of pancreatic cancer, I may need to work out: what information do I need to in terms of what I might face in the future so I can make some of those anticipatory decisions? That can be part of that information as

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well. The conversation is very important but it is also really important if we can record or write down those preferences as well.

Who can make those decisions for us? If we have lost the capacity to consent or refuse consent for treatment in a non-urgent scenario, we will refer to the Guardianship and Administration Act, and we have got the hierarchy of decision-makers. At the top of the list is the advance health directive or valid common law directive where we have, if you like, written down or formulated formally our preferences around treatment—in other words, what treatment we are happy to accept, consent to, or any treatment we do not want to receive or any treatment we refuse consent to. It is a way of recording treatment decisions only. We make that while we have capacity and it comes into operation when we have lost capacity. We refer to that, first of all, as a health professional. If I have not made an advance health directive or it does not match the situation at hand, my health professional will go down to the next tier. Have I appointed an enduring guardian? In other words, have I completed an enduring power of guardianship and appointed a subsidiary decision-maker who can make personal, lifestyle and treatment decisions on my behalf? We go to them and say, “Look, Kim needs this particular procedure; are you able to give consent or refuse consent?”, and look at what level of authority they have. If I have not appointed an enduring guardian, or they are not contactable, we go down to the next level. Has a guardian been appointed? We are most likely to see a guardian in the aged-care sector or an area where there might be great family conflict. Basically, if I have no loved ones or no-one in my life who will be able to make decisions if I have lost capacity, someone has to be appointed because health professionals cannot give treatment without consent; therefore, we have to have a guardian. The State Administrative Tribunal will appoint a guardian from the Office of the Public Advocate. If they do not exist, we go down to the first level after that. Are you married or in a de facto relationship? That now includes same-sex marriage—yay!—and de facto partners as well. So we would go to them and they would have the ability to consent or refuse consent to treatment. Not everyone has a partner, so we go down to the next level. Have they got a child who has an ongoing relationship and has capacity and is 18 or older and we can go to them and say, “Look, are you happy to give consent to Kim?” But, as I said, not everyone will have a child or they may not want to make the decision or they are not contactable. We can keep going down the levels until we find someone who gives consent.

[4.50 pm]

We have got parent and sibling, primary unpaid caregiver. That is not someone from HACC; that is someone generally who has been designated as your carer—usually it is a relative or someone very close to you. When we get down to the bottom level, it opens up more broadly, so it is your cousin, your aunty, your uncle—someone who is really close to you who can make those decisions. If we get to the bottom level and we have not identified anyone, we must then as a health professional go back to have a guardian appointed, because we must have someone to be able to provide consent.

**The CHAIR:** When you cannot find anyone and have a guardian appointed, would that be the Public Advocate?

**Mr GREEVE:** The Public Advocate will provide the guardian. We would go back to the State Administrative Tribunal and they appoint a guardian.

**Hon COLIN HOLT:** So, you assess that someone is not capable of making a decision by themselves and you go to the hierarchy. Is there a similar assessment made for the people in the hierarchy? You have assessed that a patient is not well enough to make a decision about their own treatment, then you go to the spouse and you say, “You are the next on the hierarchy.” Is there assessment made then of their capacity?

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**Mr GREEVE:** Of the spouse?

**Hon COLIN HOLT:** Of anyone down the list, you know, you keep going?

**Mr GREEVE:** As a health professional, if we approach them and we do not believe that they have capacity to make that decision, we would be in the right position then to go to the State Administrative Tribunal and it would be something for them to determine. In that situation they may go, "Actually, we need to appoint a guardian", or they may go, "Actually, no, that person's not appropriate."

**Hon COLIN HOLT:** How do you make that assessment?

**Mr GREEVE:** The thing with capacity is quite interesting, and some of the questions cover that. We are deemed to have capacity when we are 18 and older unless proven otherwise, and that is based in common law. We would assume that their partner has capacity and we would assume that our patient has capacity at 18 unless proven otherwise. Sometimes capacity can be quite difficult to assess and the Guardianship and Administration Act does not give us a lot of information about how to determine capacity. We would refer to a medical practitioner to determine that capacity or if we cannot determine it or if it is complex, we would refer it back to the State Administrative Tribunal to determine capacity. But you are right, if we had concerns about someone making those decisions or we had concerns about someone acting in the best interests, we as health professionals really should go to SAT and refer it back to them.

**Hon COLIN HOLT:** How do you make that assessment if you have concerns?

**Mr GREEVE:** From a health professional perspective, for nurses, they would look at a person and they would have concerns. Firstly, we would refer to a medical practitioner. Our practice in the Department of Health is that it would be a medical practitioner decision to determine capacity. If they cannot determine that, then they would actually say, "Right, we either have to refer to someone else", it might be a psychiatrist, a psychogeriatrician or someone else to make a determination on capacity. They could then refer it to the State Administrative Tribunal. We would refer it to a medical practitioner to make that decision.

**Hon COLIN HOLT:** Of the, say, spouse, at that level? Is that what we are talking about or are you talking about the patient?

