

# **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  
TUESDAY, 27 FEBRUARY 2018**

## **SESSION SIX**

### **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 5.05 pm**

**Ms SAMANTHA MAY JENKINSON**

**Executive Director, People with Disabilities WA, examined:**

**Mr ROSS JOYCE**

**Chief Executive Officer, Australian Federation of Disability Organisations, examined:**

**Mr PATRICK McGEE**

**National Manager, Policy Research Advocacy, Australian Federation of Disability Organisations, examined:**

**The CHAIR:** On behalf of the committee, I would like to thank you all for agreeing to appear today to provide evidence in relation to the end-of-life choices inquiry. My name is Amber-Jade Sanderson, I am the Chair of the joint select committee. I will introduce other committee members: Simon Millman, John McGrath, Dr Jeannine Purdy, Hon Colin Holt, Hon Nick Goiran, Reece Whitby and Hon Robin Chapple. The purposes 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 you say outside these proceedings. I advise that the proceedings of this hearing will be broadcast live within Parliament House and via the internet. Do you have any questions about your attendance here today?

**The WITNESSES:** No.

**The CHAIR:** Before we move to our questions, did any of you want to make a brief opening statement?

**Ms JENKINSON:** Yes, thank you very much. I thought I might just give a quick brief overview of just some of the key points that we raised in our submission. Firstly, we would like to thank you very much for asking us to provide a submission, also with our national peak body colleague, as their experience in Victoria is actually really good to give us a fuller picture of what we could provide for you. I wanted to just start by saying that this is a really difficult issue for many people with disabilities, as with the community more generally people with disabilities are very divided on the issue. A lot of that is around the balance between what is individual choice and control and then how do the laws and the things we do reflect on people with disability more broadly in society that then can influence how people then make individual choices. There is a real balance there that we saw which is why we have tried to take a very nuanced position and balance those things together. Essentially, as you would have seen from our submission, there are a lot of issues to do with the way people with disabilities are treated now within the system, how people with disabilities are portrayed now in the media and the sort of language that is often used which portrays people with disabilities in not the greatest light, which, potentially, we are concerned, might have an impact when we look at this sort of legislation if it is not done well, if it is not using the appropriate language and if it does not have the appropriate safeguards in place. In our submission we spoke to some people with disabilities that put forward their views and although unfortunately it was not very many people, what came across consistently was that when people talked about what they meant by assisted dying, it was very much about terminal illness and not about disability or other things. I think we can elaborate more in some of the answers to the questions on some of those issues. I am

glad that there is a starting point for the conversations and really hope that that perspective that we can bring can be acknowledged and recognised in whatever happens next.

**The CHAIR:** Thank you. In relation to palliative care, we have received a lot of evidence that palliative care is not 100 per cent effective for all patients at their end of life. Is palliative care generally adequate for people with disability at end of life?

[5.10 pm]

**Mr McGEE:** It is hard to know. There is not much evidence around, but I suppose what we know is that people with disabilities generally have limited equitable access to the healthcare system as a whole and that would include palliative care. That is in the face of figures that show us that people with disabilities are twice as likely to die from preventable deaths as other people. We know that equitable access to the healthcare system exists in just going to the GP; being able to go into an emergency room and get a good outcome; being able to be admitted, treated and discharged; and, of course, participate in specialist health care including palliative care. We know that it is highly unlikely or that there is a lot more value judgements made about people with disabilities in the healthcare system. Some of those value judgements are about things such as palliative care. We know that people with a disability are less likely to be treated early and to be treated in a complex and wholesome way in the same manner as you or I might have access to. Whilst we have no deliberate evidence that says people are not accessing palliative care, we know that, anecdotally speaking, palliative care is not in the reach of many people with disabilities in the same way it is in the reach of you or I.

**The CHAIR:** Could that be extended to the practice of—in your experience, what proportion of people with disability receive inadequate symptom control at end of their life?

**Mr McGEE:** Again, UNSW research is probably the most recent, and there is no direct evidence just yet. Sorry, could you repeat the question for me?

