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**TRANSCRIPT OF PROCEEDINGS**

O/N H-1135905

**THE HON RONALD SACKVILLE AO QC, Chair**

**THE HON ROSLYN ATKINSON AO, Commissioner**

**DR RHONDA GALBALLY AC, Commissioner**

**ROYAL COMMISSION INTO VIOLENCE, ABUSE, NEGLECT AND  
EXPLOITATION OF PEOPLE WITH DISABILITY**

**SYDNEY**

**10.00 AM, FRIDAY, 21 FEBRUARY 2020**

**Continued from 20.2.20**

**DAY 4**

**MS K. EASTMAN SC appears with MS S. FRASER and MS G. WRIGHT as counsel  
assisting**

**MS K. MORGAN SC appears with MS A. MUNRO for the Commonwealth of  
Australia**

**MS G. FURNESS SC appears with MR I. FRASER for the State of New South Wales**

**MS K. COLES appears for witness Kim Creevey**

COMMISSIONER SACKVILLE: Good morning, everybody. And welcome to the fourth day of this hearing at Homebush. Again, we wish to acknowledge and pay our respects to the traditional custodians of the land on which we are meeting today, the Wann-gal people. We also pay our respects to First Nations people, elders, past, present and emerging, as well as to any First Nations people present today. Yes, Ms Eastman.

MS EASTMAN: Good morning, Commissioners. Good morning, everyone in the room and those following the proceedings online. So this morning we start with Christine Regan. And today the Royal Commission will hear evidence from a number of family members, and our final witness this afternoon – or it may be sort of late morning, early afternoon – will also talk to us about her experience of visiting the doctor and her experience with the health system.

So I want to start with Christine Regan. And you will see that Ms Regan and her daughter Erin are ready to start. They're in our witness box.

15

**<CHRISTINE ANNE REGAN, AFFIRMED [10.01 am]**

**<ERIN CHRISTINE SHEEHY, AFFIRMED [10.01 am]**

COMMISSIONER SACKVILLE: Thank you very much. And thank you very much for coming to the Commission. Ms Eastman will now ask a few questions.

MS EASTMAN: So first, can I start with Erin. So your name is Erin?

MS SHEEHY: Yes.

MS EASTMAN: And you are going to work with mum today in telling the Royal Commission about parts of your life; is that right?

25

MS SHEEHY: Yes.

MS EASTMAN: Thank you, Erin. And you are Christine Anne Regan?

MS REGAN: I am.

MS EASTMAN: And you're Erin's mum?

30

MS REGAN: Mmm.

MS EASTMAN: But you're also a State Director for New South Wales and ACT for a national regulatory body?

MS REGAN: Yes.

MS EASTMAN: And you wanted to make it very clear that you are only speaking in your personal capacity today and that nothing about your evidence today is attributable to or speaking on behalf of the relevant regulatory body. Is that right?

5 MS REGAN: That's correct. Thank you.

MS EASTMAN: Okay. You've prepared a statement for the Royal Commission. That statement is dated 13 February. I might need you to say yes or no rather than nod just so it can be picked up on the transcript.

MS REGAN: Certainly, sorry.

10 MS EASTMAN: Thanks. And there's no changes to the statement?

MS REGAN: No.

MS EASTMAN: And the contents are true and correct to the best of your knowledge and belief?

MS REGAN: They are, to the best of my knowledge.

15 MS EASTMAN: So, Commissioners, a copy of the statement is in the tender bundle at part A behind tab 24. And Ms Regan has also included an article that she has written which you will see behind tab 25. And in due course, I will tender that document which will become exhibit 4.11.

COMMISSIONER SACKVILLE: Thank you. We have both of those. Thank you very much.

20 MS EASTMAN: Thank you. So Ms Regan, can I start by asking you about Erin, who's present today. So she's your eldest child?

MS REGAN: She is.

MS EASTMAN: And she's now 42 years old?

25 MS REGAN: Is that right?

MS SHEEHY: Yes.

MS EASTMAN: So she's a child of the 70s.

MS REGAN: She is.

MS EASTMAN: And in terms of – we’re going to talk about Erin’s experience and your experience with the health system. And Erin had a stroke, and this is an issue that you want to talk to the Royal Commission about today. But before we get to Erin’s stroke, you want to tell us something about Erin and her life and all of the  
5 different jobs and her schooling. And so can we start with a discussion about Erin. And Erin, we’re going to talk about you, and I understand that you might want to say to mum certain things as we go along. Is that okay?

MS SHEEHY: Yes.

MS EASTMAN: All right. So let’s start. You deal with talking about Erin in  
10 paragraph 9 of the statement. So, Ms Regan, what would you like to say about Erin?

MS REGAN: Erin used to live with my partner Stein and I at home. She has moved out last year and she’s now living in her own house with some friends. I think Erin’s – what Erin likes to do the most is karaoke, but also she does lots of work on the iPad, some reading and writing work, but Erin specialises in reading and writing,  
15 something of a skill of hers, and music.

MS EASTMAN: Music’s very important to Erin.

MS REGAN: That’s correct.

MS EASTMAN: Her favourite band is ABBA; is that right?

MS SHEEHY: Yes.

MS EASTMAN: And we’re going to talk shortly about the importance of music in  
20 terms of Erin’s life.

MS REGAN: Prior - - -

MS EASTMAN: So - - -

MS REGAN: Prior to the stroke, Erin had only gone to regular schools, sometimes  
25 in support classes, and we found – I found that was really important for Erin to model on the behaviour of other young people the same age as her, but also for her inclusion in society.