**Mr GREEVE:** At this stage we would be referring to the patient.

**Hon COLIN HOLT:** I want to go to the next level when you have made that decision: they are not capable, we need to go to the hierarchy of treatment decisions and we are going to get the spouse in to talk about making a decision on the husband's behalf.

**Mr GREEVE:** I think in that situation we would make an application to the State Administrative Tribunal and say that we have concerns that that person needs a guardian appointed. I would say that we are not in a position to assess the spouse, because they are not our patient. We would actually refer them to the State Administrative Tribunal. That is the best way I can answer that question. I have not actually come across that situation myself, so that would be the best way to answer. I would encourage health professionals to go to the State Administrative Tribunal to answer that question to make that determination.

**Hon COLIN HOLT:** I am not quite getting it. So, the spouse walks through the door to have a discussion with the patient's physician or treating specialist and they ask them, "What would you like to do for your husband's treatment?" Do they make an assessment of that person there and then of their capability of making that decision?

**Mr GREEVE:** No, we do not.

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**Hon COLIN HOLT:** That is it I am trying to get to. You just assume they are okay?

**Mr GREEVE:** No, we would assume they have capacity if they are 18 and older until proven otherwise, unless there was strong doubt, then, as a health professional we can go to the State Administrative Tribunal. Otherwise, we would just assume that they have capacity.

**Hon COLIN HOLT:** Okay, thank you.

**Mr GREEVE:** I will go to the next slide. When I look at why we do advance care planning, I think it is important to look at a level of evidence, and there is a lot of growing research and evidence all the time. This refers to high-level evidence of a randomised controlled trial that was undertaken in Victoria and published in 2010 in Austin Health. That showed that advance care planning improved end-of-life care; improved patient and family satisfaction; reduced stress, anxiety and depression in surviving relatives; and reduced the stress and anxiety for care staff.

I will go to the next slide. There is also research about why there are some barriers and difficulties around having the conversation. Rather than going through all of them, I have given you the link there, but number one really is the fact that most people feel uncomfortable talking about the D-word—that is, death. Whether you are a health professional, a patient or a member of the general public, talking about death and dying is not something we do over the coffee table and most people feel uncomfortable talking about. But from a health professional perspective, if we acknowledge the fact that we feel uncomfortable talking about death, sometimes it can make those conversations a lot easier. It can then also lead to the fact that if we have these open conversations, we can have a shared understanding and also a shared caring between health professionals and family and patients as well.

I go to the next slide. The conversation is really important and I think it is probably the most important thing that we can do. Then, ideally, if it is good, if we really feel strongly about particular treatment preferences, we formalise them. We have two statutory powers at the moment in Western Australia, the advance health directive and enduring power of guardianship. The Department of Health have also developed an advance care plan. The advance health directive is where we can formally record treatment decisions and health professionals must follow someone's advance health directive. It is the same with enduring power of guardianship; it is a statutory document where you can nominate a substitute decision-maker. The advance care plan is what we have developed in the Department of Health and other states and other areas will also have advance care plans. That is really a way of capturing all the other parts of our care that are not necessarily treatment based, because there is far more to our care than just treatment. For example, I might be coeliac or vegetarian. I might want photographs of my children or grandchildren, for example. It is a way of capturing all the other things in my care.

I might come back to this next slide in a minute and look at it a bit further. The Department of Health has developed quite a lot of resources to support consumers and health professionals around advance care planning. We have an e-learning package in which you can enter two streams, as a consumer and as a health professional, and you now get a certificate as well, which is also good for CPD points for health professionals. It has a lot of information and resources around advance care planning and also how to support people and how to make decisions around completing an advance health directive, as well as the legal aspects. We now have an advance care planning guide for patients and health professionals, as well as an advance health directive guide for patients completing one. Another aspect of the resources is that we can refer people to their My Health Record in terms of registering their information for an advance health directive and making it available.

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We have also done a huge lot of work in our department in developing resources for CALD and Aboriginal communities. We have just published an advance care planning guide for patients, a brochure, in 20 languages, including a bilingual form. We are in the process of publishing resources for Aboriginal communities. At the moment, we are at the designing the artwork stage, so we are supporting Aboriginal communities for advance care planning as well. That is the next phase.

I go to the next slide. What is the prevalence for discussions and documentation? Before we talk about prevalence, it is just highlighting the fact that completing or formalising a discussion is not the right approach for everyone. I will give you an example. For example, my mother is 84 and when I talked to her, she did not want to do an advance health directive because she has not been to hospital since she had me—or maybe once, but not very often—and so she said, “I have no idea of what I want to do in terms of what may or may not happen to me, so, for me, completing an advance health directive is very difficult.”

[5.00 pm]

I said, “Let’s do an advance care plan, so you can write down things that are important to you, where you’d like to be cared for.” For example, she does not want to die at home, she would prefer to die in a hospice or hospital, and there are certain things that she likes or does not like. I said, “At least write that down.” I can share that with my siblings so that when the time comes, we will be the persons responsible for making these decisions and we will have a sense of what she does and does not want.

