

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

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



**TRANSCRIPT OF EVIDENCE  
TAKEN AT PERTH  
THURSDAY, 1 MARCH 2018**

## **SESSION TWO**

### **Members**

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

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**Hearing commenced at 11.00 am****Ms JENNIFER LAWRENCE****Chief Executive Officer, Brightwater Care Group, examined:****Ms JANET WAGLAND****General Manager, Community, Brightwater Care Group, examined:**

**The CHAIR:** Thank you for coming in this morning to our committee. On behalf of the committee, I would like to thank you for agreeing to appear today to provide evidence in relation to the end-of-life choices inquiry. My name is Amber-Jade Sanderson; I am the Chair of the inquiry. I will introduce the other committee members. We have 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 begin with our questions, did you want to make an opening statement?

**Ms LAWRENCE:** Yes, if I may. Just so that everyone is aware, Brightwater is a leading provider of aged care and disability services. We are only in Western Australia. We have been around for 116 years and we provide services to thousands of Western Australians. We support a really diverse group of people, which is why this is an area we are quite passionate about, from people with acquired brain injury, neurodegenerative disorders, and people who are ageing, people who require rehabilitation, palliative care, transition to the community and permanent care. We believe we understand the fairly relevant and contemporary context of palliative care, and I just draw your attention to the landmark case that we initiated, at our own cost, of Mr Christian Rossiter, which clarified and supported one of our client's end-of-life process.

**The CHAIR:** Do all Brightwater facilities offer palliative care?

**Ms LAWRENCE:** Yes, we do—either internally or externally.

**The CHAIR:** Does that include access to specialist palliative care if required?

**Ms LAWRENCE:** Yes, it does.

**The CHAIR:** Does Brightwater utilise the Metropolitan Palliative Care Consultancy Service?

**Ms LAWRENCE:** Yes, we do, for our residential aged-care business, which is the vast majority of our business, but for our still sizeable disability clients, we do not utilise them; we utilise Silver Chain, because they offer a 24-hour service, and within our disability business we have less RN support, and also NDIS does not actually pay for palliative care.

**The CHAIR:** Are you able to comment on the level of service in the metropolitan service?

**Ms LAWRENCE:** Yes, they have supported us for a number of years, since 2013–14. It is an excellent service. We have got a great deal of confidence in their expertise and the quality of service that they provide. They offer current best practice advice and information around palliative care, which is

really important for our staff—our nurse practitioners, our nurses—and even for GPs and families. The team consists of clinical nurse specialists and a palliative care consultant. It is based, as you know, out of Bethesda Hospice, and it is a free service Monday to Friday, eight to five, but there is no weekend or out-of-hours service.

**The CHAIR:** You obviously utilise Silver Chain as well. How do you find Silver Chain service?

**Ms WAGLAND:** We find them excellent in being able to, once again, support staff in understanding, being able to set up pain management, pain relief, being very responsive. I think that that is an area where they are wanting to continue to build their expertise and really, in the disability space it is going to be a very necessary one. We get a lot of support from Silver Chain, particularly with our group of people with Huntington's disease.

**The CHAIR:** Are you able to describe what on-site palliative care is on offer for residents?

**Ms LAWRENCE:** In aged care we do offer end-of-life planning. Many of the people who come to us are only with us for a few months and they come to us with end-of-life planning as a conversation we need to have. We have GP support. We have clinical staff who are trained in pain management, comfort and supporting families in that end-of-life stage, and also spiritual support. All our care workers are trained in supporting people in that end-of-life process. That conversation starts as soon as older people come into aged care. Ms Wagland will comment on disability.

**Ms WAGLAND:** In disability services we often are looking at more of an advance care directive approach, rather than an advance care plan, because the care plan tends to be something that you are doing with the family. The advance care directive is something we are doing with the person themselves, with, of course, family input, and we have a lot of conversations generally with people with Huntington's disease who lose the ability to swallow, and yet have a very high metabolic rate so have high food intake requirements. We have a lot of conversations about their choices, as they get to a point where they are no longer able to swallow safely, about whether they would like to have enteral feeding, or whether they would prefer us just to continue providing what oral intake we can. Staff are supported in being able to assist people in eating who have quite complex swallowing problems. We have very good food management, so we are able to deliver highly vitamised food as well as high-calorie supplements. With that group of people we often have many of them choosing not to opt for enteral feeding, just to keep on gradually reducing their calorie intake.

**Mr J.E. McGRATH:** Just one question. You mentioned Bethesda. What is your arrangement with Bethesda?

**Ms LAWRENCE:** It is just on a case-by-case basis. Do you mean, do we have a contract?

**Mr J.E. McGRATH:** Yes, do you have a contract, and do you have an area at Bethesda that you use?

**Ms LAWRENCE:** We use them for our aged-care residents. It is residents that will need some support, but it is in daylight hours; it is an eight-to-five basis, so for anyone that needs support after hours, it is a Silver Chain conversation. But there is no contract; we just ring them when we need them.

**Hon NICK GOIRAN:** Do you have residents who have a chronic illness, but not necessarily a terminal illness?

**Ms WAGLAND:** Yes, we have a large number of those residents, particularly in our disability services. We have some younger people also living in residential aged care who would have chronic illness. We have people that we have supported for 25 to 30 years, usually people with severe acquired brain injury.

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**Hon NICK GOIRAN:** Okay, and is palliative care of use to those people who have a chronic illness but not a terminal one?

**Ms WAGLAND:** I think if you are referring to palliative care as ensuring that people are kept as well and as comfortable as possible, even with quite complex health issues, yes we would take that sort of approach, but if we are looking at palliative care as direct intervention towards the end of life, that is on a case-by-case basis when they actually reach that stage.