MS EASTMAN: So just pausing there, I think you say in paragraph 13 of the  
30 statement that when it came to making a decision about where Erin would go to school, that you gave some careful consideration to whether you might send her to what you describe in the statement as a special school or a regular school. So do you want to say something about - - -

MS REGAN: We did.

MS EASTMAN: - - - how you made that decision?

MS REGAN: When Erin was a baby, I was able to get a job as a teacher's aide in a progressive special school, as they were then known. And while I totally enjoyed the experience and I embraced it, I thought we might be able to do better with my  
5 daughter at that time. And we had moved from inner west to far – well, outer metropolitan Sydney where there were few services or supports or classes, or anything. And so a group of parents and I banded together to develop or to initiate some support classes in regular primary schools. Prior to that, she had gone to an out-of-area Catholic school for three years, and they loved having her and she loved  
10 being there.

MS EASTMAN: For high school she went to Nepean High School at Emu Plains?

MS REGAN: That's correct. Support classes.

MS EASTMAN: And she travelled there independently.

MS REGAN: She left home at 8 o'clock in the morning, caught a bus and a train,  
15 and walked a lot further than any other young person her age would be required to do to get to school.

MS EASTMAN: And she completed high school; that's right?

MS REGAN: She got her HSC.

MS EASTMAN: And then after HSC, then she had some jobs. And she's had a  
20 number of different jobs, hasn't she? So Erin, you've worked at McDonald's?

MS SHEEHY: Yes.

MS EASTMAN: And you've worked at the local newsagents?

MS SHEEHY: Yes.

MS EASTMAN: And you've also participated in the Flintwood Disability Day  
25 Services Programs?

MS REGAN: That's correct.

MS SHEEHY: Yes.

MS EASTMAN: And Ms Regan, tell me a little bit about the work that Erin was  
30 doing in her jobs. I think you say she was almost at the promotion point in terms of her work at McDonald's. She was not doing any "special work", so to speak.

MS REGAN: No.

MS EASTMAN: But just the regular work the same as everybody.

MS REGAN: She came in as entry level, as all young people do. It was facilitated by Flintwood but then left alone. And Erin was given some pretty basic quiet shifts. And then she – she went through a regular work assessment as all employees do and started to be offered busier shifts, and was in line for a promotion, so we were told by McDonald's. She was doing one or two shifts a week, and at the same time – and shifts were quite short. At the same time she was working in a local newsagents. Not sure what she was doing there but they loved her and she loved it, and that seemed to work well.

10 MS EASTMAN: And her career goal was to work in a bank?

MS REGAN: That's where the money was.

MS EASTMAN: Right. Okay. And Erin's life has been one of great activities. So at different times when she was at school she has done classical jazz and ballet training; is that right?

15 MS REGAN: Yes. In her regular school she was the only girl with any form of disability, and we didn't appreciate how much she was welcomed into that school and – until she got her 10 year medal and she got a one minute standing ovation, which I didn't see because I was crying at the time, but – but we were very surprised at that.

20 MS EASTMAN: She has done the NIDA weekend workshops. She has participated in the Special Olympics for swimming. So she had a very active and full life.

MS REGAN: And Little Athletics and drama classes, and on it goes.

MS EASTMAN: And she was the keeper of the family history; is that right?

MS REGAN: Always.

25 MS EASTMAN: She would tell the stories.

MS REGAN: That's right.

MS EASTMAN: And the photo albums and the like. Okay.

MS REGAN: And would remind us.

30 MS EASTMAN: All right. So we're to talk about some parts of Erin's life which are very sensitive and personal. And there may be a point in time in the evidence this morning where Erin might leave the room. And so we will pause before that happens, and then she will come back in when she's ready. So we're happy with those arrangements, and Erin is happy with that arrangement.

MS REGAN: Yes, we are, thank you.  
MS EASTMAN: Okay. All right. Thanks, Erin. So, Erin, I'm going to ask mum some questions before you were born.  
MS REGAN: Okay.  
5 MS SHEEHY: Okay.  
MS EASTMAN: Ready? Okay. So Erin's born in 1977. And you say in your statement that when she was born there was absolute silence in the delivery room and she's whisked away by nurses. And so you have a very clear memory of this.  
MS REGAN: I certainly do.  
10 MS EASTMAN: Right.  
MS REGAN: And I didn't realise that – about the silence because I had just given birth and I was full of the joy of giving birth, until I had my son three years later when it was all – all excitement and congratulations, and delight. And I – in that moment I realised how different Erin's first moments were.  
15 MS EASTMAN: And - - -  
MS REGAN: It was just silent.  
MS EASTMAN: Silence and - - -  
MS REGAN: Then she was taken.  
MS EASTMAN: She was taken away. And you didn't see her until the day after  
20 her birth.  
MS REGAN: The next day, with no explanation.  
MS EASTMAN: And your then husband and you were told by the doctors that she had Down syndrome.  
MS REGAN: That's correct.  
25 MS EASTMAN: And you asked a social worker at the time, "Can you get me some more information and help me understand what I now need to know?" And what was your experience of making that request and the information that you received?  
MS REGAN: She was born at a major maternity hospital. And I thought someone with Down syndrome must have been born here before Erin. So I asked for  
30 information on Down syndrome because I only know what we all see in the streets.

And she came back three days later. Three days doesn't sound long, but when you're lying in a hospital bed suddenly alone with – and all the other beds in that ward were suddenly vacated, it's a long time when your baby is not with you to – and she came back three days later and said, "I'm just here to talk about how you're feeling."

