

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 THREE

Members

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

Hearing commenced at 12.08 pm**Ms MARINA RE****Chief Executive Officer, Identitywa****Mrs GAYE MATTHEWS****Individual Submitter**

The CHAIR: Good afternoon. Welcome, Mrs Gaye Matthews, and Ms Marina Re, CEO of Identitywa. 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 and I am the chair of the joint select committee. I will introduce the committee members. We have Simon Millman; Hon Dr Sally Talbot; John McGrath; Dr Jeannine Purdy, our principal research officer; Hon Colin 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 may 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. Could you please introduce yourselves for the record.

Ms RE: My name is Marina Re. I am the chief executive officer of Identitywa.

Mrs MATTHEWS: I am Gaye Matthews. I am just a member of the public.

The CHAIR: Do you have any questions about your attendance here today?

Mrs MATTHEWS: No.

The CHAIR: Before we begin with our questions, did you want to make a brief opening statement?

Mrs MATTHEWS: I would like to.

The CHAIR: Please do.

[12.10 pm]

Mrs MATTHEWS: Firstly I would like to thank you for accepting my submission. I seek to make some relevant facts about my daughter Charissa's life and death. Charissa was not correctly diagnosed until she was 16. This diagnosis was Rett syndrome. Rett syndrome is a rare genetic neurological and developmental disorder that affects the way the brain develops, causing a progressive inability to use muscles for eye, speech and body movements. It occurs almost exclusively in girls. We do know that Rett syndrome allows normal development from anywhere between six and 24 months, when there is a catastrophic reversal and final cessation of all normal development. Charissa's reversal began at six months. The paediatrician's response to my question of, "What do we do now?" and his then misdiagnosis of 1972 was, "You do everything for her. She is severely brain damaged. You could put her in a home for such children and forget about her." This was not an option. We had wanted this child, loved her dearly and decided that although we would now have to care for her in all things, she was a person of great worth. One of my goals as her mother and advocate would be to ensure that all those who entered her life would respect her and acknowledge her worth.

As Charissa had no speech, I insisted that no-one should assume she could not understand the words or body language of others. Sadly, those who least valued her being were many in the medical world. Fortunately, there were those who did so and helped us at the end of her life to assist us in our hope for a good death for her. Charissa trusted us, her parents, and me particularly as her advocate in all things. We chose not to have surgery for tube feeding at the end of her life as there were no guarantees this would work. We had major problems in the past with general anaesthetics and she had lost the ability to swallow.

Because of the aspiration pneumonia and imminent respiratory failure and after it was discussed and carefully explained to us by the Silver Chain palliative care team, palliative sedation was the option we chose to give her comfort prior to her very gentle death.

The CHAIR: Thank you, Ms Matthews. Ms Re, do you have an opening statement?

Ms RE: Yes. I am very appreciative of the opportunity afforded to Identitywa to address additional questions as requested by the joint select committee. Just as a way of an introduction, Identitywa was established to support individuals to have a good life. We provide homes for people with high support needs, most of whom are unable to give consent. Significant decisions in their lives are typically made by family members or guardians. We have 150 people in our care and many families choose us because it is known that we have respect for the individual and that we have a long and honourable tradition of caring, protecting and nurturing people with profound disabilities. Implicit in this is that Identitywa cares. That is its foundation. We have an understanding of palliative care that is in keeping with the ethos of the organisation, and that is around caring for the whole person. It is holistic and it goes beyond pain management. It is about caring for the person psychologically, socially and spiritually. We work closely with families and medical professionals to support appropriate and respectful treatment. We are respectful of each individual's and family's wishes.

Our basic position around voluntary assisted death is that we have particular concerns about the vulnerability of people who lack decision-making capacity and the fact that others will be called upon to make those decisions. There are particular risks and vulnerabilities and those vulnerabilities may be linked to financial issues, funding issues, access to scarce and expensive medical care and treatments. The impact of these factors, which are external to the individual, we believe cannot be overstated. We also have a real concern that high-quality palliative care should not become less available as a result of assisted dying becoming legislation.

The CHAIR: Thank you for sharing your story, Ms Matthews. It is very valuable for the committee. Can I just ask some questions of Ms Re around palliative care. Does Identitywa provide palliative care directly?

Ms RE: We do not provide it directly. However, we do provide support workers for individuals in terms of general care and we do have examples of people within our homes who are in receipt of palliative care, but typically it is provided by specialist providers like Silver Chain and we assist with that. But we do not have medically trained staff as part of our support team.