**Hon NICK GOIRAN:** Sure. Now those residents that you have with a chronic illness that is not a terminal illness, do they have access to the NDIS?

**Ms WAGLAND:** Yes they do, they are gradually rolling into that scheme as it rolls into town—yes, they do. In fact, our group who have the highest level of care need, who happen to live in a facility in Marangaroo, will actually become NDIS eligible from July this year, so we will be negotiating with the NDIS. There will be some complexities about nursing care levels, because the NDIS does not fund registered nursing, so for us it is really about scope of practice for support workers, how much enrolled nursing we can have in place, and how we actually set up, I guess, a more community wellbeing-type of approach, where we are able to access some nursing under the NDIS.

[11.10 am]

**Hon NICK GOIRAN:** Those residents who qualify for the NDIS because of their chronic illness which is not terminal, they cannot access palliative care under the NDIS arrangement.

**Ms WAGLAND:** No, the NDIS does not fund palliative care. They would regard it as a health issue and would encourage services to access whatever health support is out there. As we already use Silver Chain, we would continue to access that. We also provide nursing services to people who are ageing in the community. If we found that we were not able to access appropriate services through Silver Chain, we would upskill our own nursing staff and bring them in on a consulting basis. It is important to us that people who have lived with us for that many years are supported to die in their own home if that is what their choice is. We would look at what mechanisms we can put in place to support that to happen.

**Hon NICK GOIRAN:** Sure. I am not necessarily talking about somebody at the end of life; I am just talking about a person with a significant disability, a chronic illness. They qualify for NDIS. Palliative care would be of assistance, yet it is not covered.

**Ms WAGLAND:** No, it is not funded. Community nursing is, but only as for therapy, where it is short, interventionist and very much about building people's capacity to live and be well within the framework of their disability, but not on a 24/7 or a regular care, intervention approach.

**Hon NICK GOIRAN:** Community nursing does not cover Silver Chain?

**Ms WAGLAND:** No. Silver Chain would be funded through the state. The state health department funds Silver Chain services, and we access them through HACC at the moment.

**Hon ROBIN CHAPPLE:** Brightwater—how many nursing staff or medical professionals do you have on board, or do you bring them in as necessary?

**Ms LAWRENCE:** That is a hard question. We have 24 sites, for instance. Each of those sites would have a doctor that is available. We do not pay for those services, but doctors will come in and Medicare pays for their services. We facilitate that arrangement. We also have some specialist doctors that we pay ourselves. We have a specialist geriatrician and a psychogeriatrician. We have nursing available across all of our sites. I could not give you an exact number, but at each of those sites we have nursing available, whether people are living in their own home in the community or in one of our facilities.

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**Hon ROBIN CHAPPLE:** In that regard, do the doctors or the geriatricians actually have palliative skills?

**Ms WAGLAND:** The geriatrician certainly would; yes.

**Hon ROBIN CHAPPLE:** In some cases there would be no need to bring a palliative care specialist in because it can be dealt with in house, so to speak?

**Ms WAGLAND:** That would be the case for residential aged care. However, the geriatrician does not have coverage over our disability sites. We would access whatever specialist support is required from the community. We do that anyway for neurological support, for any other specialist doctors and psychiatrists that we require for that group.

**Ms LAWRENCE:** The other comment I would make is that the GP or geriatrician would come in and put down a prescription for how palliative care should roll out, but the actual delivery of palliative care, we often leave someone like Silver Chain or the Bethesda service to actually deliver it.

**Hon ROBIN CHAPPLE:** That is useful. When it comes to end-of-life planning, there are two components to that. There is obviously the plan—the larger plan which you develop—but then end-of-life directives. Are they done on a particular form? Is it your structure or is it a national or a state structure that you use?

**Ms WAGLAND:** There is a couple of forms. There is the one that the Department of Health has developed, which is the most commonly used one. We actually have one that we are looking at rolling out more across the whole of the organisation, which is the one we originally developed to support Christian Rossiter. When that court hearing came about, we recognised, as did he and his brother, that he could die from something other than not eating. We actually did an advance care directive with him as well and we put a lot of work in ensuring that it was clear. The challenge with advance care direction is that the general public, general people, do not actually normally understand what possible health issues could come their way. This form offers a sense of direction as to what people are looking for as well as giving them some understanding as to the choices they need to make.

**Hon ROBIN CHAPPLE:** Could we by any chance get a copy of your form?

**Ms WAGLAND:** Sure.

**Hon ROBIN CHAPPLE:** Because we are looking at that issue quite broadly, so that might be very useful to see what you are proposing.

**The CHAIR:** We will delve into the advance health directives a little further on. I want to take you back, Ms Wagland, to a comment that you made around the people who are living with disability. The first question is: Is your cohort of people living with disability in a separate facility to the aged-care cohort, or are they mixed?

**Ms WAGLAND:** We have a number of smaller and slightly larger facilities for people who have disability. We have two facilities for people with Huntington's disease. One is a 12-bed facility for people who are more at the end stage—at the more complex end of the care need—and we also have a small six-bed facility for people who are more at the mid stage of deterioration to try to keep them well, more active and participating. We then have varying levels of size and complexity for people with brain injury as well, so the one facility for those who have got really high and complex needs, many of whom are either minimally conscious or have minimal capacity to interact, right through to those who are out and independently accessing the community with strong support from us.

**The CHAIR:** So they are not mixed with the aged care?

**Ms WAGLAND:** Not mixed with aged care at all.

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**Ms LAWRENCE:** We do have some young people, though, that are in aged-care facilities. That is a historical thing across Australia that you get some people who enter aged care because of their level of disability.