5 MS EASTMAN: How did that make you feel?

MS REGAN: I was fed up to the eye teeth with how I was feeling. I needed information. And she said, "That's not my role." I could not believe it.

MS EASTMAN: And shortly after Erin's birth she suffered a heart attack and she had to be taken into intensive care; is that right?

10 MS REGAN: That's correct.

MS EASTMAN: And your recollection is receiving no support from hospital other than offers of Valium?

MS REGAN: That's right.

MS EASTMAN: Which you declined.

15 MS REGAN: I declined by saying, "Will the Valium take the Down syndrome away?" And they said, "No", and I said, "Well, why am I taking it?" Because I was pretty sensible, but they didn't want to deal with me being a little sad and in grief, which I thought was a natural reaction that I just wanted to get through to move to the next thing, whatever that was.

20 MS EASTMAN: And I think you say in paragraph 23 of the statement that in lots of ways Erin's birth was a baptism by fire.

MS REGAN: I learned how it was going to be.

MS EASTMAN: For both of you, was it? And that you had, I think, reached a very firm decision that you were going to parent Erin in a particular way. When the  
25 nurses said to you in the hospital, "If you want, we can make arrangements to take the baby away to a place where she will be looked after", you and your then husband were very strong in saying "No".

MS REGAN: It was a little bit stronger than that - - -

MS EASTMAN: All right.

30 MS REGAN: - - - because it was saying, "We think you should send this baby to a place where it can be looked after because you can't." And they had decided. And they took my husband aside every time he visited before he got to my bed to

convince him that that's what should happen. And I knew with every fibre of my being that wasn't right for us.

MS EASTMAN: Right. So when you left the hospital and returned home, how were the first few weeks, months and first few years of Erin's life?

5 MS REGAN: I'm very lucky in that my family is very supportive. Erin needed major heart surgery in next two years, and our paediatrician had advised against it, deciding that – saying that she only has a one-in-five chance of survival. And I said, “And so what's our prospect?” And they said, “A slow and painful decline over five years with Erin's heart condition.” But he didn't want the operation. So we decided  
10 to make our own decision, thinking a one-in-five is at least a chance in life, and we decided to take it.

MS EASTMAN: And just in terms of these early years, I think you do say – and I'm just stepping back a little bit – that you – when you did your own research to find out what resources were out there at the time to assist you to understand what Erin's  
15 needs would be as an infant and as a small child, that there was an organisation called the Subnormal Children's Welfare Association.

MS REGAN: That's right.

MS EASTMAN: All right.

MS REGAN: Terrible name.

20 MS EASTMAN: That's 1977.

MS REGAN: That's right. Terrible name but fantastic help.

MS EASTMAN: But – so notwithstanding the name that when you made contact with this association, the first person you spoke to is the first person who said to you, I assume outside the family, “Congratulations on the birth of your daughter.” And  
25 that was a significant change for you.

MS REGAN: She was actually the first person - - -

MS EASTMAN: The very first person.

MS REGAN: - - - that said that. And that was on day 5, because my mother had organised for the social worker to visit me when I said, “No one's telling me  
30 anything”, and overnight she turned up and she said, “Congratulations.” And I realised then that's the first time someone had said, “Congratulations, you've got a baby girl.”

MS EASTMAN: And others were giving you pot plants and chocolates.

MS REGAN: I got lots of pot plants and chocolates.

MS EASTMAN: And it was only when your son was born that maybe babies' clothes and other sorts of presents was forthcoming.

MS REGAN: Yes.

5 MS EASTMAN: So this is all part of the baptism of fire.

MS REGAN: Yes.

MS EASTMAN: And when Erin was 20 months she had the heart condition. So this is when you had the strong conversation with the paediatrician; is that right?

MS REGAN: That's correct.

10 MS EASTMAN: That you decided that you would make the decision that Erin would have the surgery.

MS REGAN: We did. He wasn't for it, but he did go ahead and arrange it and - - -

MS EASTMAN: But he didn't end up continuing as your treating paediatrician; is that right?

15 MS REGAN: He dropped us. He didn't want to see us anymore because we didn't do what he wanted.

MS EASTMAN: Okay. You knew this was a very risky operation for Erin to have. And so you said at the time, "Well, we will make a life." And so in those three months leading up to the operation, you, your then husband and Erin basically went

20 on road trips.

MS REGAN: Everywhere and did everything.

MS EASTMAN: You went everywhere, you took photos, and you went around. So this might have been the beginning of Erin's sort of special skill of being the custodian of the family history.

25 MS REGAN: Very.

MS EASTMAN: Why did you feel you needed to do that? Some might say, "She's a tiny baby."

MS REGAN: Erin had already taught me that there's a lot more to a person than your size or your understanding. And she – if this was going to be the end of her

30 time with us, then she was going out with a bang, and she was going to have

memories that she could take with her to wherever the next place is, and so would we because she was really important to us.

MS EASTMAN: So she had the operation, and that was a fairly traumatic time for everybody. And so I think you say in your statement, just witnessing how physical  
5 that was in terms of Erin having things probed and prodded in her, being able to find veins and just the trauma of the operation is something that's still very strong in your memory; is that right?

MS REGAN: I can picture it as we speak. She was 20 months at the time, but she was the size of about an eight or nine-month-old baby, the size. So she was very  
10 tiny. And they – they couldn't get enough drugs into her so they did have to put drips into her wrists and her elbows and her knees and her ankles, and she was such a tiny baby. And yet she was still singing My Hands Are Clapping with all those things when – when we were singing to her.