The CHAIR: They would come into the residential homes?

Ms RE: Absolutely. We work together as a team and we support the family, support the individual, support the specialist staff.

The CHAIR: Do you think that people with disability receive adequate palliative care at end of life for their specific needs?

Ms RE: In terms of the services that we provide, I would say yes, because generally our support staff, who know the individuals very, very well, typically have a very low threshold in terms of raising their hand if someone is in pain. Because they know the individual well, they are able to pick up those

cues. I would say typically for us, if we have any suggestion that someone is in pain, and particularly in terms of palliative care, we would actually act immediately and work together to ensure that the appropriate care was given.

The CHAIR: And that includes adequate symptom control, so pain relief?

Ms RE: Yes.

The CHAIR: In terms of the number of residents that you would have who receive palliative care, are you able to provide those figures to the committee, over, say, the last five years?

Ms RE: Over the past five years, it would be around maybe five or six people.

Hon ROBIN CHAPPLE: So, if you have someone who suddenly is in pain or in need of extra palliative care, do you have residential care that can provide that on an immediate basis or do you have to call somebody in?

Ms RE: We have to call someone in. We do not have medical staff on site, but usually what happens in those situations is people may have been in hospital and may be managed in that way, and then the family or the individual may make a decision that they do not want to remain in hospital and want to return home, and at that point we work as a team with Silver Chain, or whoever the providers are, to ensure we have exactly what that person requires.

The CHAIR: In terms of refusal of treatment, following the decision in Rossiter, the law in Western Australia clearly permits a patient who is reliant upon others for the necessities of life to refuse life-sustaining treatment. In your experience, do people with disabilities refuse life-sustaining treatment around the end of life?

Ms RE: We have not had a lot of experience with this, but we had one person who was able to indicate to us very clearly that they were refusing treatment, and that was someone who had a neurological condition. He did not have a cognitive disability. He had a neurological condition that was familial. He had direct experience of the death of two of his siblings, so he knew exactly what was going to come for him. So, he was able to understand the condition and its progression. He had had repeated visits to hospital and was eventually told by the doctor that antibiotics were unlikely to work in the future. From that point, he decided that he did not want to go to hospital any further and he wanted to return home. At that point, in conjunction with him and his family, we initiated palliative care processes. That worked to his satisfaction and to the satisfaction of the family as well.

The CHAIR: In your experience, do substitute decision-makers for people with disability refuse life-sustaining treatments around the end of life?

[12.20 pm]

Ms RE: We do have evidence that families have chosen not to pursue medical intervention.

The CHAIR: Okay. In your experience does it make a difference where that substitute decision-maker is connected to the person personally, or when it is the Public Advocate?

Ms RE: Most certainly, from an operational point of view, the Public Advocate is often less emotional and can be more objective in making those sorts of medical decisions and giving an opinion. However, the other side of the coin is that they often may have less knowledge of the individual. They may not be aware of anything or be able to understand any communication that the person is trying to express, so from our point of view there are two sides there. The nature of the decision may be more objective, but in many cases the Public Advocate may not actually know the individual that they are making a decision on, and that is a concern to us.

The CHAIR: Have family and carers expressed any concerns to you regarding the refusal of treatments at the end of life?

Ms RE: What we find is that families are aware of treatment options but in most cases they are not prepared to make any decisions until they are right at that moment. We have not had any particular families express major concerns, but it is not a discussion that many of our families, even in terms of the work we do around advance care planning, really choose to have until that moment.

The CHAIR: Does Identitywa have a position in relation to withdrawal of treatment?

Ms RE: The organisation has a strong ethos. It was formed by a group of families 40 years ago, so whatever we do, we do in conjunction most certainly with families and key individuals, and we obviously work very closely with GPs, hospitals and whatever. From our point of view, we respect the wishes of families and other decision-makers. It is not a decision we make alone or at all, so really our role is to be respectful of others' wishes.

Hon ROBIN CHAPPLE: I apologise; it is not actually on this topic. Going back to the background of the organisation, in your submission you state that you accommodate about 150 people who live in your homes across the metropolitan area. How many people actually pass away in your institutions? Do you have a figure on that?

Ms RE: It is increasing every year because the people that we support, the average age now is between about 45 and 55, so over a period of time, that has crept up. Each year there will be probably anywhere between five and 10 people who would pass away.