**The CHAIR:** Can you just go back to the scenario you were talking about, I think it was particularly around Huntington's disease, which is obviously an area that you specialise in, and someone reaching the end of their life and choosing not to eat or drink. Can you just talk us through the trajectory of that for that individual?

**Ms WAGLAND:** Often by the time they will come to our more complex care area they will already be on something like a soft diet, so they are not eating a standard diet. We have this conundrum, I guess, of having to support them to continue to eat, because they have a high metabolic rate associated with the disease, yet they also have this issue of their swallowing deteriorating. We will start to have conversations with them and their family as early as we possibly can about what choices they would like to make regarding when they get to a stage where they are no longer able to swallow effectively, do they want to go down the track of us supporting them to have a PEG inserted for enteral feeding. Then we will continue to review that with them. It is part of our normal goal-setting review process with everybody, but also as we see changes in that person. If their swallow deteriorates further, we will have further conversations with them and their family, because we want to be sure that what they are telling us is consistent. Even though it is well documented, even though all have been asked the question before, sometimes people change their minds. Especially if we have someone, for instance, whose swallow deteriorates ahead of the rest of their physical functioning. They may not want to opt to not have a PEG put in, because they want to keep as active and as well as possible. In general, we are finding more and more that people are choosing not to have a PEG inserted and we support them very effectively, even if we get down to a stage where they may be having five or six teaspoonsful of high calorie supplements. We try not to feed them for more than about half an hour, because otherwise then they get very fatigued, so we also monitor and manage their fatigue levels. We will look at the times of day for each individual where they are least fatigued and utilise those times for supporting them to try and eat. What we do see is people then will drop down in weight as they have changes, then they will plateau for a period, then they drop again and plateau, and that generally seems to be the trajectory that we see. We take the same approach with fluids—so, food and fluids.

[11.20 am]

**The CHAIR:** I just want to explore this a little bit further. If that person essentially stops eating and drinking, are they provided with medication to make them comfortable?

**Ms WAGLAND:** Yes, and, once again, it is highly variable, the level of discomfort and pain that people will experience through that final stage of life, and that is where we rely on Silver Chain. We have some people who do not require any support at all from Silver Chain, and we have others who actually require quite strong pain management. It is variable.

**The CHAIR:** What would be recorded on the death certificate?

**Ms WAGLAND:** That is a question I would have to go back and ask the nursing staff.

**The CHAIR:** Would you mind?

**Ms WAGLAND:** We can get that information for you.

**The CHAIR:** We will put that on notice. Where an individual chooses to stop eating or drinking and essentially passes away, it would be very useful for the committee to know what was on the death certificate.

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**Mr J.E. McGRATH:** Further to that, where you have got residents who have stopped eating and drinking, most of the doctors that we have had before us in this inquiry have said that in their experience, if people wish to stop eating and drinking, a lot of time it is caused by the fact that they cannot swallow. It is not that they want to stop, but they cannot swallow, and also they are getting weaker, and as you get weaker, you do not eat as much. Could you sort of quantify some ballpark figure about what percentage of these people actually make the decision that they want to end it, or others where it is happening because they cannot physically swallow?

**Ms WAGLAND:** I guess the context is I have supported people with Huntington's disease in Brightwater probably for about 20 years. From my memory, the vast majority by far follow that process of just gradually reducing their intake. It is not an active decision that "I'm going to stop eating and I want to die", which is why the Christian Rossiter experience was such a contrast to that process. It is a very different process, somebody gradually losing the ability to eat and not choosing to have an artificial feeding tube put in, as opposed to somebody who has already got the artificial feeding tube in there and you feel obliged to actually use it to keep them alive. He was very different. Occasionally, I know people with Huntington's disease will actively take their own lives. But the people that we are supporting, by far the vast majority, will just follow the natural process. Occasionally, we have someone choose to have a peg put in, and then ultimately they will probably die by something like an aspiration pneumonia from their own saliva or something like that.

**The CHAIR:** In the instances where people with Huntington's have taken their own lives, how have they done that?

**Ms WAGLAND:** I would have to go back and talk to the Huntington's association. We do not have that contact with people, because we are having contact with them when they get to the stage where they are not able to care for themselves. I do know from having had contact with the Huntington's association and the Huntington's families for so long that there are the occasional people actively committing suicide.

**The CHAIR:** Before they become completely debilitated?

**Ms WAGLAND:** Yes, that is right.

**The CHAIR:** Would you say you distinguish someone in that phase of, essentially, choosing to reduce their intake by whether they have capacity to make that choice?

**Ms WAGLAND:** That is why we start those conversations really, really early on. The other thing we would like to try and encourage people to do is then also select an enduring guardian, and having that as part of the legislation has really been helpful for us. But, equally, it is important if we can have an end-of-life health directive put in place, because then that also guides the guardian in the decision-making. So we hope to follow that process as well.

**The CHAIR:** Do you distinguish that decision from a suicide attempt?

**Ms WAGLAND:** Yes, very clearly. It is not a suicide attempt. It is them managing the natural course of the disease, basically.

**The CHAIR:** Is it a difficult process for the patient and family? I know everyone is individual, but can you give us a time frame for how long it might take someone to die from when they make that decision?