MS EASTMAN: So the immediate days after the operation were the critical period.  
15 I think you say the first 10 days you knew would be critical.

MS REGAN: Yes.

MS EASTMAN: And you were with Erin all of the time; is that right?

MS REGAN: That's correct.

MS EASTMAN: And the real question was whether she would survive the  
20 operation.

MS REGAN: That's right. And after the operation when I finally got to talk to a doctor, it turned out that her condition was not a one-in-five chance of survival, it was a four-in-five chance of survival, but we wouldn't have known that had she not had the operation.

MS EASTMAN: So there's a three-month recovery period after that operation, and  
25 then she was home?

MS REGAN: Mmm.

MS EASTMAN: And then there were a few minor issues and one critical issue that happened shortly after. But for the most part, Erin then goes on to do all of the  
30 things that you've talked about, all the sporting, dancing, music, school, jobs – everything else.

MS REGAN: Didn't look back.

MS EASTMAN: Okay. And in terms of her overall health, it's the case, isn't it, that her health was up to the point – we will get to talk about the stroke, her health - - -

MS REGAN: She - - -

5 MS EASTMAN: - - - was generally good. She had a few - - -

MS REGAN: She had some – what we - - -

MS EASTMAN: Few things.

MS REGAN: - - - started to school new and exciting medical adventures. She was most of the time in good health, but when she had some kind of health crisis it was generally either very serious or critical, and it was generally bolt out of the blue, and then we would deal with it and she would just bounce back every time.

10 MS EASTMAN: So a few things happened as she became a teenager where you noticed the reaction and response, perhaps, of the medical practitioners that you thought, “This might not necessarily be appropriate, or thinking about Erin as a person.” And one of the examples that you give in the statement is when she was 15 years old and she developed a serious skin condition.

MS REGAN: Yes.

MS EASTMAN: So you had to go and see a specialist. And his recommendation was that Erin not wear underwear for three months until the skin condition had resolved.

20 MS REGAN: That's correct.

MS EASTMAN: And is it fair to say, reading your statement, that you were somewhat incredulous at that suggestion, telling the practitioner Erin travels independently on a bus every day, she wears a school uniform, she needs to wear underwear.

25 MS REGAN: As any other 15-year-old girl would.

MS EASTMAN: And his response was to be so annoyed that he stood up and walked out of his office.

MS REGAN: Out of his own office. He left us.

30 MS EASTMAN: Was that the entirety of the conversation? I mean, how did you - - -

MS REGAN: He - - -

MS EASTMAN: - - - manage that conversation? And what was the impact on Erin while this discussion was happening?

MS REGAN: Well, Erin was just watching because it became a very intense, still calm but very intense exchange. There was his resident in the room at the same time.

5 And when I said, "I don't think we can do that. What's the next best thing we can do for her treatment?" He said, "I've told you what she needs to do. I'm the expert here. That's what I expect you to do." And it was kind of like end of story. And I said, "But you understand she's a 15-year-old girl who travels on buses and trains and has a short skirt." And he just stood up and walked out of his office in a huff.

10 After that, I spoke to the resident and said, "Did I say something wrong? Is that what - is what I said unreasonable?" And she said, "I think that he felt very strongly in his opinions." And so that was just the way it was.

MS EASTMAN: You say in the statement that it appeared to you that the practitioner had just assumed that because Erin lives with Down syndrome that she must be shepherded everywhere and that there was no concept of her having any independent life.

MS REGAN: Absolutely. Absolutely. And, in fact, he didn't even speak to her the whole time.

MS EASTMAN: You had another occasion where a practitioner hasn't spoken to Erin, and you deal with this at paragraph 33 of the statement. So Erin decided that she wanted to have her eyes straightened, and you weren't too keen on this at all.

MS REGAN: No.

MS EASTMAN: But you decided that this was something that Erin wanted to do so you would support her - - -

25 MS REGAN: Yes.

MS EASTMAN: - - - in the choices that she wanted to make.

MS REGAN: Mmm.

MS EASTMAN: Did you try to convince her out of it?

MS REGAN: I did.

30 MS EASTMAN: Or once she had made her mind up, that was it. What happened?

MS REGAN: I did. And I was against it because I didn't want us to have unnecessary procedures, but I said, "Well, let's talk about it." And we talked about it for nine months, and she was determined. And I thought, "This is something she wants. Who am I to say no?" And this was totally her decision.

MS EASTMAN: So arrangements were made for that particular procedure. And when you went to see the doctors conducting that procedure, the doctors just spoke to you and not to Erin; is that right?

MS REGAN: Didn't – almost didn't acknowledge her.

5 MS EASTMAN: But you didn't think that they were being deliberately rude or discourteous.

MS REGAN: I didn't have any hostile feelings from them, they just didn't count her. She was like the object of their operation but not a person like I was just sitting next to the bed.

10 MS EASTMAN: All right. And you had to say to them, "Tell Erin. Speak to Erin."

MS REGAN: Yes, because she could answer questions and – and give them the information they wanted.

MS EASTMAN: All right. And so I think you say in the statement that over the course of Erin's life this had become an extremely common occurrence when you  
15 attended hospitals or medical centres.

MS REGAN: It did. I've got to say we had some really, really good doctors, but it's the doctors that can change the course of your life with bad decisions or bad advice, that really stick in your mind and – which feel threatening.

MS EASTMAN: All right. So now I want to turn to Erin's stroke, which has really  
20 been a very significant turning point in your life and very significant for Erin. So if you need a break at any time or you want to read part of the statement or you would like me to read it, just let me know.

MS REGAN: Okay. Thank you.