**The CHAIR:** Around palliative care at end of life, in your experience, what proportion of people with disability receive inadequate symptom control?

**Mr McGEE:** I do not think there is any evidence to know that. But what we know, we can extrapolate from other things. For example, the New South Wales' ombudsman report said that there was an ongoing need for people to receive appropriate care and support during the end of their life, and that would include adequate symptom control during that time. There is lots of evidence to show that people are not getting the same deal as people who do not have disabilities, but there is not any hard evidence to show exactly how much and how often.

**The CHAIR:** In your submission you have indicated that PWDWA and AFDO support further training in connection by palliative care specialists to disability advocacy and disability support providers. Is either PWDWA or AFDO in a position to provide or recommend training for palliative care services in Western Australia?

**Mr JOYCE:** The short answer is yes. We would be more than happy to do that, and both organisations would be happy to do that. It has to do with providing that greater access to palliative care and the greater understanding from the specialists involved. We see that as a priority in providing that service—that there is greater knowledge and greater support provided to people with disability, and greater training provided to the members of the specialists in palliative care. The longer answer is, obviously, with appropriate funding, that is achievable. We would be more than happy to work on a plan and strategy on how to bring that about for the people of Western Australia.

**Ms JENKINSON:** There is not anything in place currently that we are aware of.

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**Hon NICK GOIRAN:** So, in summary, am I hearing from you that for people with disabilities in Western Australia the access to palliative care is less than it is for people without a disability?

**Ms JENKINSON:** We can only speculate that that is the case based on the evidence around access to health systems generally. Essentially, there is no direct evidence to say that.

**Hon NICK GOIRAN:** If we remove palliative care from the conversation and I rephrase the question with regard to access to just health services generally, not necessarily palliative care, would that be the case?

**Ms JENKINSON:** I would say probably yes. I would have to look, but the Disability Health Network, which is one of the mechanisms put in place to try to address exactly that issue, has recognised gaps within the health system around access for people with disabilities and understanding of disability within the health system.

**Mr McGEE:** If I give you an example from Victoria, in Melbourne, which is a city of about 4.5 million people now, there are three female doctors who are experts in providing GP medical access for women with disabilities in the whole city. So if I am a woman with a disability who needs specialist GP knowledge from another female doctor in order to understand and live with my disability, there are only three other women doctors in the entire city who could provide that type of medical support at the GP level. If you talk about specialists, there is only one centre in the city that has specialist disability-specific medical knowledge and there are two and a half positions in that centre at Monash. If you take those numbers, you can safely say that specialist disability medical knowledge is not available to the vast numbers of people with a disability. You could safely say that if you moved out of the metropolitan area of Melbourne, you will not find any specialist disability knowledge. That is not to say that you will not find GPs who are well motivated to try to do a good job, but whether they do the right job and whether they have access to the right amount of information and the right amount of support to provide the medical response necessary, that is where the issue lies. I could go and find a particular doctor with the expertise that I am looking for pretty easily, but a person with a disability would be unable to find that same specialist disability support.

**Ms JENKINSON:** Generally as a person with a disability—this is from my own experience—you, personally, educate the doctor every time you see a different doctor.

**Mr McGEE:** One more thing, if I am in an emergency situation and I go into an emergency room in a hospital, you are really very much up against a lack of knowledge around disability. Often people will conflate cognitive impairment with mental illness; often people will bring values to your situation that they would not bring to a person with capacity—those sorts of experiences.

**Hon ROBIN CHAPPLE:** Do you find those values that are brought forward in that situation are really what creates a negative view of your situation in a hospital or in an emergency?

**Mr McGEE:** Yes. It is funny how it plays out. It can go either way. People sometimes can have an enhanced experience, because someone's values are such that they want to put extra effort into the fact that you have a disability and you are before them, so they go to an extra effort for that. Other people will make a value judgement that, "Well, you know, with your disability, your life isn't worth living anyway; therefore, my effort of level isn't going to be so great." Many, many, people, though, are just unsure of what to do. The majority of people are just plain and simple unsure what to do.