**Ms WAGLAND:** We have got people who have lived with us for over 10 years in that high-end stage, because we support them very, very well, so often we are having those conversations a lot with that person. Many people with Huntington's, because it is a genetic disability, know what the outcome is going to be of the disease. We have people who have seen their father die and have seen their grandfather die of Huntington's and now it is them, so they understand what the trajectory of the

disease is. We have the odd person where it is a new diagnosis in the family. That still occasionally happens. When that happens, people will have more of a challenge in being able to understand and make the decisions, because they will not know what it is going to look like. So it is up to us to actually provide them with information as to what the deterioration in swallowing means to them and what sorts of choices they are going to have to make. It would be far preferable for us if some of those conversations started earlier. We have actually had quite a lot of discussion with the Huntington's association of WA about commencing the same discussions in the same way, back when they are supporting people. But they are much more about an advocacy agency, so there is really not anyone who has a responsibility for those early stage conversations.

**The CHAIR:** Is it a difficult job?

**Ms WAGLAND:** It is a difficult conversation.

**The CHAIR:** Yes. Is it challenging for staff to manage the very end-of-life process in those instances?

**Ms WAGLAND:** It is actually the most challenging for the speech pathologists, who do not like anyone on their watch actually losing their ability to swallow, so they are the group that have had the most difficult conversations. Yes, it is difficult for staff. We do find that the support workers that we have tend to be ones that we have had in the same facility for a number of years. They understand what the process is. They understand what end of life looks like for all of those clients. They are very well trained, very good at supporting people, very understanding. But it is a difficult job. For nursing staff who do come in and offer support, and for the rest of the allied health staff, it is not a natural thing for any health professional to be sitting back and supporting someone through a dying process; we would rather people were improving. But it is a fact of life. So, really, our aim with all of the people with Huntington's disease is how do we support them to live well for longer, how do we maximise their participation within the community and within their family, and how do we support them to have as good a life as they can while we are providing that support and accommodation to them.

**The CHAIR:** Do you have clients who request an end of life earlier than would normally be the case?

**Ms WAGLAND:** Occasionally, but usually it is a rash kind of statement, and we have not had anyone other than Christian actively follow through on it.

**Hon NICK GOIRAN:** You talked earlier about the benefit of somebody appointing an enduring guardian and said that is helpful and also for there to be an advance health directive. When you gave that evidence, you mentioned the directive being a good guide for a guardian. Can you just talk me through that, in the sense of does the guardian have any power to override the advance health directive?

**Ms WAGLAND:** My understanding is that the guardian does have power to override the advance health directive, but only in circumstances where there is a medical treatment that the person could not possibly have understood would be available to them. That is generally the understanding of it. Do the guardians always follow directly to the letter the non-interventionist approach that somebody has put in there? I would say for most family members, it is really difficult when you ring them up and say, "Look, your son is now experiencing severe pneumonia. His choice is not to have antibiotics. Are you happy for that to happen?" We will find that people occasionally will pull back and say, "No, I want you to intervene and do something." But generally they will get to a stage, after it starts to happen more regularly, that they will agree. It is just too difficult for the person to go through that all the time. It is really hard for family to make a decision that they are not going to treat somebody whom they love. Even with the advance directives supposedly being the legal ruling as to what people want, we still have to be guided by what the family members want because we also have to consider the impact on them in the process.

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[11.30 am]

**Hon ROBIN CHAPPLE:** In relation again to the end of life, the people with Huntington's and the placement of a PEG, you seem to indicate that a number of people do not go with a PEG. Do you have any statistics around that?

**Ms WAGLAND:** I would tell you that there is no-one at the moment of the 12 people whom we are supporting in the high-care environment who have a PEG in place. Usually we maybe have one. We have gone from a period when everybody would have had a PEG about 20 years ago to now when we are probably lucky to have one or two.

**Hon ROBIN CHAPPLE:** And that is the patient's choice.

**Ms WAGLAND:** That is their choice. That is a long discussion about what they want to do. If they come to us and they are not able to make that decision, we have the discussion with the family about what they think the person would have wanted.

**Hon ROBIN CHAPPLE:** Without putting any words into your mouth, that is for sure, the people who decide not to have a PEG do so because they think that that would be futile in their whole end-of-life process and by not having the PEG, their life expectancy would be reduced?

**Ms WAGLAND:** Yes.

**The CHAIR:** I am just interested in that shift over the last 10 years and why that might have come about. Were people actively choosing to have a PEG 10 or 20 years ago or was that the medical community?

**Ms WAGLAND:** I think it was a belief of the medical community that it was appropriate. To some extent, including the speech pathology community, if people were not able to eat, the next step was for them to have a PEG. For health practitioners, it is about keeping people alive. It was important for us as an organisation to start to have some conversations about what was best for the person and what choices they could make and what we could legally and ethically support them to be able to do. We have found the transition initially was harder for the staff. The people from the Huntington's community, when you have those conversations, to them it gives them something real to be making choices that they know will have an improved longer term outcome for them depending on what they see as improved. If they would prefer to have a PEG inserted and be fed through central means, and they feel that that gives them longer with their families, for them, that is an improved outcome. For those who do not want to go through the suffering of really not being able to contribute and interact with their environment, which is often what the end result is, they will choose to not have the PEG inserted.

**The CHAIR:** Do you use sedatives at the end of life in a terminal phase, and opiates?

**Ms WAGLAND:** Yes, as part of pain management.

**The CHAIR:** And that sort of terminal sedation?

**Ms WAGLAND:** Yes.

**The CHAIR:** Is that a consented to treatment?

**Ms WAGLAND:** It is consented to by family.

**The CHAIR:** We have had some surveys and reports that say that palliative sedation really only treats—there is still a very small percentage of people whose pain it does not control. We have heard it is between one and five per cent. Are you confident that in the instances of the people whom you care for that it controls their pain or are there instances in which it does not?

**Ms WAGLAND:** There has been the odd incident in which it has not. I could probably recall two or three in the last 10 years. That of course is distressing for the person, distressing for the families and

distressing for the staff. We have always actively continued to work with the doctor and the nursing support team to be able to manage that. But yes, there is occasionally someone for whom medication does not seem to have a very effective impact on reducing pain.