MS EASTMAN: So I think – continuing on the theme of the baptism of fire and  
25 things happening unexpectedly, Erin's 25 years old and then, very unexpectedly, she experiences and suffers a stroke.

MS REGAN: Yes.

MS EASTMAN: And you remember this very clearly because this is the same day as the Bali bombing in October 2002.

30 MS REGAN: It was happening at the same time, we later found out. So it was at midnight. Erin – I had a migraine, and I got migraines and I had taken big migraine drugs that generally knock me out. My partner, Stein, woke me and said, "Erin seems to be fussing in the bathroom", and it was midnight. So that's very unusual, so we went in. Erin was fussing about and didn't seem to know where she was. And

I said “Well –” sorted her out, and we walked – I then said, “Well, back to bed”, and her bedroom was about three metres away. And she didn’t seem to know where to go. And when she started to walk, I realised she was limping. And so I – and she was a little agitated but then calmed.

5 MS EASTMAN: Had you seen Erin like this before?

MS REGAN: Never. Never. This was very, very extraordinary symptoms and behaviours. So we settled her. I went in to Stein and said, “Something big has happened.” And I was a bit frightened, and I kind of got back into bed and, thank goodness, Stein said, “No, we’re – we’re going to the hospital now.” And he drove

10

us.  
MS EASTMAN: Right. So you took her to the emergency department at about 2 am in the morning.

MS REGAN: That’s right.

MS EASTMAN: And so what happened when you got to the emergency  
15 department?

MS REGAN: They said, “Don’t worry about it. 25-year-old women don’t have strokes. It’s just a virus. We’ve got a virus with these same symptoms.” And we thought, “Okay.” But they did a few tests, and by 6 o’clock we were taken into the ‘interview room’ and - - -

20 MS EASTMAN: When you say “interview room” - - -

MS REGAN: Yes.

MS EASTMAN: - - - what does that mean?

MS REGAN: It – I’ve – I’ve learnt about interview rooms in hospitals. They are the place where you receive bad news. They are not the place where you receive  
25 good news because you receive that at your bedside. So when we were asked to go into the interview room, I knew it was bad.

MS EASTMAN: Right. And what were you told?

MS REGAN: That she had had a massive stroke and that her – the rest of her life will change.

30 MS EASTMAN: So she had no control over her bodily functions and she was paralysed down her right side. But she couldn’t speak or swallow. And one thing that was very distressing for you is that she didn’t recognise you.

MS REGAN: It took me a little while to realise while she was friendly and engaging, she didn't know who I was.

MS EASTMAN: And a day or two after her stroke, that's when you realised that her memory had gone - - -

5 MS REGAN: Had - - -

MS EASTMAN: - - - completely.

MS REGAN: Had been wiped.

MS EASTMAN: And so for you it was in the recovery phase rebuilding Erin's memories.

10 MS REGAN: Yes.

MS EASTMAN: So she had gone from being the custodian of the memories of the family to you then taking all of that that she contributed to the family to then help her re-establish where she was from a family perspective but who she was as well.

15 MS REGAN: As a person. And one of the things that we did, which we thought we were helping Erin regain her memories, was by displaying all around her emergency bed her bowling trophies and her literacy trophies and the photos of her in New Zealand on Franz Glacier, Franz Josef Glacier and a whole pile of things just arrayed around. We thought we were doing that for Erin's memory, but the better impact was suddenly to the doctors and nurses this was a person with a life rather than a  
20 Down syndrome in a bed. And it did change some people's attitudes. And it was an eye-opener for me.

MS EASTMAN: So I want to ask you some questions now about a conversation with one of the medical practitioners about three days after Erin's stroke. And I'm just going to pause at this moment because this might be a time when Erin might  
25 want to just go outside. And she will be back.

MS REGAN: Erin, will you go back out with Stein while I talk a little bit and then come back in?

MS EASTMAN: Thanks, Erin. So this is three days, things are looking fairly grim. Erin's friendly and engaged, but she's not understanding what's going on. And so  
30 this is why - so just explain, Erin's - this is something that Erin hasn't - you haven't discussed with Erin, and it's still a very sensitive topic and very distressing for you.

MS REGAN: And while I have shared this, not for many years but recently, I have to be in a particular mindset - - -

MS EASTMAN: Okay. So - - -

MS REGAN: - - - to do that. And I generally don't talk about Erin's whole life. It's just generally like a little snapshot. So - - -

MS EASTMAN: Okay. We will do this slowly, and just let me know at any time.

MS REGAN: Sure.

5 MS EASTMAN: So you've got a young doctor who came up to see you.

MS REGAN: Yes.

MS EASTMAN: And asked you to step away from Erin's bed.

MS REGAN: Yes.

MS EASTMAN: And - - -

10 MS REGAN: Thank goodness.

MS EASTMAN: He or she said, "We've got her pain under control right now. We're ready to discharge her."

MS REGAN: I had been a disability worker for many years, and I had worked with the Stroke Recovery Association – but just as one of a number of organisations I

15 worked with, not particularly. I just knew that when you have a stroke, there's generally a long recovery and a rehabilitation. And this doctor just said, "Well, she can go home now. We've got her pain under control," on day three.

MS EASTMAN: You were shocked?

MS REGAN: I didn't understand it.

20 MS EASTMAN: So you asked the doctor, "Isn't there any recovery or" - - -

MS REGAN: Yes.

MS EASTMAN: "- - - physiotherapy. What do we have to do to help with the stroke? What would you do for any other 25 year old woman with this condition?" So you asked those questions.