Hon ROBIN CHAPPLE: Thank you. It was just that clarification.

The CHAIR: We will now look at the areas of terminal sedation and palliative starvation. The committee has received evidence regarding the practice of terminal sedation. Have people with disabilities in your care who are approaching the end of life been treated with terminal sedation in your homes?

Ms RE: It is not something that we are aware of. I guess we have a sense that what is practised is palliative sedation and our understanding is that that is really about giving people comfort. This situation where somebody is deliberately sedated to death is not something we are aware of, but we do understand that there is that dual effect—that with increasing levels, that may be a consequence, but most certainly what we would see is that the palliation is around controlling pain and making people comfortable.

The CHAIR: Are you aware of clients being in your care who have then been transferred to hospitals or hospices and treated with palliative sedation?

Ms RE: There is a sense that that has happened, but I could not actually give you dates and times or whatever. But it would seem that sometimes someone has been transferred to hospital and things have happened quite quickly.

The CHAIR: Who would be the decision-maker in that instance?

Ms RE: It would be the family, absolutely.

Hon ROBIN CHAPPLE: Just on that again, your organisation does not normally expect people to pass in your structure, but if they reach that stage and have gone to a hospital or some other facility, is that the norm?

Ms RE: We are very comfortable with people passing away within our houses, and that is something that we have worked on very deliberately in terms of training our staff and supporting our staff to be comfortable with dying. We have people who are living within our houses for whom that has

been their home for 25 or 30 years; that is their home, full stop. If they choose or the family chooses for them to receive care and to pass away within their home, we support that 100 per cent. That is not something we shy away from at all.

Hon ROBIN CHAPPLE: I am just trying to get that clarification.

Ms RE: If there is an issue that we are not able to treat the person or they require specialist ventilation or whatever else, that needs to happen within a hospital environment, then absolutely; that is the environment.

Mrs MATTHEWS: Can I make a comment on that? It was very much our experience with our daughter's death that that was something that we really felt very strongly about—that Carissa should go to her home. We had worked for 32 years at getting her a home away from the family home because we were obviously going to die and she could not do a thing for herself and therefore she needed support. When it came to the point where it was apparent that this illness was going to be the reason for her death—Rett syndrome does not kill people, it is illness that kills people, or specifically women. When it came to that point—I had not yet spoken to my mother's death, but I had had a lot to do with palliative care with her death, which was in my submission, and I had also started asking about palliative care for Carissa in the hospital. This is a subjective feeling, but I very much feel that if we had just left Carissa in hospital, they would have suspended treatment. They just kept saying, "We're not going to do anything more; you can't do anything more", and I really had to fight to get palliative care put in place in that hospital because they just felt Carissa had no worth whatsoever; she was severely disabled, she was obviously not going to live and sooner rather than later it was going to happen. So I contacted Marina as the CEO and said, "Can we bring her home?" We could have taken her to our place, but that was not Carissa's home. She had been in this home for 10 years, she was a 41-year-old woman, and she definitely saw herself in that place, and the staff wanted her to be part of that. So when we organised the palliative care—I think we were one of the early ones to do that—we also requested that the palliative care team speak to the support staff within the home, too. It was very much important that that whole embracing, caring environment was around Carissa at that time.

Hon ROBIN CHAPPLE: Can I ask you a bit of a personal question? When your daughter went into the hospital, you were saying that there was just no interest in support. Were you ever aware whether a DNR was placed on her bed?

Mrs MATTHEWS: It would not have been placed if I were sitting there, and I sat there for 24 hours a day.

Hon ROBIN CHAPPLE: So there was no DNR?

Mrs MATTHEWS: No. Absolutely not.

Hon COLIN HOLT: Thanks for coming in. In your submission, almost on the last line, you say more consideration needs to be given to the decisions made by the Public Guardian of uninformed, distant relatives if legislation is to be considered. Can you expand on that at all?

Mrs MATTHEWS: Sorry, my submission?

Hon COLIN HOLT: Yes, it is the last paragraph, last line really.

Mrs MATTHEWS: Sorry, yes. More consideration needs to be given to the decisions made by the Public Guardian, yes.

Hon COLIN HOLT: Can you just expand on that a little bit for us?

[12.30 pm]

Mrs MATTHEWS: The public guardian does not know these people; they do not know them. We had enduring power of attorney and we had to apply and go in there regularly for this. They insisted that we take Carissa in there and that they had to review it. There was a strong belief that once you are 18, you can make your own decisions whether you are disabled or not, which is a ridiculous comment that people make. But we had to keep going in and having her checked.