**The CHAIR:** Can you describe what those symptoms are and how they manifest?

**Ms WAGLAND:** High distress. We had one lady who continued to urinate for a whole month after she had not had a drink at all. She was in pain, she was distressed, she was agitated and she was actually on quite high levels of opiates. It is extremely distressing in those circumstances but it is very rare and it is something that we still have to manage as well as we can in consultation with the doctor.

**Hon NICK GOIRAN:** Is that when sedation techniques are used in those two or three cases?

**Ms WAGLAND:** It depends what you are talking about by sedation techniques.

**Hon NICK GOIRAN:** In the questions that you have just been asked, I think we started with terminal sedation and then we moved to palliative sedation. Throughout the course of the inquiry, people have been talking about all these different terms. I remain concerned that people are not talking about the same thing. I would be really happy for you to just explain to us what is the practice of sedation.

**Ms WAGLAND:** The schedule of medication—the opiates that they are using—will have a sedatory effect. I am not a nurse so it is not my area of expertise. Ultimately, they can result in death, as you would know, because they have an impact on people's respiratory function and they get to the stage in which they are no longer able to breathe. That is what my understanding of them is but I cannot really make a clinical comment because I am not from a nursing background. I am an occupational therapist so it is out of my scope.

**The CHAIR:** That is a very fair point.

**Hon NICK GOIRAN:** If the committee wants to pursue that line further, is there someone within the Brightwater Care Group that we could ask those technical questions about sedation?

**Ms LAWRENCE:** I think it is more appropriate to ask a medical practitioner, quite frankly—Silver Chain and/or the Bethesda group, people who are specialised in palliative care.

**The CHAIR:** In those instances, it would be Silver Chain that is providing the care in the Brightwater facility?

**Ms LAWRENCE:** Yes, under a doctor's direction.

**Hon ROBIN CHAPPLE:** Just on that a little bit further, if I may. We talked about sedation. Okay, you have somebody who is particularly distressed at that time and you indicated that you would help that person. Are there other ways of helping that person other than sedation?

**Ms WAGLAND:** Yes. We have just the normal relaxation things like warm baths, aromatherapy—all of those.

**Ms LAWRENCE:** Massage. There are all sorts of things we use. Our care workers are well trained in that comfort technique and some of it is quite effective.

**Ms WAGLAND:** In the case of that particular lady I was referring to, we used all those techniques to reduce her agitation.

**Hon NICK GOIRAN:** In this space of palliative care, I have heard of—I do not know if you want to call it a technique—a process of dignity therapy started by Harvey Chochinov. Is that something that has been raised or is common at Brightwater?

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**Ms WAGLAND:** I have never heard of dignity therapy. I do know that we do everything that we can to promote the dignity of the people who live with us but I have never heard of it within this framework.

**The CHAIR:** For those one to two people—those rare cases—in the last 10 years who are at the very end of their lives and highly distressed, is that when sedation does not work or is that when the doctor would look at using sedation?

**Ms WAGLAND:** The doctor was already using quite high doses of sedation.

**Mr R.R. WHITBY:** You are unable to bring that patient to an unconscious state, even with high doses of sedation?

**Ms WAGLAND:** That is correct.

**The CHAIR:** Utility and refusal of medical treatment is an area that Brightwater would be well versed in, better than most service providers. Who do you think should make the assessment that treatment is futile or burdensome—the person, their doctor, the substitute decision-maker or Brightwater?

**Ms WAGLAND:** Brightwater certainly should not be making that decision. I think that any decisions around anything that is important in people's lives should be one in which the person themselves when they have the capacity, if not the key decision-maker in their family, does it on the basis of good information from the most professional and in this case it would be the doctor.

[11.40 am]

**The CHAIR:** Can you provide an indication of the number of residents at Brightwater where life-sustaining treatment has been withdrawn on a doctor's assessment that it is futile?

**Ms LAWRENCE:** We do not provide an acute service. We cannot give that sort of indication.

**The CHAIR:** In relation to the Rossiter case, do you think the right of a competent patient, including those reliant upon others for the necessities of life, to refuse medical treatment, is now well understood by medical professionals?

**Ms LAWRENCE:** No.

**Ms WAGLAND:** No.

**The CHAIR:** Can you elaborate on why you think that is?

**Ms LAWRENCE:** It is a very complex area. We learnt a lot through that court case. I suppose it was a deliberate decision by us to take it to court because it would be debated by minds that were far more clever than ours. I suppose we have had lots of conversations internally. Our board, for example, had a conversation about what is right, what is wrong, and the ethics and morality around this. We did get some palliative care and ethics professionals in to talk us and we found that this is an area that is not well understood and everyone has their own position. Even post the case, which gave us quite a clear indication about our legal rights and the patient's legal rights, most medical professionals really, we find, are not that clear about this particular circumstance. Palliative care physicians, we have had a number of comments about the fact that, "Ah, this has made things a lot more clear for us." Even in specialist palliative care land, that case was quite illuminating for them because they now have more direction about the legality of someone choosing to end their life. Does that answer your question?

**Ms WAGLAND:** I think it is also important to note that when Christian came to us, he actually came to us from a tertiary hospital. He had been expressing those same wishes in that environment. He also had a guardian from the Office of the Public Advocate who had been appointed. Neither OPA or the hospital had taken any proactive approach to address what he was articulating. A lot of that

was because of a lack of understanding as to what they could do. We had to, right from the very beginning, address his decision-making capacity and go back to the SAT on his behalf. Then we also had to inform him about the impact of his decisions from a lifestyle point of view because he was also talking about whether he should have the tracheostomy removed, which would have been a terrible death, and not then having the discussion around not eating. Really, it is not an easily understood area. It is also a really challenging area because you are often dealing with people, as we were with Christian, who did not actually understand the implications of some of his choices from a medical and from a personal impact point of view.