Advance health directives are quite powerful if people know what they do and do not want. But for some people, even with having an advance care planning discussion, they may not have a sense of what is going to happen to them. Therefore, maybe having an advance health directive can be something that they can park and do it later; at least maybe appoint an enduring guardian who can make decisions. In some ways, an enduring power of guardianship is more fluid, so they can interact with the doctors at the time and say, “Hey, this is what is happening for Kim” and make those decisions at the time—maybe consider that or an advance care plan, and come back to an advance health directive when they are really sure about what they do and do not want. But a lot of our resources now are being developed to support people to think about why they want to do a directive. Before you can do a directive, you need to think about why you are doing it and what the purpose of it is. Is it the fact that my focus is around comfort and quality of life, or is my focus around other specific treatments? The resources are now focused on supporting people about the “why”. Once you have got the why, you can move forward a lot more easily to complete it, but just recognising that it is not necessarily for everyone. There should not be a KPI for every place that people must do a directive. It really depends on your personal circumstances and preferences.

Therefore, we do not actually have any data to tell us how many have completed a directive in WA. We do have some evidence that suggests that about eight per cent of Western Australians have completed an advance care directive, with about 14 per cent nationally. But we believe that to get more information accurately, a lot more research would have to be done to get a much more accurate picture, because, as we know, there is no register, so it is very difficult to get that accurate number.

**Hon NICK GOIRAN:** Mr Greeve, did you say 18 per cent?

**Mr GREEVE:** No, approximately eight per cent. There is some evidence, but what I am saying is that the accuracy of that information—to confirm that, we would need to do a lot more research. That is just some evidence that we have heard. Roughly, that is really anecdotal. I think to get a really strong picture, we would need to do a survey or something to undertake that. We do not have an accurate picture.

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Who is responsible for disseminating information? I would say it is everyone's responsibility in Health: it is right from the Department of Health as system manager, primary care, acute care and aged care. In the beginning, in terms of education, I have been involved with advance health directives when they first came out. We did a lot of education and rollouts of training and partnering with the Office of the Public Advocate. We have a very close relationship. We did road trips, informing people. But now particularly in our role of system manager, my role in that has very much changed in terms of we do not really now deliver education to health professionals directly; we provide resources, policy and information to support that, hence why we do a lot more work around engaging in resources. We realise now to actually get the message out there, we have to collaborate with other partners, hence the Department of Health has funded Palliative Care WA and they have developed a consortium. That is a combination—I know they will be presenting that; I think they are coming tomorrow. That consists of NGOs, private and public sector, on how we can work together and get the message out there, because the Department of Health alone cannot achieve that, to get that message out more sustainably.

How can advance care planning documentation be available when needed? We need a policy. We do not have a policy at the moment. That is a work in process. I hope that will be out early next year. We have standardised the location of advance care planning documentation. We now have a barcode and a medical record number on the advance health directives, so they will all be located in the same place, in a patient's medical records, to improve access at point of care. We now have a clinical alert for the presence of the advance health directives. In the patient admission system, if you hand in your directive, a flag will come up. It will identify you and the fact that you have presented an advance health directive. Just under 700 people so far have presented advance health records to the public sector and, therefore, a clinical alert has been raised.

On My Health Record, you can register and upload your directive. As from the end of next year, that will be opt-out; at the moment, it is opt-in. That could have some implications for us in terms of what we can engage with them. We developed the advance health directive alert card that folds up —

**Hon ROBIN CHAPPLE:** Can I go back a second, please, if I may? My Health Record—my understanding is that there is a code that runs with you through all your medical presentations. We have just discovered that there have been a number, especially in the Kimberley, of multiple codes for individuals. We are trying to resolve that at the moment. Would My Health Record be associated with that departmental code?

**Mr GREEVE:** No. My Health Record is, as I said, that is a commonwealth initiative, under Medicare. At the moment, the only way you can register with My Health Record is you do it yourself and submit your documents on there and you have control of who can access —

**Hon ROBIN CHAPPLE:** It is not carried with the health department?

**Mr GREEVE:** No.

**Ms BOLLETER:** It is not linked to the UMRN; if that is what you are asking.

**Mr GREEVE:** You have an alert card in your pack. We have given you those resources. It is a cute little card that you can fold out. It tells you who has a copy of your advance health directive, enduring power of guardianship and who your emergency contact is. The reality is that if you have some untoward event, people are going to go through your belongings. You can have a little card. Once again, it increases access to your advance health directive at point of care.

**Hon ROBIN CHAPPLE:** Again, on that one, if I may. If you have an advance health care directive—a number of people have taken them out over a number of years—and you do not have that card, is

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there any way of testing? You have a patient before you and they are not able to provide direct information themselves, is there any way to establish whether they do have an advance health care directive?