One of Charissa's means of communication, which we understood, was to raspberry. Nobody else understood that, but she raspberried if she was hungry, if she did not like people, if she was tired—whatever. They had a different tone and I could tell, after 41 years, what that raspberry was about. I remember taking her in one day and they sat there at the public advocacy and said, "What is she raspberrying about?" I said, "Because she should be going to horseriding today and she's not pleased about being here", and they looked at me as though I was completely mad. At that stage, her top weight was only ever 27 kilos; she was tiny. She was kyphotic, so she leant forward. She was scoliosed and so her back was twisted. For people who did not understand that this was a woman of worth, she was really very cross about having to sit through this ridiculous situation of discussing whether or not her advocacy would go on and whether or not I was allowed to spend her money.

It is important that people understand that the intellectually disabled person—we put disabled labels on people who are very capable of making their own decisions. I am very concerned in this case, and to do with this submission, that these people that cannot make those decisions for themselves are just going to get swept up in the whole thing without that discussion. I think that is where that was coming from. We really need to know the people and we really need to know the people who know those people and translate that to those who are making decisions about them. Does that clarify your question?

Hon COLIN HOLT: Thank you.

Ms RE: Can I just add to that?

The CHAIR: Yes.

Ms RE: We have had occasions that people in our care have been unwell—for example, had a really bad cough or bronchitis or whatever—and have been taken to an emergency department, and this has happened more than once. Then there has been a discussion that the treatment would be a course of antibiotics and did we want the person to be treated. I guess when that happens, the question is really: why would that discussion need to take place in the first place? If that was an able-bodied person, if that was someone fit and healthy and whatever else, there would be no question about that. That does not happen all the time, but it does happen. Gaye's comment about the way that people are viewed in terms of the quality of their existence and how they are valued as individuals is something that is of great concern to us. People with disabilities, particularly people with severe disabilities, both intellectual and physical disabilities, most certainly are devalued by our society and there can be, on occasion, a different set of rules that apply.

The CHAIR: That is a very interesting point. Ms Matthews, I think this is probably a question for you, but I am interested to hear both of your views. It is around the futility of medical treatment. You have obviously had experience of this. Doctors are under an obligation to administer what they consider futile medical treatment. In your view, does doctors' application of the principle of futility compromise their relationship with their patients or patients' families?

Mrs MATTHEWS: It should not if there is open discussion. In Charissa's case at the end of her life, she could not swallow and so we had to make that decision as to whether we would have her entubed. She was totally exhausted. Can I say that most of the Rett girls do not live to that age. The year that Charissa died, five Rett girls through Australia—there are probably only 30 girls or women

in Australia at this time with Rett syndrome—had died that year and three of them were under 12 and one was 21 and Charissa was 41. So she was, in Rett terms, an old lady. They just did not live that long when they were so severely disabled, which Charissa was. We had had experiences in the past of Charissa having to go to hospital for other things, with doctors saying to us, “Do you want us to treat her? Do you want to be brave about this?” We said, “Yes, definitely. If it is treated properly, this will not be the end of her life. If that changes, talk to us again about that and then we will make other decisions, but for the time being, we want that treatment.” So if doctors can refuse that, I sometimes wonder can they then refuse, if legislation is made, for people to demand an end of life. So there are those two sides to that issue that worries me.

Hon NICK GOIRAN: Mrs Matthews, a few times when I have been listening to you this afternoon, I get the sense during your journey in dealing with the medical practitioners that you felt a sense of pressure from them in terms of what you should or should not do and the decisions that you made. I am interested in your observation that around the country, women with Rett’s do not typically live to the age that your daughter did. To the extent that your experience can inform us, do you think it is fair for us to assume that other people in your position might have felt pressured by the doctors to take a different course? Are you in a position to comment on that?