**Hon NICK GOIRAN:** With regard to that particular patient, are you in a position to disclose what were the circumstances that led him to have the condition that he had?

**Ms WAGLAND:** He had a fall which actually caused high-level spinal damage. He had already had a pre-existing incident where he had had a moderate brain injury, which is why he had a guardian in place at the time. But the fall meant that he was no longer able to breathe without a tracheostomy or able to move either his arms or his legs. He was totally quadriplegic.

**The CHAIR:** Was his condition degenerative?

**Ms WAGLAND:** No.

**Hon NICK GOIRAN:** Are you able to disclose the circumstances of the fall?

**Ms WAGLAND:** He had tripped over on a pathway when he was visiting his mother in a residential aged-care facility.

**The CHAIR:** With regards to Brightwater's role, the Guardianship and Administration Act limits the capacity of paid carers, other than those providing home care, to be substitute decision-makers. What legal role do you think Brightwater has in overseeing residents' medical treatment?

**Ms WAGLAND:** I think our legal role is to follow the directions of medical practitioners.

**The CHAIR:** Do you think it is an appropriate restriction that paid carers are not to be substitute decision-makers?

**Ms LAWRENCE:** Yes.

**Ms WAGLAND:** Yes.

**The CHAIR:** Because of a conflict of interest?

**Ms LAWRENCE:** Yes.

**Ms WAGLAND:** Yes, and we do not know people well enough. Even people who have lived with us for 27 years, their family know them far better than what we do, ultimately.

**The CHAIR:** I move to voluntary assisted dying. Your submission states —

The dignity of risk is a principle that supports a person centred approach to dying. It is accompanied by service practices that ensure the least restrictive approach to supporting an individual's end of life plan.

Does a person-centred approach include allowing people to make decisions regarding their end of life?

**Ms WAGLAND:** Yes.

**Ms LAWRENCE:** Yes.

**The CHAIR:** If voluntary assisted dying were provided in WA, would Brightwater Care Group facilitate VAD by visiting doctors in its facilities?

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**Ms LAWRENCE:** We have watched the conversation around voluntary assisted dying carefully and we have followed the Victorian case very carefully. This is not a conversation we have had with our board yet, so we do not have a formal position on that yet.

**The CHAIR:** That is perfectly fine.

If it were to be introduced, what protections would be required for staff or patients?

**Ms WAGLAND:** We actually believe that to have some third party that people could actually go to and have further discussions that would support both the organisation and the individual would be quite an effective way of supporting the process. I think that then brings in an independent third person to oversee what has happened in the conversations. I would hope that all organisations would act extremely ethically and bring in appropriate consultation within those processes, but as we have just talked about with Christian, it is not an easy conversation nor are there really easily manufactured decisions. Everybody is different and their mechanisms of choosing to die would be different as well.

**Ms LAWRENCE:** I think having a third party statutory body that oversees this would also lessen the impact on staff and provide some sort of leadership for organisations like ours, I suppose, because it is not an easy decision.

**The CHAIR:** Advance care planning and health directives is one of the terms of reference of this inquiry. We are hearing evidence that people are not really using the advance healthcare directives. You have certainly stated that you have people arriving who have not undertaken any advance healthcare planning, let alone healthcare directives. Do you have a view on why people are not doing that?

**Ms WAGLAND:** I think it is just complicated. It would be, I guess, like asking me to draw the plans to my house, if I was building a new one. It is not their area of expertise. People find it very difficult to picture all the possible scenarios, but also people do not think they are going to die. Often, when you start to confront that by actually articulating what you want your death to look like, you are starting to confront something that is not always palatable to people.

**Ms LAWRENCE:** I do not think it is well understood by the legal profession either. I had a personal experience recently and I think I knew more than the legal professional who was trying to help me through it. Actually navigating the process around choices is not well understood. I think we could do a lot more as a society to help people through that process.

**The CHAIR:** Do you have a view as to whether you prefer advance care plans or advance healthcare directives?

**Ms WAGLAND:** I do. I prefer a directive. Even when families know people really, really well, they often still have difficulties being able to pinpoint exactly what that person would have chosen. I think they sometimes feel like they are making a decision that maybe the rest of the family will not be happy about. Sometimes it causes family conflict, and so an advance care directive at least makes it very clear as to what the person themselves would have wished.

**The CHAIR:** Do you think it would benefit from a central register?

**Ms WAGLAND:** Yes.

**The CHAIR:** And education in the community?

**Ms WAGLAND:** Yes.

**Ms LAWRENCE:** Yes.

[11.50 am]

**Hon NICK GOIRAN:** Is My Health something that Brightwater would have access to?

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**Ms LAWRENCE:** We would. We are just starting to talk about that. We do not use it at the moment.

**Hon NICK GOIRAN:** But you can opt in.

**Ms LAWRENCE:** I think we can opt in.

**Hon NICK GOIRAN:** That is a conversation you are starting. So if the advance health directives were registered there, that would be useful for your organisation?

**Ms LAWRENCE:** Most definitely. I make the comment, though, that some organisations—we have got a long way as a disability and aged-care industry to get our IT systems up to a point where they are good at talking to other IT systems, so there may be a period of building capacity and development in that area.

**Hon NICK GOIRAN:** For Brightwater to opt into My Health, I am assuming there will be some kind of cost associated with that.