**Ms JENKINSON:** I think that is where different disabilities actually have a different response sometimes, too, depending on how able the person themselves is to say, "Hey, wait a minute! That's not right", and whether or not you have support around those other factors.

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**The CHAIR:** Would it be fair to say that the barriers for people with disability in accessing health care equitably would be similar to the barriers in accessing palliative care?

[5.20 pm]

**Mr McGEE:** Yes, absolutely. In fact, what they have said in the palliative care stuff is that it is about participation, and it is about that sense of being unsure. It's important to delineate between different types of disability as well. So, a person in the wheelchair with good circles of support who has spent a life advocating for themselves, who has been educated and participated in decision-making throughout their life, they are likely to go into that situation and be able to change the outcome even if it was maybe tending against them, because they are used to having done that all their lives. But if I have but a mild intellectual disability or a psychosocial impairment, I am used to people boxing me in and I am more likely than not unable to participate in making the outcome better for myself than others. In that situation in which you have a person who is unable to communicate their wishes and want better outcome, and a person who is unsure on how to interact, those two things come together and the outcome is generally then a poor outcome for people.

**The CHAIR:** I am going to have on to refusal of treatment. Following the decision in Rossiter, the law in Western Australia clearly permits a patient to refuse life-sustaining treatment, although the patient is reliant upon others for their necessities of life. In your experience to people with a disability refuse life-sustaining treatment around the end of life?

**Ms JENKINSON:** Again, it is very difficult to say. There is not a lot of evidence or data that are easy to collect on this issue. But one of the things I would like to talk about with this question is the use of the Rossiter case, because he was not end of life, and I think that is it. It is a very interesting case. I do not know much about his circumstances personally, but having lived in a nursing home environment myself for four years and seeing how people lost control of their lives, I can understand if that was his only experience of disability why that may have been a choice that he made in the end. I would be very wary that the precedent that has been set by that is not about an end-of-life-choice and not to conflate the two.

**Mr McGEE:** We also wondered about this man and if he was not in a nursing home, but living in his own home in the community with family and support and connected to activities that gave him a sense of worth and belonging, the question is whether would he have chosen the same thing. It takes you back to the very heart of the values, and the individual experience in the circumstances that surround it all have to line up exactly for these things to play out in particular ways. We know that if people with disabilities have interactions in the community, have a sense of belonging, have a sense of worth, then their values about themselves improve and you are less vulnerable to these things that might lead you to a place where you want to kill yourself, which is what happened in Rossiter.

**Ms JENKINSON:** I think the other part of that as well is around that I do not know how long Mr Rossiter had had his injury for. From my experience, and knowing many people who have acquired disabilities, some at that same level, it can take seven to 10 years to get to the point of going, "Okay, yes this is life", and move on. I think the other concern is that people actually can adapt and change given the right supports when disability happens. We see the same with degenerative disabilities as well when people might start out being able bodied and go, "When I hit that point, knock me off, I do not want to be around", but then they do hit that point and if they have had all the right support go, "Actually, life's not too bad. I think I could keep going for a bit longer." I guess that is where we have also pointed out some of the issues around language as well and how those things that impact on what the view is. I have had people talk about me in the media about how I suffer with quadriplegia and that I am wheelchair bound, about which my joke is only

when my husband wants kinky sex! But that is the language that is used to betray people with disabilities a lot in the media. We can talk a bit more about that, but I guess it is tied in a bit with the fact that refusing life-sustaining treatment around the end of life is a question related to the choices and supports around palliative care and once in place and, in our opinion, not the Rossiter case.

**Mr McGEE:** We would use “voluntary assisted dying” as the phrase we want rather than saying “euthanasia”, “dying with dignity” or “assisted suicide”. Likewise, things like “unbearable suffering” and “quality of life” are value-laden and they lead you into a place where it can get very murky very quickly. It is best to be very clear.

**Hon NICK GOIRAN:** I am just appreciating your comments about the need for interaction with the community and the sense of isolation, because I did meet Christian Rossiter, and when I met with him and talked to him, it was abundantly clear that there was no family connection and support—talking to him about what if somebody would come and visit and so forth and the difficulties around that. I think you make a very good point about the need for people not to feel isolated and feel connected with community.