**Mr GREEVE:** Currently, there are only a couple of ways that we can achieve that. If someone is registered with My Health Record, there is an urgent criteria where the emergency staff can access your My Health Record. If you happen to have registered with My Health Record, uploaded your AHD or EPG, and then you have a critical event in an emergency department, they will be able to access that. At the moment, as we noticed, not everyone has registered with My Health Record. If you have submitted your advance health directive in advance to a hospital and, hence, there is a clinical alert—for example, my advance health directive is at Royal Perth Hospital, so if I happen to go camping in Esperance and I have an event, on the patient admission system it will come up that Kim has an advance health directive, and they will know it is at Royal Perth. Then they can contact Royal Perth and get my advance health directive down to Esperance. Other than that, we would not know unless someone tells us that; there would be no other way. What we encourage people is that they need to inform people, so tell people that they have a directive. Pass on a copy to your GP; you can register. As I said, the other thing people might do is MedicAlert and register that, so it increases access. But other than that, we would not know unless people tell or give it to us.

**Hon ROBIN CHAPPLE:** I was really considering the large number of people who jumped on board in the early days with the advance health care directive, which was just in paper form. They filled it out and they keep it in their backpack or wherever. I am just concerned that a lot of people might get missed in the whole process.

**Mr GREEVE:** I am sure there would be, unless they actually hand it in or tell their loved ones where it is. For example, in our household we have everything in the one box, so all my nieces and everyone knows where to go to get that information. Other people might have the bottom drawer episode and just hope for the best that it will be there. Unless you actually tell people that, like I say, it can be harder to access it.

**Hon ROBIN CHAPPLE:** Is there going to be any media encouraging people who have already got them to go into My Health Record and register?

**Mr GREEVE:** In terms of My Health Record, that is outside our jurisdiction of what they might be doing. That is a commonwealth initiative. I think it will be interesting to see what happens next year when they do the opt-out rather than opt-in.

**Ms BOLLETER:** A commonwealth government committee is looking at raising community awareness about advance care planning, so we are part of that process and watching with interest to see outcomes there too.

**Hon NICK GOIRAN:** Can I just follow up on that? As much as it is a commonwealth initiative, this My Health Record, nothing would stop the Western Australian government from communicating to its citizens or its residents in saying, “Please be aware that there is this portal, this place, where you can register your advance health care directive.”

[5.10 pm]

**Mr GREEVE:** When we promote advance care planning, we talk about My Health Record, and definite information, as we have information on our resources and on our website. We talk about My Health Record as one of the ways of sharing that information.

**Hon NICK GOIRAN:** On the list of questions—I mean your presentation is excellent, it is covering off on a lot of these things—it says, “Is there a need for a system of registering statutory instruments

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to ensure health providers are aware of their existence in relation to a particular patient?" Hearing this discussion, I take it that is the best place at the moment, the best we have got?

**Mr GREEVE:** This is all we have at the moment. As we know, the register was not passed. The Attorney General has recently done a review in terms of the Guardianship and Administration Act. When that question was raised, what we as the Department of Health raised is that we would support a register if it was fully funded, had 24/7 access and was compulsory to register an advance health directive. We said there was no point having a register unless people can access it when it is needed and it is also safe for people, so people who are going to be scrutinising your directive—you know, only people who need it—but it is 24/7 and all there; there is no point having some that are registered and some not. If it was fully funded and 24/7, then we would fully support it. But in terms of whether or not it is actually the best approach, I think a lot more research would have to be done because I do not think there is enough research to support whether that is the best approach, even though some other countries have such a system. I think more research needs to be done, but we would support it if it was fully funded and we could have it 24/7. My personal opinion is that I would support a register. I think it has a lot of benefits; a lot of countries do it very well. That is just my personal opinion. But for us, as the Department of Health, we would support it if it was fully funded and 24/7.

**The CHAIR:** I want to ask you some more specific questions about topics you covered earlier, particularly in relation to the SAT. In cases of uncertainty, how frequently do Department of Health professionals make applications to the SAT for a declaration of incapacity?

**Mr GREEVE:** We would not have that information; I would best refer back to them. The problem is that a lot of applications, when they go to the State Administrative Tribunal, are quite confidential, so only the parties who are named on the application would hear about it. I would actually refer back to SAT. We would not have been given that information.

**The CHAIR:** Following that—I think I know the answer to this that you will probably give—does the department monitor all AHDs and EPGs referred to the SAT for declaration?

**Mr GREEVE:** No, we do not. Can I just double-check which number we are up to, so when we are moving forward, I might be able to look back?

**The CHAIR:** On statutory instruments.

**Mr GREEVE:** Yes, lovely. Sorry about that.

**The CHAIR:** That is all right. What percentages of the overall AHDs and EPGs are referred to for declaration by the SAT? You do not keep that data?

**Mr GREEVE:** We would not have that information, unfortunately; sorry.

**The CHAIR:** You have talked about some of the training and promotional work that the department has done. What training and advice is available to health professionals on issues of consent and treatment in the operation of those statutory instruments?