**Ms LAWRENCE:** Not for us. Our IT systems are actually quite sophisticated. My point was around smaller providers. There are a lot of small providers in this space and they may not have the systems that could actually talk to My Health.

**Hon NICK GOIRAN:** Whatever IT systems you have in Brightwater are sufficient to enable you to engage My Health and it is just a case of when that would happen.

**Ms LAWRENCE:** Choosing to do it.

**Hon NICK GOIRAN:** Choosing to do it. Thanks.

**The CHAIR:** What else do you think could be improved around the advance health care directives to improve that uptake and therefore support organisations like Brightwater?

**Ms WAGLAND:** I think the document itself actually needs to be one that puts plain language into it so that people actually understand what they are making the decisions about. The approach we took was to at least have a front page that gave a bit of a framework that gives people three choices up-front: Do you want really hard, active intervention? Do you want to have intervention that would be reasonable but stops at a point of basically going over the top? I do not know the words but that is really what it is saying. But the third choice is: You just want to be kept comfortable. That enables us to frame the rest of the decisions which are more direct about going to hospital, having tracheostomy or PEG, having antibiotics—those sorts of decisions. But it at least supported people thinking about, “What would I really want?” If you start to talk to people about end of life, it is often that kind of thinking that you hear a difference about. Some people just want you to go in all guns blazing and are quite happy to end up quite debilitated but be alive. Other people do not want to end up in that sort of position and will articulate, “No I don’t really want that; I wouldn’t want to be a vegetable. I wouldn’t want to be in a position where I can’t do things for myself. I want people to try, but not to that sort of extent of intervention”. Even that kind of discussion helps people at least frame what they would want should they be confronted with a catastrophic injury or severe illness, and then it is also helping them understand what the outcomes of those sorts of illnesses or injuries could be.

**The CHAIR:** Is this a document that you have put together?

**Ms WAGLAND:** Yes.

**The CHAIR:** Would we be able to get a copy of that?

**Ms WAGLAND:** Yes. I will send a copy of that.

**The CHAIR:** Please. We will write to you with a list of everything we would like.

**Ms WAGLAND:** The other thing I think is important—we have had a few discussions about this—is distinguishing people’s capacity to be able to fill in their own advance health directive and their

capacity to appoint an enduring guardian. I see them as two totally different things. Often, the decision is made: Oh, well, they cannot make end-of-life choices anymore because they have lost the cognitive capacity to do that, so people then do not explore the ability for somebody to appoint an enduring guardian. Enduring guardianship is about relationships and who you would trust. Often people with mild-to-moderate, or even heading towards severe, dementia, can still indicate who they would prefer to make those sorts of decisions for them. I do not think we explore that enough.

**The CHAIR:** On that, do you think there is scope for the act to be amended so that, prior to an individual lacking capacity, there is direction for supported decision-making?

**Ms WAGLAND:** Yes. I think supported decision-making in general within the framework of advocacy would be very important and I do not think we do it enough.

**The CHAIR:** As opposed to the best-interest test, which is currently the —

**Ms WAGLAND:** Test.

**Hon COLIN HOLT:** You have probably answered some of this, but I want to go back over it. Do you do advance health care directives as a matter of course for your residents and people you interact with?

**Ms WAGLAND:** We do with people who are coming to us with Huntington's disease. It may not be necessarily on the formal form but it is part of the normal documentation process. With the guys with Huntington's, because they have such wide-ranging implications of the disease process, we would have a standard format that we would talk to them about and get direction from them about what they want. So, yes. We also have conversations with people with brain injury. People who are in residential aged care quite often come to us when they are not able to make those sorts of decisions.

**Hon COLIN HOLT:** You do not do it as a matter of course for people in aged care as an example, not as a policy?

**Ms LAWRENCE:** We try, but many people come to us unable to make their own decisions. We will have that conversation with the family. Some people come to us with their own advance care directive, but not many, particularly older people.

**Hon COLIN HOLT:** Leaving aside people with Huntington's or acquired brain injury, how often do you revisit an advance health care directive with them, even those of a low number, I understand?

**Ms WAGLAND:** If they have capacity to go back over it, yes, we would revisit that as part of their normal review process. The challenge is that even the ones who come to us in residential aged care often have lost capacity to be able to contribute to that discussion, but we go over it with family: "This is what your family member has indicated to us."

**Ms LAWRENCE:** Because it is important we have that conversation regularly with the family, particularly if they are large families who may have forgotten what mum or dad has actually put down on that form or may have differing views, which happens very often.

**The CHAIR:** There are also instances where people change their minds. How do you accommodate that?

**Ms WAGLAND:** If they can tell us that and understand the implications of what they are saying. We also have a structured decision-making framework within the organisation, which is really about providing people with information, talking to them about the consequences of the decision they are going to make and then revisiting that the next day or a couple of days later to make sure they are consistent in their answers. We use that for all really complex decisions of which health management and end-of-life planning would be part of.

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**Hon COLIN HOLT:** If someone comes to you and they have an advance care directive, how do you know it is the most current?

**Ms WAGLAND:** There is an interesting question. We would have to believe them, if they have brought it with them themselves.

**Hon NICK GOIRAN:** Hence the need for a register.

**Ms WAGLAND:** Yes, that is right.

**Ms LAWRENCE:** Yes. It is a good question, probably one we have not thought about.

**Hon COLIN HOLT:** Interesting?

**Ms LAWRENCE:** Yes.

**Mr R.R. WHITBY:** It seem that health care directives are quite problematic in that very few take them up and the issues of changing circumstances and changing minds et cetera. Would your idea for this sort of cover sheet—dealing with a more general approach, moderate approach or all guns blazing, as you described it—be more beneficial than the directive that actually is very prescriptive and drills down to detail? Would it be better to have a sort of document that, I guess, does not scare people to the degree a directive might?