Mrs MATTHEWS: I think on the part of the doctors, it is ignorance of the understanding of the being of a person. I understand where they are coming from. They are in busy emergency, which is where the kids end up generally. If suddenly they are sick, they get put into an ambulance and sent in. So they are busy ER departments. I remember at Royal Perth, Charissa was taken in for one problem that she had and they would not let either her father or myself go in with her while they took her in to be assessed. I kept going and saying, “She cannot speak. She can do nothing for herself, so will you please let me go in?” It was 45 minutes before somebody came out and said, “Is Charissa’s Matthews’ mother out here?”, so I went in. I was very angry; I was very angry. When I got in there, there was a young doctor sitting on the side of the bed crying and I thought: Charissa must have died. I could see Charissa’s feet but I could not see the rest of her. I said, “What are you crying about?” I do not take fools lightly. She said, “I can’t get her to tell me what’s wrong.” I said, “Go and get me a real doctor and let’s get on with this” and once everything was sorted, I discharged her myself. They were terrified that I was going to sue them, I think. I said to them, “Nothing to do with the fact, but I want her taken away and treated by somebody who knows her and you people just either do not have the time or the inclination to do that tonight.” I believe that that has not been a situation. People who understand the Rett women in the world, these girls go in generally through a severe epilepsy situation and will die through an epileptic fit. It is not generally something that I would suggest that families are put in that position to have to have a do not resuscitate thing put on them. They die very quickly if that happens. They regurgitate vomit when they are fitting and, of course, that kills them. But, no, I do not believe that those girls die because of that. It is just that they are so severely disabled and so able to have all sorts of infections and have no resistance. Charissa was 27 kilos and she never reached more than that, but they do not have the resistance to deal with the common illnesses that we all have to deal with.

The CHAIR: I am going to move on to voluntary assisted dying. The committee has received evidence from People with Disabilities (WA) and the Australian Federation of Disability Organisations. Would you like to comment on their views regarding personal choice and access to VAD by people with disability?

Ms RE: Yes. It would be our view that that particular submission and their discussion is very limited and demonstrates unrepresentative consultation. I do not believe it reflects the views of people with disabilities, their carers or families. I think there are significant risks to those with limited

decision-making capacity, and that is the group of people primarily that Identitywa works with. I do not think the submission from PWD gives that enough emphasis at all.

[12.40 pm]

The CHAIR: Do you think they are representing people with physical disability as opposed to intellectual disability?

Ms RE: Yes, absolutely, and I think they are representing people's physical disabilities, many of whom do not have a decision-making impairment. I do not think there was a voice of carers or families strongly within that submission. We know in Australia—in WA, absolutely—the majority of care is provided by families and carers and, typically, families and carers are the decision-makers as well for people with limited decision-making. That is not represented at all in that submission. From our position, there are significant risks for people that do not have a voice of their own.

The CHAIR: Has anyone in the care of Identity ever sought information or requested voluntary assisted dying or euthanasia?

Ms RE: No.

The CHAIR: Should VAD be introduced in Western Australia, what protections would you like to see built into the legislation?

Ms RE: I think the issue of the decision-maker or the substitute decision-maker is absolutely paramount. In some ways, I would almost like to see an exemption for people who are not able to give their own consent. I think that would be the ultimate safeguard—full stop. But the involvement of people who know the individual well is absolutely paramount. That, of course, brings in the potential for all sorts of conflict of interest and, in many cases for people that we support, there are people that we support that do not have any family contact at all. Their only decision-maker is a Public Guardian who may not have any sort of working knowledge of the individual. They may be responsible in terms of paying bills and a few things like that, and that is about it. As an organisation, we would not be willing to be a substitute decision-maker in those sorts of situations. But as I said, for people who are unable to give their consent, I think it is completely different to what applies to other people in the community who are able to make their wishes known quite clearly. It is a different kettle of fish, absolutely.

The CHAIR: Mrs Matthews, do you have anything to add to that?

Mrs MATTHEWS: Yes, I can only support that. My feeling is very much that people with severe intellectual disability just cannot be put into that position—there is no way that they can be—and therefore, there should be an exemption about that. Bodies such as PWD should not be seen to be representing that if they are not actually talking to the substitute carers of families as they advise. Even though families sometimes cannot be the substitute people for their son or daughter, or brother or sister, there is generally some way, when those people go into care, that there is some idea of how they have been treated in their lives. I also worry that there is a financial impediment through the national disability insurance company, too. I have been around for a thousand years in the disability field and I feel very much that everything is down to dollars. Perhaps if you have run through your extended dollars that they have deemed was relevant to give you a certain quality of life, is that going to be rescheduled again or, if you are sick, do you get sent off to hospital and not resuscitated for that sort of thing? It is hugely emotive but also very sensitive but practical—something that has to be considered by any legislation that is going through. For years and years and years, people with intellectual disability have just been lumped in with the disabled label and that cannot happen for our people.