**Mr GREEVE:** We have information on our e-learning resources. That is one area that we definitely have available. In terms of that, it would also be—I think it was covered this morning—talking about undergraduate departments that would cover that information as well. We have some information on our e-learning resource. My boss here has just reminded me that we also have our advance care planning telephone support line, which is mainly me. How I could forget that, who knows! It is a 24/7 number, but because I am not there, obviously like today, they leave a message and we call them back. Our service is unique nationally, because it supports health professionals and consumers. Now we also get a lot more email as well; people are becoming more tech savvy.

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**The CHAIR:** The GAA and AHDs do not operate if circumstances have changed, so that a person making an advance health care directive would not have reasonably anticipated or so that a reasonable person in the same position would have changed their mind. Are health professionals required to record when they do not follow AHD for these reasons?

**Mr GREEVE:** From our perspective, there is actually a lot of lack of guidance within the Guardianship and Administration Act and in policy and in terms of how this information is recorded. But we would encourage health professionals if there is any doubt or concerns about an advance health directive around validity, to refer it back to the State Administrative Tribunal.

**The CHAIR:** That obviously could not operate in an emergency?

**Mr GREEVE:** In an urgent situation, health professionals are covered under the urgent clause to give treatment, but for ongoing treatment or in a non-urgent situation, we would refer people then to the State Administrative Tribunal.

**The CHAIR:** For example, if someone had a “do not resuscitate” on their advance health care directive, and their circumstances had changed and they were not in a position to enforce that, that patient would be resuscitated in an emergency situation?

**Mr GREEVE:** Unfortunately, there is always a potential, even with the completion of an advance health directive, that in an urgent situation we could get treatment that we do not want. For example, I may put on my advance health directive that if I became a quadriplegic, I do not want to be ventilated or have surgery, but in the absence of my advance health directive or anyone being there, under an urgent situation, the emergency department’s focus is on reducing pain and suffering, so they would give treatment. But any ongoing treatment they would have to have consent for or if they find my advance health directive or if there are any concerns about the directive, then treatment can be withdrawn. But we can all actually potentially get treatment, in an urgent situation.

**The CHAIR:** The SAT can make an order recognising statutory instruments made in other jurisdictions. How does the department become aware if this occurs? How frequently would it occur?

**Mr GREEVE:** I would refer you back to the State Administrative Tribunal. We would not have a lot of information or evidence on that.

**The CHAIR:** Are you aware of any work that is being done to standardise and mutually recognise advance care planning across Australia?

**Mr GREEVE:** From our perspective, just what my colleague was saying a minute ago, we are part of an inter-jurisdictional advance care planning group. Every state participates in that—that is, the advance care planning inter-jurisdictional interest group. We meet regularly by teleconference. We share what each state is doing and how we can work together. That is organised through the commonwealth. We work together on that front.

**Hon ROBIN CHAPPLE:** Just on that, there is an advance care health directive, everybody knows about it. Are medical professionals obliged to respect the advance care health directive or can they, for whatever reason, not follow the advance care directive?

**Mr GREEVE:** They are obliged to follow the advance health directive unless the advance health directive is invalid. For example, there are conditions where an advance health directive can be invalid or inoperative, if, for example, they believe someone has completed an advance directive due to coercion, or if the advance health directive has got something so fundamentally incorrect in it. For example, I might put on there, “Ventilate me with nitrogen rather than air.” We cannot do

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something like that. In that situation, we encourage health professionals to not ignore an advance health directive but go straight to the State Administrative Tribunal and get clarification. They will then rule whether or not the advance health directive is invalid. Otherwise, health professionals are obliged to follow someone's advance health directive.

**Hon ROBIN CHAPPLE:** Following on from that, if a medical professional for religious reasons did not want to follow on with the advance care directive, is there an ability for them to decline on the basis of moral or religious grounds?

**Mr GREEVE:** When you are talking about an advance health directive, when it comes down to treatment—I am trying to think. When it comes down to what is in an advance health directive, people are deciding what treatment they will consent or refuse consent to. In terms of health professionals, I think they would need to follow there in terms of their professional role of what they can do. Think of abortion, for example, in terms of health professionals who make a conscientious objection, but it does not override the fact that the advance health directive is valid. A person has a right to consent or refuse to have treatment. They may actually then have to refer that to someone else. If there were concerns, they could then go back to the State Administrative Tribunal. They would go back to their hierarchy.

[5.20 pm]

**Hon SALLY TALBOT:** I just wanted to explore a bit more the connection between an advance care directive and an advance care plan. You spoke about your mum. I do not know whether it was literally your mum or whether it was just an example you have been using. I want to ask you when there might be occasions—which I think is what you indicated in relation to your story about your mum—when an advance care plan is better than an advance care directive or more practical for them.