**Ms WAGLAND:** The document has both. That is the front sheet to it. I think what it helps is people then being able to step back and consider the implications of the more defined decisions. If I want people to be all guns blazing, therefore I am going to have the full on antibiotics; you are going to do all the surgery I need; you will bring out the CPR, the whole deal because I just want to be alive and I have already made that statement at the beginning of this process. What it actually brings to the document is the context of how people will feel about the challenges of that process, because CPR in itself is not a comfortable experience and many people end up with broken ribs and things like that from it.

**Mr R.R. WHITBY:** Do you think people are aware of that fact when they say, yes, I want to be resuscitated, but they might not understand the trauma that can bring?

**Ms WAGLAND:** No they are not. I had the same conversation with my mother some years ago. I know that quite often they are not, because people see it on the television as a miracle that we have done the CPR and the person lived and now they have opened their eyes.

**The CHAIR:** Gets up and walks away.

[12 noon]

**Ms WAGLAND:** That is exactly right. That is what people think CPR is about, but it is often not that simple, and it is more than CPR; it is also if someone has a tracheostomy or a PEG inserted, what the long-term implications are. It is important to have some context to that decision-making that is simplified for the person as to how they envisaged active intervention into their health care to be and the consequences of it.

**Ms LAWRENCE:** I suppose our opinion is that the general public do not know what scenarios might come up in their lives and they cannot actually conceive of those scenarios, so giving them some understanding about, “If this happens and you need to be resuscitated, this is what the actual sequelae could be from that intervention; do you want that?” I think training people so that they can advise people who are going through an advance care directive can only be beneficial.

**Hon ROBIN CHAPPLE:** Last but not least, DNR—do not resuscitate. That appears on some of your directives and forms. How is that described? Is it by the patients themselves, doctors, nurses, family or a mix?

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**Ms WAGLAND:** Often it is something that happens when somebody is in hospital. They will come to us having had an accident or illness. Often the hospital will have had that discussion with them and they will have a DNR written on their hospital file. I have found that even doctors do not understand that a not-for-resus order does not translate into not for antibiotics and not for having a peg inserted. It is about resuscitation. People do not really actually understand that it does not cover off on all the other interventions.

**Hon ROBIN CHAPPLE:** If you had a DNR, it would arrive with the patient?

**Ms WAGLAND:** Yes, it would.

**Hon ROBIN CHAPPLE:** You do not have those sorts of discussions within your organisation?

**Ms WAGLAND:** We will have assessed the person before they come to us; we will have noted that they have a not-for-resus order. People will sometimes, or often, rescind that because that has been associated with them being highly unwell and there would be a conversation: “Do you want to be resuscitated if it could leave you with a longstanding disability?” That would have happened in the hospital.

**Ms LAWRENCE:** But our conversation is more a broader conversation; not just the resuscitation. It is about your treatment options for the rest of your life.

**Ms WAGLAND:** That is right, which is what palliative care is all about. It is those options about staying well, feeling well, even towards end of life.

**Hon ROBIN CHAPPLE:** In that conversation you just had, you indicated that people might arrive with a DNR and then remove it.

**Ms WAGLAND:** Yes.

**Hon ROBIN CHAPPLE:** Is that something that happens quite often?

**Ms WAGLAND:** I could not tell you how many times, but yes.

**Ms LAWRENCE:** I could not give you the stats, but yes, because they may have been in hospital and had a stroke or a broken hip and had a conversation with the doctor in the hospital. When they come into residential aged care or into one of our facilities, it is actually quite nice living in aged care in one of our facilities and they may choose to say, “Hang on! I still have a life to live.”

**Hon ROBIN CHAPPLE:** I am fascinated by DNRs, as everybody knows! When the patient arrives with a DNR, that would have been established by the doctor?

**Ms LAWRENCE:** Yes.

**Hon ROBIN CHAPPLE:** The doctor in consultation with the patient?

**Ms WAGLAND:** Yes—or their family.

**Hon ROBIN CHAPPLE:** The patient has arrived at one stage with a DNR—gets to you; everything is lovely; no more DNR?

**Ms WAGLAND:** That is right.

**Hon ROBIN CHAPPLE:** Got it.

**The CHAIR:** Are there any circumstances in which you would not consider yourself bound by an advance health directive?

**Ms WAGLAND:** The only circumstance, as I said earlier, would be if we knew of some medical intervention that the person could not have possibly known about; then we would have an obligation to talk about that with their key decision-maker.

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**The CHAIR:** One more question: if voluntary assisted dying was brought into effect in WA and statutory advance health directives enabled subsequently incapacitated patients to access VAD, what would be your view on that?

**Ms LAWRENCE:** I think I have answered that. We are still forming an organisational position on that and are watching the debates statewide and nationally. We have to have a conversation with our board.

**Ms WAGLAND:** We cannot possibly make a decision until we see what the legislation actually looks like and what support systems and structures are put around it. That will influence the approach that we take.

**The CHAIR:** Thank you very much 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 of 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 transcript of evidence. The committee will write to you with the questions we have taken on notice during the hearing.

I wanted to ask that if the committee thought it would be useful, would you be open to allowing us to visit the high-care Huntington's facility?

**Ms LAWRENCE:** Yes; very happy.

**The CHAIR:** We would do that in a way that perhaps did not mean we all landed at one place, but worked within the facility. We will stay in touch about that.

**Ms LAWRENCE:** Yes.

**The CHAIR:** Thank you very much

**Hearing concluded at 12.06 pm**

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