Hon NICK GOIRAN: The committee received some evidence from some interstate academics. For the benefit of my colleagues, I am referring to book J, page 1417. That submission says that the state has an interest in preserving the life of a healthy and well person but that this value of life falls away when a person has a medical condition that will cause their death. I wondered if either of you would like to comment on that. I know you do not have the submission in front of you, but they are drawing a distinction between when the state has an interest in preserving life and when life is less valuable.

Mrs MATTHEWS: My reaction is: Why? Why is it not the same thing? If they have an interest in preserving life, with the quality of life that that entails, then they should also have an interest in a palliative care and concern about that person's death too. So that all should be put into place with the right training for people in palliative care. I do not think there is enough awareness of palliative care, even among GPs. We were very lucky. You will have read the part of my submission about my mother's death where she was just so blessed with a GP who understood palliative care and that came into place well before the end of her life. Also, I was aware of it and so I insisted on that. But there are a lot of doctors that really do not quite understand palliative care. I did ask the man who was in charge of the hospice at Murdoch this question about whether or not, now, this issue of voluntary assisted dying is really getting in the way of more information about palliative care. I think we need to be careful that those two things do not pull each other apart. I think they are both very much in line with the fact that if someone is dying, there is a palliative care and it is not just to do with pain. It is about their spiritual, social and every other aspect of life. I think that is part of it. My answer to you would be that there is as much interest in making sure that a person has a quality of death as they do a quality of life.

Hon NICK GOIRAN: Maybe, Madam Chair, in fairness to the witnesses who have not had the opportunity to read that submission, can I ask: if the committee was to send you that submission, would you be willing to consider it and write to us with any further thoughts you have on that issue?

Ms RE: Yes, absolutely.

Hon NICK GOIRAN: Thanks.

The CHAIR: On the issue of advance care planning and substitute decision-makers, you stated in your submission that a number of your clients have substitute decision-makers and that you encourage clients to develop advance care plans. How do you go about developing advance health care plans where there are substitute decision-makers?

Ms RE: In the same way—I have a sample of our booklet here. We involve the substitute decision-makers in the discussion. I guess what we do is identify people who are at risk because of either suffering from a terminal condition or at risk of some sort of major medical treatment being required. We involve the substitute decision-makers in exactly the same way as we do families. If there are families involved as well, then it becomes a joint discussion.

The CHAIR: Do you regard the advance health care plans as binding on Identity?

Ms RE: No, not necessarily. They are an aid to actually prepare people for what might be coming up and for us to be aware of what people's wishes are, but if that were to change, they are not binding.

The CHAIR: How many people in your care have advance care plans?

Ms RE: At the moment, about eight people have them. Once again, that is something we have only instituted in the last couple of years and we are trying to support, particularly families, with getting on board. What we have found is that for us to get to a point of having an advance care plan is probably as a consequence of a number of conversations over a period of time. It is not something that people respond to quickly. It is something they actually have to come to terms with and think about.

Hon NICK GOIRAN: Further to this, you mentioned there were eight people. What is that in proportion to your overall population?

Ms RE: At this point in time, we have about 150 people living with us, so that might sit at around five or six per cent.

Hon NICK GOIRAN: Would you say in your experience that that is a pretty typical percentage?

Ms RE: It is a growing percentage and, obviously, we do not do it unless we have to. Unless we identify people who are at risk, then it is not a path we go down.

The CHAIR: Is it not a standard procedure?

Ms RE: It is not a standard procedure for people that are well and healthy, absolutely.

The CHAIR: How many people in your care do not have substitute decision-makers?

Ms RE: There would be about 10.

The CHAIR: Do they have advance health care directives?

Ms RE: No.

The CHAIR: Thank you for your evidence today. The transcript of this hearing will be forwarded to you for correction of minor errors.

Hon NICK GOIRAN: Sorry, can I say one last thing?

The CHAIR: Yes.

Hon NICK GOIRAN: Mrs Matthews, I just wanted to say I think every Western Australian wants you to be their mum.

Mrs MATTHEWS: Thank you; not this week!

The CHAIR: 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 the evidence, please provide this in an email for consideration by the committee when you return your corrected transcript. The committee will write to you with questions taken on notice during the hearing. In addition, we will include the proposed questions that we were unable to address due to time constraints. Mrs Matthews, in particular, thank you very much for your evidence today and, Mrs Re, thank you very much for your time.

Hearing concluded at 12.51 pm