**Mr GREEVE:** We recommend that if you feel strongly about a treatment decision, that you complete an advance health directive. For one, it is the statutory form that health professionals are obliged to follow and we have the State Administrative Tribunal set up to respond—within the framework of the Guardianship and Administration Act—to address one quickly in cases where there are concerns about someone's directive. Not everyone may feel comfortable doing an advance health directive. Under common law we can write down any treatment we do or do not want. We can write things down on a piece of paper. An advance care plan, in a sense, is a way of us writing on a piece of paper about our care and treatment. We can write down a treatment decision. We can write down care. But we actually encourage people, if they want to do treatment, to do an advance health directive. If they want to record the care part, which is not treatment, do an advance care plan. That is how we promote an advance care plan. Therefore, that is a way of capturing all the other care. For us that is not treatment. Some people may not feel comfortable doing an advance health directive, so they can still write treatment in an advance care plan, although it is not a statutory form like an advance health directive.

At the moment, there is no case law to support that an advance care plan could be a common law directive. In theory, a common law directive is where you write down a decision on a piece of paper. In the future we could have case law that could support an advance care plan being a common law directive, but at the moment there is no case law. For example, if someone were to go to hospital and they do an advance health directive or write information on an advance care plan, if they lose capacity, both of those documents could go to the State Administrative Tribunal. We may, in the future, have common law passed that an advance care plan is a common law directive. It is still a way of expressing treatment or care, but we would encourage, in the current framework of things without that common law, that if they have a treatment, do an advance health directive and use an

advance care plan for care and outside treatment. But people can use it for both. They can write down things they want. An advance health directive, if you like, is an example of a living will. An advance care plan could be an example of a living will, although we have no common law at the moment to support that—but we may in the future. That is where, in the context, it still could be important.

The other way of looking at it is that if you care for me in the hospital and I give you my advance care plan and you know who I am and I have written things down, I have actually written down under common law what I do and do not want. I have told you, so you should really, as a health professional, follow that, because you know that is what I want. But people could be confused or concerned if I came in and I did not have capacity. It is not a witnessed document like an advance health directive. Some people might not feel comfortable with an advance health directive, but we could still go to the State Administrative Tribunal as a health professional and have that looked at. I do not know if I have confused you even more. I am sorry.

**Hon SALLY TALBOT:** No, you have not confused me at all. I do not want to put words into your mouth, but would it be the case that when you are talking to a person, whether it is a family member or a patient, about advance health directives and they say to you, “No, there’s no point in me doing this because I don’t have any firm ideas”, do you find that you, when they do their advance care plan, have what you might call an “um to ah” situation where they suddenly realise that they do, in fact, have quite strong views and you are then able to say, “You didn’t think that you wanted all this but now we see that you have some firm ideas, so let’s do an advance health directive”?

**Mr GREEVE:** I get so many people who ring up first of all and say either, “I want to write down something. I don’t know how to do it” or “My GP has told me to ring you. I don’t know what an advance health directive is. Should I do it?” They have no formulation. The first thing I ask them is why they want to do it. Why now? It could be the fact that they have been told to ring me and they say, “Hello. I’m not quite sure what it is about”, or it could be the fact that they have a life-limiting condition or someone close to them has a life-limiting condition. Their health condition has changed and they are starting to think about the planning or they could be a particularly organised person. They want to get all their ducks in a row. A lot of people can come for that reason and have a conversation. By asking them why, it goes back to the thing of if you can frame why you want to do the directive—why it is important to them—then you can then start tailoring the conversation, like the reason they want to do it is because they are really worried about their quality of life. For example, if they became a quadriplegic and they were in a situation in which quality of life is a concern for them, for example—or dementia—and they are worried about their quality of life, they can then frame their questions around their treatment decisions in an advance health directive. Other people may be very specifically treatment focused. They have particular concerns about things. So you can start teasing out the why and say, “Look, you have a diagnosis now. Maybe go back to your GP or go back to your specialist and get some more information.” Often people think: I do not know what to do now. They may want to get a bit more information and come back to it later. Then I say, “Look, you can always do an advance care plan or appoint an enduring guardian.” For some people, they do not actually need it, because if they have a conversation with their partner and their children and everyone is on board and everyone knows what they want, then that information is already there. They do not need to have an advance health directive because they already have the hierarchy of people responsible. A disadvantage of not documenting it is that corporate knowledge could be lost. If, for example, I have told my partner and children or my niece what I want and they all go off to New Zealand on holiday and I suddenly become unwell, that corporate knowledge is lost. At least if I have an advance health directive, the things that are most important to me can be passed on.

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**Hon Dr SALLY TALBOT:** Thank you for that. I am still not quite clear.

**Mr GREEVE:** I am sorry.

**Hon Dr SALLY TALBOT:** It is not your problem. It is mine. I am not explaining it properly. What I am interested in is the sense in which an advance care plan articulates into an advance health directive. In the process of doing a plan, which appears to be less formal or less of a challenge to a person who might be in an emotional state anyway and is inclined to say, “I don’t know why I have been sent to you anyway because I don’t have any particular ideas I want to put on paper”, are you able to get them to a place where they see that the statutory form is actually the preferable way to go?