**Ms JENKINSON:** And an institutionalised environment does not always help for people to see beyond that, especially when someone’s been there for a long time.

**Mr McGEE:** I think you may still make a decision to engage in voluntary assisted dying even if you are connected. You know, you still make that decision, it is just that it is a better place from which to make that decision than a place that is one of isolation and disconnectedness. It just feels healthier and more informed.

**The CHAIR:** Because it is a choice.

**Mr McGEE:** Yes, it becomes a choice, that is right.

**The CHAIR:** I think I am hearing you say that there is very little hard evidence around palliative care practices to be able to answer very specific questions around terminal sedation, so I will not linger there. I want to touch on futility and get your opinions on doctors not being under any obligation to administer futile medical treatment. We heard some very powerful evidence only today from Mrs Gaye Matthews, who had a very profoundly disabled daughter with Rett syndrome who died at 41. She lived a relatively long life, beyond what was generally expected, and had several hospital admissions. As part of that she was constantly being asked by the doctor, “Do you really want her to have antibiotics? Do you really want to continue this life?” She had to fight every day for that, essentially. From the perspective of your members, the people you represent, what is the interaction with the medical community like around non-beneficial or what they consider futile treatment?

[5.30 pm]

**Mr McGEE:** It is complex and its reflective of the circumstance that you just described. I mean, I think in society generally, which the medical profession is part of, there is a sense for that particular group of people who are very disabled that it is hard to understand the quality of the lived experience. It is hard to understand the joy of living for that group of people. But it is not until you actually come into contact on a day-to-day level where you see the little joys and you see the love that goes on from family members to people with disabilities. I have worked in institutions, particularly Kew Cottages in Melbourne, in a ward where everybody was always in bed and life was pretty grim, but there were these moments in which people engaged in a life that had a bit of joy to it, and in those moments you could see it reflected in their eyes and their expressions. So, I think it is important to understand that the joy of life is very subjective and you should not be judging it

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from the position of standing up on two legs, with two arms and a house to go to and some gin and tonic to be drunk—if that is your tippie!

I think it is very important to understand that many people do not have that direct experience. It is easy to sit outside of that and question whether or not that life is worth living, but it is the family and the person themselves who that question should be asked of, not you or I sitting outside of that. The problem is that for doctors they are coming into contact with that situation at times of crisis, and at times of crisis it is inevitable that those questions will be asked. They should not really be asked because at times of crisis for you and me they would not be asked. It would be asked, “What do we want?”, not “Should we really?” I think that is the difference. We would say that futility is a necessary medical decision that can be made, but there is a point at which futility from a doctor’s point of view should stop and there should be a sort of independent assessment against the person’s experience of life that is fed into the process, so that it is not just the doctor making a decision about the futility of that person’s life. It remains with the doctor to make an assessment about the futility of treatment. Then you would go to the person’s life and would work it out from there. That is very important.

I have been a guardian in the Office of the Public Advocate in Victoria for 11 years and I was a part of making decisions about end-of-life for people—about refusal of treatment. It was always initiated at the point by either the person themselves refusing or the doctor saying, “I think there’s a time for us to consider.” No one was ever racing into this. No one was ever galloping down willy-nilly. It was a very painful time often, and a very considered time often. Everybody was very cognisant of the gravity of what they were doing. Everybody felt that they played their part in the way and the manner which was legislatively and ethically described. My experience is that it was done always very carefully. Futility is a treatment decision but it has implications and we should not be stacking it up and leaving it just as the only factor for consideration when it is in relation to an end-of-life matter.

**Mr J.E. McGRATH:** On the subject of futility, from your experience, with the specialist, when he or she decides that it is pretty futile—would they then go to the family and if the family said, “We want you to try a bit harder; we want you to keep going”, do they normally agree with the family? Surely they would not override the family.