25 MS REGAN: I did.

MS EASTMAN: And then the doctor then rattled off, "Here's our nine month stroke protocol."

MS REGAN: Very comfortably.

MS EASTMAN: And you remember this conversation very clearly. And then you said, “So you’re not going to give that nine month stroke protocol to Erin.”

MS REGAN: To this 25 year old daughter – 25 year old woman, because of her face. And he – he sort of sat back suddenly, like I had said something strange. And he said - - -

MS EASTMAN: What did he say?

MS REGAN: He said, “Oh, look, she has Down syndrome. How hard are you going to try?” I felt like I had been punched in the gut.

MS EASTMAN: And even today this is something that causes you enormous distress.

MS REGAN: It does, because it was just unbelievable. Unbelievable. There was no medical reason for her not to do rehabilitation. And this man was just going to send her home to a life of paralysis and no control and possibly an early departure from this world just because he had decided how important it was for her to be alive or something. I don’t know, but it wasn’t a medical decision.

MS EASTMAN: I mean, you were quite confronting – confronted, but you also confronted him, and you said, “Well, how would you feel if someone said that to you about your daughter?” And his response is, “This is a very serious stroke.” And you said, “Yes, it is. We want the same treatment that you will give anyone else.”

MS REGAN: Anyone else.

MS EASTMAN: What gave you that courage to stand up to him at that point in time?

MS REGAN: I’ve got to tell you, I don’t know, and I still don’t know where that came from, but I am so grateful it came. It was a private conversation – luckily away from Erin’s bed because Erin could hear and understand everything we were saying, and she totally would have understood the impact of those words. And she hasn’t heard them, which is – there’s no need to insult her. But all we wanted was the treatment you get for the condition you have. And we weren’t even being offered it.

MS EASTMAN: Do you see that conversation as being absolutely critical to what happened next? Because the doctor agreed to sign Erin up to the stroke protocol, and you never saw him again, and you then ended up with Erin being moved to the rehabilitation ward. But do you reflect that if you had not had that conversation in the tone and the manner that you did, that this could have been a very different outcome?

MS REGAN: It absolutely would have, and she just plain didn’t deserve it. She has taught me too much over the time to just not be treated like a person. And not only

that, but what she brings to our lives is something that I hadn't experienced in any other way, even though my sons are fantastic. But this is different. And for someone to not even know her and not offer her what any other citizen would have was amazing, and for some reason I was so quietly disturbed and angry by it, I had a stroke of inspiration, and that sustained me, but I still think that came from Erin.

5 MS EASTMAN: So then we move to Erin's recovery. And whenever you're ready and you think Erin's ready to come back in, just let Emma know and she can come in.

MS REGAN: Just a couple more things and then she can come in.

10 MS EASTMAN: Okay. All right. So Erin's recovery started by moving to the hospital's rehabilitation ward.

MS REGAN: Yes.

MS EASTMAN: And so in terms of talking about the stroke protocol – and I think the concept of stroke protocol may be known to a number of people in the room, the Commissioners and those following the broadcast, and it's – you're able to look  
15 online now at stroke protocols.

MS REGAN: Mmm.

MS EASTMAN: But back in 2002 when Erin experienced her stroke, what was the stroke protocol at that point in time? Because that might be helpful just if you could  
20 explain that, and then we can then look at what the different steps were in the rehabilitation and recovery.

MS REGAN: We were told that she would get fairly intensive physiotherapy while she was in the rehab ward, that she would get occupational therapy, and that she would get speech pathology as part of a holistic way of approaching all the aspects of  
25 Erin's particular stroke. And so that's kind of what we expected because we thought we had been written up for it.

MS EASTMAN: Okay. So she is in the rehabilitation ward for a period of six months – sorry, six weeks.

MS REGAN: Yes, six weeks.

30 MS EASTMAN: And - - -

MS REGAN: Actually – actually, I think she was in hospital for six weeks.

MS EASTMAN: Yes.

MS REGAN: So most of that was in the rehabilitation ward.

MS EASTMAN: All right. And so in terms of just the allied health professionals who were involved in her rehabilitation – with the speech therapist, you say that was great. The speech therapist saw Erin every day.

MS REGAN: That's right.

5 MS EASTMAN: In terms of physiotherapy, your understanding was that the hospital would provide physiotherapy once or twice a day.

MS REGAN: Yes, at least once or twice a day.

MS EASTMAN: There was one session in the whole six-week period; is that right?

MS REGAN: We got one. And I didn't understand why we weren't getting more.

10 And they weren't particularly helpful, but we were going to do whatever it took to find Erin's new life, and we – we just weren't offered another appointment. So I started to go to the nurses' table and say, "Oh, we haven't got our next appointment. I was out of the room for a few minutes. Did we miss when they came to get us," very politely but very insistently, and they just never got round to us again.

15 MS EASTMAN: You had the perception that maybe you had become one of "those" mums.

MS REGAN: Absolutely.

MS EASTMAN: That she thought that you might be a nuisance or - - -

MS REGAN: Troublemaker. Nuisance.

20 MS EASTMAN: You had that sense by just making those inquiries.

MS REGAN: I wear those badges with pride.

MS EASTMAN: Right. But you did, I think you say, had wonderful doctors and nurses.

MS REGAN: We did at that time.

25 MS EASTMAN: Who were very actively engaged in the rehabilitation process, and that they made a difference both in terms of what they did but also the attitude and the support that they provided for you and Erin; is that right?

MS REGAN: They did. We had some nurses who decided Erin needed some extra, and went out of their way. We had some doctors who treated Erin's medical  
30 conditions with care and with inclusion. But we also had some spectacular failures at that time.