**Mr GREEVE:** Sometimes I do. The way I put it to them in that situation is that they can do it this way but also one of the advantages of having a statutory document is that if there are problems in terms of the operation of their advance health directive, it can be resolved very quickly, whereas sometimes if it is an advance care plan and it goes through SAT, it could get caught up for quite a while to be resolved if they cannot resolve it. An advance health directive, for one, health professionals feel more comfortable because it has been witnessed and signed and they are familiar with it. An advance care plan is something that some people may be not quite as familiar with. That is one reason; we could talk them through that. But sometimes people might want to do both. They might say, “I have this down in terms of my care”, then I realise I have something more formal and I explain the advantages of doing that. At the end of the day, I explain that it is very much their choice, their preference and is totally up to them what they want to do and by no means —

**Hon Dr SALLY TALBOT:** Do you think the statutory form, the advance health directive, is a bit intimidating? Are people reluctant to go down the path? You described your mother, for example, who said, “No, I would not want to do that.”

**Mr GREEVE:** I can speak from my personal opinion of myself.

**Hon Dr SALLY TALBOT:** A personal opinion based on a lot of experience.

**Mr GREEVE:** I find that when people ring up, the first thing people say is, “Look, I got the advance health directive. I love the guidebook. I still do not know how to complete it.” That is why we did version 2 of “Preparing an Advance Health Directive”. Once again, we have a little workbook section. We put more information on e-learning. Once again, it is focusing on the why. It is trying to get people to think about why they want to do the directive. Once they can think about the why it is easy to frame the directive. The other thing is that the way we complete the advance health directive is consistent with the national framework for advance care directives. Some countries have a tick box. We did not do that because people felt obliged with a tick box. They might tick things that are not appropriate for them. The way we have set out the advance health directive encourages a more cognitive process of thinking about why they want to do it and writing it down. That is much deeper thinking than just doing a tick box. But, yes, it can be hard at first. Since we have amended version 2 of “Preparing an Advance Health Directive”, I think we have had a lot more positive feedback—even in a resource. I think that mental process of why they want to do it helps that blockage.

**The CHAIR:** I just want to take you to the hierarchy of decision-makers. Is the hierarchy of treatment decision-makers well understood by medical professionals and people in the broader community?

**Mr GREEVE:** We do not have that information; there is a lack of evidence in support of whether that is well known by everyone. One way, as an example—an opportunity would be a survey or something like that to get more evidence for that to be achieved.

[5.30 pm]

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**The CHAIR:** You are not aware of any studies in WA that have examined that?

**Mr GREEVE:** No.

**The CHAIR:** Are the wishes of treatment decision-makers ever not binding on medical officers—a spouse, for example?

**Mr GREEVE:** I think that refers back to what I was talking about before. For example, there are circumstances in which an advance health directive could be seen to be inoperative or invalid, under the Guardianship and Administration Act, so there would be situations where it could be deemed to be invalid, due to coercion, for example.

**The CHAIR:** Sorry, I am actually referring directly to the treatment decision-makers, not the directive. Where there is no directive, and you go straight to the hierarchy of decision-makers, and they make a particular decision, is it ever not binding on medical officers?

**Mr GREEVE:** Situations where it could be not binding, for example, would be if the health professionals believe that treatment is futile or inappropriate, so health professionals are not obliged to give a treatment if it is clinically inappropriate or futile, so that would be a prime situation where—sorry.

**The CHAIR:** That is all right. Is the provision in the WA legislation requiring treatment decisions to be made in accordance with the decision-maker's opinion of what is in the best interests of the patient rather than what the patient would have wanted appropriate?

**Mr GREEVE:** We do not have a policy in order to answer that adequately.

**The CHAIR:** I guess the question is getting to whether it is more appropriate for the decision-makers to look at the person's wishes rather than what their own individual view would be in terms of that treatment.

**Ms BOLLETER:** A substitute decision-maker is expected to make the decision based on the knowledge that they have around the person's wishes. If they have had a conversation with that person and they know what their wishes are, or they know that person well enough to know what their wishes are likely to be, then that is what they are expected to make the decision about. Is that your question?

**The CHAIR:** Yes.

**Mr J.E. McGRATH:** Further to that, Chair, if someone was a Jehovah's Witness and they had put on their directive that they will not have a blood transfusion, the doctor has got to not do the blood transfusion, surely, or does he?

**Mr GREEVE:** In terms of the advance health directive, we can consent or refuse consent to any treatment we want to, so, therefore, we are obliged to follow what is in the advance health directive.

**The CHAIR:** But it may not be in line with someone's wishes, but it would be in their best interests.

**Mr GREEVE:** I am really not very sure of the question.

**Hon Dr SALLY TALBOT:** What is in the directive would be their wishes.

**The CHAIR:** Yes, what is in the directive is their wishes.

**Mr J.E. McGRATH:** Yes, but what if the doctor said, "If I don't give this person a blood transfusion, they'll die"? He cannot give the blood transfusion because he has got a directive there that says, "I don't want one."