**Mr McGEE:** That is all about what is in place at that time. Most smart people have got themselves powers of attorney or advance care directives or there might be guardians—formal decision-making people made. Those things would have been worked out and decided prior to this event occurring. For people who do not have anything in place, it gets very legally murky because if the person is incapacitated and unable to participate and you do not know their wishes, the decision about who makes the final decision becomes a medical decision. That is where we would say always make sure that you have your wishes known in some way, either formally or informally, because who knows what might happen. It is the case that increasingly those things are being taken up, but there is still a large group of people to whom that situation happens where they do not have their wishes written down. There is no formal decision-making. In that case it is the doctors who decide. Some doctors will decide. Some doctors will go to the family. Some doctors will want some sort of a process applied. It depends on the experience of the doctor. I think, for example, if I am in a major metropolitan hospital in inner-city Melbourne, it is highly likely the expertise of the treating doctor team will be such that they know their legal position on this. But if I am in Alice Springs Hospital, where there is a high degree of teaching staff from other countries, many of whom come for just their time whilst they are a resident at the Alice Springs Hospital, they are unlikely to know that stuff. The outcomes and the decisions that get made because of that set of circumstances can be very different for the person to whom the outcomes are applying.

**The CHAIR:** In relation to voluntary assisted dying, we really appreciated your submission. You support the principle that disability should not be the reason that people access assisted dying nor should it be the reason that people are prevented from assisted dying. Can you elaborate on this?

**Ms JENKINSON:** Really, it comes down to the idea that disability should not be the reason. It should not be part of the criteria. I think, again, it is that balance of, if people have got support, if they have got good information, then the individual choice factor comes in as being something that is an informed thing. I think it also came back to the experience we were hearing from our members that when you ask them, “Who do you mean when you talk about—at what point is somebody going to look for voluntary assisted dying?” These were people with disabilities themselves. Their view of what did voluntary assisted dying mean? It meant people with terminal illness. It did not mean people with disabilities. Essentially, there might be people with a disability who choose it, but what we were hearing was it is in the context of a terminal illness choice, not in the context of a disability choice.

**Hon ROBIN CHAPPLE:** How do you think we generally successfully portray that to the broader community? There are elements of the disability community who feel very threatened by end-of-life choices. I think in most cases, looking at the Victorian legislation and others within the Australian region, that is certainly not the case. But there is a fear. It stems around this whole issue of dignity, I suppose, coming back to that sort of word. I am seeking your advice. How would you overcome those fears?

**Ms JENKINSON:** I think part of it is about safeguards and protections that you might have in legislation. We talked about having a human rights framework around what that means, and getting those core principles back to the human rights, but also about the language used. We do think that there is a problem in the way that people talk about burden, suffering and quality of life. We would not want to see words like that used that have too much of a subjective bias in them. I think that is what we have liked in the Victorian legislation—that it was actually really clear about who is this for. It is very specific—the cohort of people. The reality is that, certainly from what we hear, that is the cohort that are looking for—that is what everybody thinks about when they think about it. The other thing we talked about partly in our submission, but also in terms of—there might be times when you have a tribunal or a panel or something to help with decision-making. They are very wary of that being just based on a medical aspect only, but needing to actually include—whether it is advocates, community people, people from the community or the disability community—just in terms of the issues with the health system that we already have.

**The CHAIR:** Do think there is an inherent bias?

**Ms JENKINSON:** There is potential for one.

**Mr JOYCE:** It needs a bit of balance.

**The CHAIR:** Or a broader —

**Ms JENKINSON:** More that it has a broader balance. And also the role of whether it is independent advocates, guardians or other people, particularly if people may have any sort of cognitive disability or their social circumstances are not great—that there are other people who are external. The role of an advocate generally is to help people understand what is happening and to make sure that their view is heard and help them be informed about what is happening and the choices that they might make.

[5.40 pm]

**Mr R.R. WHITBY:** What about the issue of capacity and intellectual disability; is there ever scope for carers or family or other decision-makers to make a decision there?



**Mr McGEE:** If I can just quickly touch on—the first thing—then I will just come and that question because that is one of the questions I want to answer.

**Ms JENKINSON:** Patrick has more experience in that area.

**Mr McGEE:** The first thing is involving people with disabilities in your structures, in your decision-making processes, and giving them the authority to participate as an active and equal member in the process sends a very powerful message about you wanting to make sure that people with disabilities do not feel threatened by this stuff. Having representatives with disabilities sends a very powerful message. That is the first thing.