MS EASTMAN: Okay. And one of the issues that you were turning your mind to during this six-week period was to not only assist Erin to recover her memory, her sense of herself but you also wanted to work to Erin recovering her opportunities to return to work, so her outside independent and even economic life; is that right?

5 MS REGAN: Yes. Not so much the economic life but certainly her inclusion with people outside the family was really important, and her to build her own life, as any young person might want to do.

MS EASTMAN: And so you went to the Commonwealth Rehabilitation Service to get some advice about rehabilitation in a return to work fashion. So your  
10 understanding was that the service at the time was responsible for getting people back to work after accidents, injuries and strokes.

MS REGAN: Mmm.

MS EASTMAN: So how did that experience go?

MS REGAN: I – in the nine-month stroke protocol, part of that was also going, if  
15 you had jobs, to the CRS to return to work. And I thought, “Great, Erin can return to work. What can we get?” We were – it took a bit to get an appointment. And then when we finally met, Erin and I, there were nine people in the room at our appointment because they wanted to tell us that they didn’t have the facilities, which is code for not a priority, not going to help.

20 MS EASTMAN: So did she have any assistance in terms of rehabilitation in that return to work sense?

MS REGAN: Nothing.

MS EASTMAN: Now, also in your statement you talk about the challenges of a  
25 neuropsychiatric assessment. And it took a long time to get that assessment, but when the assessment was done, it struck you as being inappropriate for people with intellectual disability, because there were some complex questions, it required Erin to finish some proverbs, and some of the questions were not appropriate. So this is something that you wanted to raise in terms of the way in which assessments might be made for people with intellectual disability who have experienced stroke.

30 MS REGAN: I do, because I wanted Erin to go through all the steps of her recovery. And the site of Erin’s stroke did affect aspects of Erin’s personality, and so it was very clear she needed a neuropsych appointment and specialist intervention. And to kick that off we needed an assessment, and to get that we were only able to get an assessment because the neuropsychiatrist or psychiatrist that I rang suddenly  
35 was interested but said, “We can’t offer you a place except if you can come at late notice for a cancellation.” Which we did. We got a call one day and we were there the next. And when we got there, we found a completely inappropriate assessment which didn’t deviate. There was no energy put into, how can I make this work? It

was just, “Fill this out.” However, the neuropsychiatrist was surprised and interested that we needed the same supports that anyone else would get, and was wanting to talk about why and what Erin’s life was like and what we hoped for Erin’s life.

MS EASTMAN: All right.

5 MS REGAN: But it also struck me that that neuropsych assessment would have been impossible for anyone with low literacy, who didn’t speak English as a first language, who had diverse cultures. Any of those groups, a very large number of people, would not have been able to go through that neuro, as it was then.

10 MS EASTMAN: Right. So then we move to after the hospital phase of rehabilitation and Erin comes back to live with you; is that right? And you decided that you were going to take her rehabilitation into your own hands.

MS REGAN: Erin can come back in now.

MS EASTMAN: Okay. She might have something to say - - -

MS REGAN: That’s right.

15 MS EASTMAN: - - - to the exercise program.

MS REGAN: Yes. Maybe they’ve gone for a walk.

MS EASTMAN: If you want – I’m happy to keep going until she comes in. It’s up – just let me know.

MS REGAN: You can continue. She can just come in. Yes, that’s fine.

20 MS EASTMAN: In terms of taking rehabilitation into your own hands, I think you say Erin hated doing exercises on her own.

MS REGAN: Yes.

25 MS EASTMAN: And so simply sort of saying, “Here’s a piece of paper, here’s the exercises to do” – you said, “Right. I think the best way to do this is at the supermarket.”

MS REGAN: We took - - -

MS EASTMAN: So you went to Woolworths. And how did the rehabilitation and Woolworths work?

COMMISSIONER SACKVILLE: I think Erin is coming.

30 MS REGAN: Here she comes. Good.

MS EASTMAN: Thank you, Erin.

MS REGAN: We decided to take a strengths-based approach – what’s Erin good at, what are her skills, what are they are talents, what is she interested in. And she hates exercise – so do I – but she loved grocery shopping. And so we found that we could  
5 do all the exercises we needed to do if we went to Woolies and I asked her to fill the trolley with her bad arm, and then I needed her to unfill the trolley, and we did that for two hours every day for months and months and months.

MS EASTMAN: You took a year off working didn’t you - - -

MS REGAN: Yes.

10 MS EASTMAN: - - - at this stage. You said, “I’m going to devote this year to Erin’s rehabilitation.”

MS REGAN: Yes.

MS EASTMAN: And so that was the daily trip to Woolworths and the trolley work. But it worked, didn’t it? It was – really helped her strength.

15 MS REGAN: She loved it. Yes, it cost us a fortune, but she loved it.

MS EASTMAN: This might have been pre the scanning.

MS REGAN: Certainly was.

MS EASTMAN: One interesting thing you raise in your statement is that at this stage Erin is 25 years old and that had some consequences in terms of your private  
20 health insurance. So up to that point in time she had been covered by your private health - - -

MS REGAN: The family, yes.

MS EASTMAN: - - - insurance and family.

MS REGAN: Yes.

25 MS EASTMAN: But once she turned 25, that was no longer available to her.

MS REGAN: No.

MS EASTMAN: And that you wanted her to have some private health insurance but the exercise of trying to find an insurer for her was nigh-on impossible, wasn’t it?