**Mr GREEVE:** In an advance health directive, as I said, we can anticipate treatment in advance and consent or refuse consent, so the medical practitioner is obliged to follow the advance health directive. For example, if you use a situation where people are haemorrhaging, we might think it is in our best interests, or we might think that they have made a poor decision, but if they have made their decisions, we are obliged to follow them, even though we may personally disagree with that decision.

**Hon COLIN HOLT:** What if there was not an advance health directive, and you had to go to the next of kin—this is a question I think you were getting to—and the next of kin says, “Well, I know they’re a Jehovah’s Witness, so they don’t want a blood transfusion, but I reckon I’ve got a dilemma here, because I can see that they really need it”? Is that just their decision then, or is there some interference, or is there something that the medical practitioner does?

**Mr GREEVE:** We would go down the hierarchy, so they can consent or refuse consent to treatment, so we would go to them, and health professionals would take their consent or refusal of consent to treatment, but once again, if we as health professionals had concerns about that decision—once again, if I knew that person was a Jehovah’s Witness and there were other people around who had concerns, we really then should go to the State Administrative Tribunal and let them make that determination. They can actually move quite quickly. The fastest I have heard of SAT moving is a matter of several hours, so in that situation we can actually even go after hours to the State Administrative Tribunal.

**The CHAIR:** That was going to be one of my questions around the SAT. Obviously, emergency situations are one thing, but how quickly can you get a decision out of the SAT?

**Mr GREEVE:** What I have heard from the Office of the Public Advocate is that the fastest that they have heard about this situation was a matter of three hours; that is the fastest that they have heard. I do not know if that is a standard KPI. I cannot comment; SAT would be the one to answer the question, but I have heard that they can, in an urgent situation, respond very quickly; they have got after-hours support.

**The CHAIR:** My final question is: is the existing legal framework for advance care planning unduly complex, in your view?

**Mr GREEVE:** That is too difficult a question to answer.

**Hon NICK GOIRAN:** You spoke of advance health care directives and enduring powers of guardianship as the two statutory instruments that are available. I think on one of them you mentioned that there had been a statutory review done.

**Mr GREEVE:** Yes. The Attorney General has done a review of the Guardianship and Administration Act.

**Hon NICK GOIRAN:** And that covers both of those instruments?

**Mr GREEVE:** The Attorney General would be a good person to talk to in terms of any problems that there might be in terms of those from either a public or a health professional perspective that we are not aware of. At the moment, we are not aware of the full outcome of that, and as part of that outcome, no changes have been made, so they would definitely be an area to contact.

**Hon NICK GOIRAN:** So you are aware that a review has been done, but as far as you know a report on the review has not been made publicly available.

**Mr GREEVE:** I do not believe it has been made publicly available.

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**Hon NICK GOIRAN:** You also mentioned advance care plans and that that is a non-statutory instrument that has been brought about by the Department of Health. Is that a policy decision that was made; and, if it is, when did that commence?

**Mr GREEVE:** I think you have an example in your pack, if you want to have a look at one. We introduced the advance care plan in about 2012. That came about from feedback that we received from consumers around some people not necessarily wanting to do an advance health directive. Initially we saw an advance care plan as being a way of people completing it as a common law directive, but we realised, when we took legal advice, that we cannot promote it that way because there is no common law that actually says an advance care plan is a common law directive. Therefore, we encourage the advance care plan as being a way of capturing all the other parts of our care, and if you want treatment decisions to be done, you do an advance health directive. But it is a great way of capturing all those other things of your care and still informing your person responsible in the hierarchy about what you do and do not want.

**Hon NICK GOIRAN:** My last question is: you mentioned about a consortium.

**Mr GREEVE:** Yes.

**Hon NICK GOIRAN:** Who are the consortium, and what do they do? You mentioned that they might be coming to give us evidence tomorrow, but I am not too sure that that is the case.

**Mr GREEVE:** Palliative Care WA, I know, are coming tomorrow, so I am sure they will be covering the consortium. I have not got a list of the consortium in front of me, and if they do not cover it, I can definitely give that information to you on notice. We are part of that. It is a mixture of NGOs, government and non-government. We have had several meetings so far, and the idea around that is: how do we in WA collaborate and get the message out more broadly? Particularly within the Department of Health, we can only do so much, and we have only got so much resources. The other way is really, particularly in primary care, if we can get people to be aware of advance care planning before they hit aged care, before they hit hospital, when they have lost capacity, and get the message out there. If we are talking about who should do it, everyone should do it, but we really need to collaborate, so that is where that has come from.

I am sorry I got stuck before; I just got a bit nervous.

**The CHAIR:** No. You have given excellent evidence.

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 that period, it will be deemed to be correct. New material cannot be added via these corrections and the sense of your evidence cannot be altered. Should you wish to provide additional information or elaborate on particular points, please include a supplementary submission for the committee's consideration when you return your corrected transcript of evidence. The committee will write to you with the questions taken on notice during the hearing. In addition, we will include the proposed questions that we were unable to address due to time constraints. Thank you very much.

**Hearing concluded at 5.40 pm**

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