Talking to other parts of government about funding better access to the healthcare system would go a long way in sending a message to people with disabilities that this is not a threat to them. I think those are two key things. I think another thing is that to make explicit reference, in the material you present and deliver on, that people with disabilities will be included in the decision-making process at all points is another key way to overcome those considerations and fears.

In terms of people with a cognitive impairment, again we would use the same principle that an intellectual disability per se should not prevent you from participating in voluntary assisted dying. I think, though, there is a point around the impact of the capacity. So, we would talk about people with a mild intellectual disability who have strong histories of participation in decision-making, who have good agency for connection to community, who have a good strong circle of support around them and have evidence of being able to advocate for themselves. In their own context with support, they are probably likely to be able to participate in a process around voluntary assisted dying. We would want some independent advocate to be sitting beside them through that process just to value-add to the safeguarding and to make sure that they fully understood what it was that they were doing. It would be the same for you and I, but you and I might go and choose who that is and that might come from our friends and family. Sometimes people with disabilities, their friends and families create a bit of a barrier to that independent advice because of the nature of their intellectual disability. But I think there is a point at which you would say some people with impaired decision-making capacity would not be able to participate in this process.

There is no evidence from overseas in the Netherlands or Oregon that people with disabilities are fronting up in large numbers seeking out voluntary assisted dying anyway —

**Mr JOYCE:** Or being pushed that way.

**Mr McGEE:** Yes, or being pushed that way. That is right. There is hardly anyone. I think it was 10 out of 224 cases where disability was an issue in the Netherlands. The Netherlands had a particular—disability was not a characteristic that made it illegal to pursue that. We are being very careful and we should be very careful, but it is not a significant issue. The statistics are telling us that it is about what is going on in our heads, rather than, in fact, what is going on out there that we are attending to.

**Mr S.A. MILLMAN:** Thanks for that. I had a couple of questions on that point. Firstly, that is a complex structure that you are proposing for people with a mild mental impairment in order to access—I should say at the outset, I agree with the philosophical proposition that it is a system and the system should not discriminate against people with disability merely because they have got the disability, but in terms of the structure, just two questions: one, where would you locate that independent advocate? We have had the Office of the Public Advocate giving evidence already and I did not get a chance to ask that question. For example, would you locate that person in that office?

**Mr McGEE:** Yes, I think so. I think it is the safest place.

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**Mr S.A. MILLMAN:** Secondly, that is more expansive than what is currently on the statute books in Victoria; that is right, is it not?

**Mr McGEE:** They have dealt cognitive impairment out.

**Mr S.A. MILLMAN:** That is what I thought.

**Mr McGEE:** I just think though that the CRPD compels us to treat people with disabilities in the same manner as we would treat ourselves, so I think there is a question that has to be asked. You may decide that that is beyond your capacity here or your expertise or the life of this particular inquiry, and I think that would be equally as fine an outcome for the minute, but we need to ask the questions, because it is a new place that we are all in around disability.

**Hon NICK GOIRAN:** Just on this whole issue, what risks do you see if legislation was to be brought in?

**Mr JOYCE:** For intellectual disability?

**The CHAIR:** Both.

**Hon NICK GOIRAN:** For the disability sector generally.

**Ms JENKINSON:** I think the risks probably fall into the questions that we answered around the futile medical treatment stuff, because it is that interface at that level. Our experience is that if people have got to the point of having a terminal illness, it is generally people with disability if there has been an issue it is actually—the issue has already passed. It has been an issue with the health system earlier. So, that is probably where we see the highest risk. Look, to be honest, I am not sure how many people might end up actually accessing. I think a lot of it depends on how good your palliative care system is as well. If your palliative care system is working well, the numbers of people I do not think are going to be particularly high.

**Hon NICK GOIRAN:** Sure. I am not concerned about the number. I am concerned about the one person with a disability who might choose to access the system and, as a legislator, I have the same level of responsibility to that one Western Australian as to all the rest. You did indicate earlier in your evidence that often doctors do not know what to do.

**Mr McGEE:** That is where the risk is, by the way. I think the risk is not so much for the person themselves because I can imagine in a well-functioning disability system in Perth, that person will come surrounded with people, generally speaking. If they are not surrounded by people when they get there, certainly by the time that decision needs to be made, they will be surrounded by people. It is just the nature of the way our systems are structured.

**Ms JENKINSON:** It also depends on what the legislation looks like. If the legislation is beyond terminal illness at an end stage, then that is when the risk becomes complicated.

**Mr McGEE:** I think the risks are more around the healthcare system and the way it is structured and its capacity to deal with the person that arrives on its doorstep with a terminal illness saying, “I want voluntary assisted dying, please.” The risks are that they will not be taken seriously, I think. That is where the risks lay. In not being taken seriously, no-one is given the opportunity to the seriously consider the circumstances for that person and make an informed decision either way, yes or no. That is where the risk lay. The risk is that we will continue to treat people with disabilities differently in this particular very personal exercise simply because of the disability.

**Hon COLIN HOLT:** I wonder if I can ask Nick’s question in a slightly different way. I know you have provided some commentary around Oregon and the Netherlands. Safeguards in other legislation in Victoria and New South Wales, which has recently been debated as well—are there adequate

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safeguards? Is there adequate provision for people with disabilities to participate as an alternative view in both of those legislative frameworks put forward?

**Mr McGEE:** I am sure you are aware that the Victorian legislation has the most safeguards ever. They have taken pretty much every —

**Hon COLIN HOLT:** I want to know from a disability viewpoint.

**Mr McGEE:** My sense is that the Victorian legislation has the right amount of safeguards. They are comprehensive. They are widespread. They are far reaching. They took account of the people who were very opposed to the legislation. People with disabilities get a guernsey in that? I mean—no.

I guess no. Just because they do not get a guernsey and equitable access to health care, why is that going to be different in this circumstance?

[5.50 pm]

**The CHAIR:** Can I clarify that: you do not think they will have the same kind of access to the legislation as those without a disability—is that what you are saying—because of the safeguards?

**Mr JOYCE:** The same involvement.

**Mr McGEE:** Will they have the same involvement?

**Mr JOYCE:** As anyone else.

**Mr McGEE:** I do not think so.

**Mr JOYCE:** No.

**Ms JENKINSON:** I think what is interesting, though, is that we spoke to some of the people with disabilities who were involved in the committees around the formulation of the Victorian legislation and they made a conscious effort to involve people with disabilities in the pieces of work that led up to the legislation. I know that they are also including some of those same people to be involved then in what a palliative care system looks like at the policy level as well, after the legislation, so I think that is a positive.

**Mr McGEE:** Can I qualify my statement? If I am a person in a wheelchair who is educated and lives my life at home and in the community like anybody else does, good finances, good stable home life, has participated in decision-making all my life and in fact make all my decisions, then that person probably will have the same type of access as you and I, but if I do not have those attributes in my life and I have a disability, then it is highly unlikely I am going to participate in something so complex. It is hard enough for me to get the DSP let alone participate in decisions about whether I am going to end my life. I just do not think there is the environment where, if I have a cognitive impairment and I am living in a group home that is funded by the NDIS, whether the local residential care worker is going to be suitably trained enough to help me make that decision and participate in that decision, even to initiate that sort of decision. It is highly likely that they will put me in a hospital.

**The CHAIR:** Consent is obviously such a difficult issue, a complex issue. Is it fair to say that there are differing views in the sector, though, around the involvement of people with significant cognitive impairment? We heard some evidence today from Marina Re, the CEO of Identity WA, who was less supportive of your submission and felt that everyone with a cognitive impairment, however mild or profound, should be excluded from the legislation. There are differing views within the sector, which I makes it difficult for legislators. Is that a reasonable proposition?

**The WITNESSES:** Yes.

**Mr McGEE:** It is also why you get paid the big bucks!

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**Ms JENKINSON:** We cannot help you with that one, sorry!

**Mr McGEE:** It is good that there is a diversity of opinions around this. That is the way it should be. I point out a couple of things. The person you talked to is a service provider. They have a very different job to do than an organisation like ours, which is an advocacy organisation. We both care very deeply about people with disabilities, but the circumstances in which we are operating are very, very different. That is why it is important that you spoke to that person and why you are now speaking to us. You need to weigh those things up, and that is what you are here to do.

**Hon ROBIN CHAPPLE:** Sam, when it comes to the service — I am not talking about end-of-life choices here, I am talking about service provision to people with disabilities. I have heard that there might be two aspects to that, one very positive and one quite negative. If it comes to a situation where somebody with a disability is in hospital and gets close to the end of life, how do you feel the medical profession deals with that when it comes to somebody with not a cognitive impairment but a physical impairment? How do you feel they deal with that? Do they slap a DNR on the bottom of the bed more quickly than if they were another person?

**Ms JENKINSON:** I have not had that experience yet myself. It is really interesting because, again, there are different views. We would say that anecdotally we have heard that that is more likely to happen. Prue Hawkins and Stella Young both had similar disabilities and have talked about that; they have had that experience in hospitals of being asked, “So, shall we put the DNR on?” “No.” So I think that is a real risk. You often go into a hospital environment being ready to fight to go home again.

**Mr McGEE:** Survive!

**Ms JENKINSON:** To survive, and at an emotional level, that is actually very true. I do not know if you have had anyone from motor neuron —

**The CHAIR:** They are coming later in the week.

**Ms JENKINSON:** Okay, great. I do not know what their perspective is; we were not able to get anyone with motor neuron disease to talk to us. I saw that some of the people that I know over east, though, with similar disabilities have quite a different view than those of other activists in the area. But I think it still comes down to how the health system interacts with the person and actually really listening to what they have to say. I think the biggest issue is when communication ability is taken away; that is when it becomes fraught, I think, because the person is not able to engage, necessarily.

**Mr JOYCE:** I think it gets back to the issue we discussed earlier about palliative care and the need for specialists to have greater understanding of, and training in, disability. It is the same thing for the medical profession. They have a very good medical understanding about disability conditions and what one can do, but that is different from having an understanding about a person’s lived experience of disability and a greater appreciation for the person. I think that is what is missing in the medical context—that it strictly works on that medical model. What we are talking about is actually connecting with people, and doctors are normally pretty good at that. But again, I think we get back to a lack of understanding in the medical profession in that regard.

**Ms JENKINSON:** I also think that with degenerative disabilities, that is why we have talked about how the advance health directives and advance care planning should not say what your choice might be, essentially because our experience is that people change and adapt over time and what they might think at one point on their journey, they might not think at another point on the journey. That is certainly our experience. My experience with the health system is that I do get worried every time I go under in hospital, and I wish I did not have to be.

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**Mr McGEE:** Can I just say one final thing about the value stuff around how we value and what we see as valued life. Many, many nursing homes serve up an NFR form as part of the admission criteria. That is a value statement, because what they are doing is saying, “You’re about to enter into a nursing home. You’re a not for resuscitation option here.” That is not to say that that conversation should not occur with a person going into an aged care facility, but it should not be served up as part of the admission package. I think that goes some way to the same set of values that exist around people with disabilities. It is that lack of nuanced understanding that just because I have a disability it means I am not going to enjoy my life in the same way that you are, therefore it is of lesser value.

**The CHAIR:** Thanks for your evidence before the committee today. The transcript of this hearing will be forwarded to you for correction of minor errors. Any such corrections must be made and the transcript returned within 10 working days from the date of the email attached to the transcript. If the transcript is not returned within this period, it will be deemed to be correct. New material cannot be added via these corrections and the sense of your evidence cannot be altered. If you wish to provide clarifying information or elaborate on your evidence, please provide this in an email for consideration by the committee when you return your corrected transcript of evidence. The committee will write to you with any questions that were taken on notice. In addition, we may include the proposed questions that we were unable to address today due to time constraints. Thank you all very, very much for your evidence today.

**Hearing concluded at 5.59 pm**

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