MS REGAN: As she became ineligible, she almost had the stroke almost immediately. And so it became a pre-existing condition, and that kind of knocked us out of any affordable health insurance.

5 MS EASTMAN: So that's a fairly stressful time that you've taken the year off work to support the rehabilitation, but it's also at that very time that the insurance wasn't available.

MS REGAN: That's right.

MS EASTMAN: So that was a pretty stressful time family-wise as well.

10 MS REGAN: Luckily my family decided to pool some money – a significant amount of money – to support Erin's rehabilitation, and that makes us privileged, but thank God they did, because that enabled us to continue with Erin's rehabilitation.

MS EASTMAN: The next thing I want to ask you – and you deal with this in some detail in the statement at paragraph 67 and following – we spoke a little earlier about how important music has been in Erin's life.

15 MS REGAN: Mmm.

MS EASTMAN: And also it's very significant, isn't it, in relation to her rehabilitation? What would you like to tell the Royal Commission about the matters that you've identified in your statement in relation to the importance of the music therapy?

20 MS REGAN: We clearly were not getting access to the regular forms of stroke recovery. My partner said using a strengths-based approach – what's she good at? Music. She could play the piano a little bit, she could play the drums before the stroke. My partner being a musician had found out that there was a music therapy centre opened in our local university, University of Western Sydney, newly opened.  
25 So he approached the centre and said, "We would like you to work with our daughter on stroke recovery." They initially just declined because that was not part of their initial brief. However, luckily it was in the early days and they did not have a full client load, and we said, "We will pay for whatever you think is right", and we had – they agreed, "Let's have a go." And we had three sessions a week. Two of those  
30 sessions we paid for. They weren't very expensive, as it turns out, because it was part of an experiment. And Erin's day program at that time decided to divert the money they weren't spending on Erin's day program and pay for one of those sessions as well. And we went to music therapy. It was brilliant because it was about body movement, it was about disciplined thinking with – with rhythms, it was  
35 about understanding the music, and it reached so many parts of Erin's rehabilitation, and she loved it. And frankly, so did I.

MS EASTMAN: But this is also then working with the day program allowing Erin to start to reintegrate outside the home, in terms of building up her base of her friends again and also having those outside stimuli; is that right?

5 MS REGAN: I'm very grateful to our day program. At the time it was against the rules to have someone in a day program spot because you weren't entitled to them then. You just got a spot if there was a vacancy. And if you didn't attend for two  
10 months in a row you would lose your spot. And if you lost your spot there was a two-year wait for another spot, which would have been adding insult to injury for us when we most needed that intervention. So they did two things. They spent – they paid for one of Erin's music therapy sessions each week – I think for about a year  
15 and a half or two years. And then they would bring some of Erin's friends from the day program over to our house for two hours twice a week. And she would – she didn't know who they were but she became familiar, which was excellent for people outside of the family.

MS EASTMAN: So the – just in summary, the rehabilitation was a long process and a very intense process for that first year after her stroke; is that right?

MS REGAN: I think for the first 10 years.

MS EASTMAN: 10 years it has taken.

MS REGAN: But most – most intensive in the first two years.

20 MS EASTMAN: All right. Can I jump now to ask you - - -

COMMISSIONER SACKVILLE: Sorry, can I just ask one question. You said that you were unable to get private health insurance because of the pre-existing condition. What sort of services did you have to pay for that would have been covered by private health insurance, had you been eligible?

25 MS REGAN: We paid very expensive private speech therapy because one thing we didn't cover was when we were discharged we were promised to have outpatient speech therapy, and we were promised that we were on the list, but they never got round to us, despite the fact that I rang up several times and they just said, "Oh, yes, you know", but a month had gone by, two months and we had no – so we knew then  
30 how we were being treated. And we paid for very, very expensive private speech pathology which brought Erin back. That was critical to Erin's recovery. The music therapy, I think also assisting with my – my family's money also assisted us to live because while we were at home it was quite expensive. We had many doctors and specialists' appointments at that time as well.

35 MS EASTMAN: So 10 years after Erin's stroke she had an episode of a major organ failure. That was in May 2013. Is that right?

MS REGAN: That's correct.

MS EASTMAN: And you've set this out in some detail in your statement. One thing I think you say is that your experience of the Nepean Hospital was a bit different this time. The doctors spoke directly to her. What was different and how did you feel that Erin was treated when she attended in May 2013?

5 MS REGAN: In 2002 at Nepean Hospital, good – a few good doctors and a few interested nurses would speak to Erin like a person. Mostly they didn't. Mostly she was a job and they just did whatever job, if they did the job. In 2013, suddenly Erin had a really terrible condition where she could not move and her body had swollen and it was pretty awful for a little while. But they spoke directly to her and they  
10 asked her questions, and when she couldn't answer, they asked her was it okay to speak to me. That's what should happen for an adult. And it was very, very different.

MS EASTMAN: And 17 years on you still see yourself in stroke recovery.

MS REGAN: Absolutely.

15 MS EASTMAN: And for Erin, what has that meant for her? And I know that we've done a little bit about life before the stroke and life after the stroke, but at the present time, how – how do you describe Erin's life?

MS REGAN: Erin has a good life. Erin has had a job in a coffee shop, which surprised us because she doesn't like coffee.

20 MS EASTMAN: She doesn't like coffee or tea, does she, but she likes coffee shops.

MS REGAN: She loves coffee shops. And so she had a job in a local coffee shop until that was sold. She – she's quite a different person. She has a medical regime that we didn't even have before the stroke. She has some conditions arising from the stroke or that are simultaneously occurred that we still deal with. But she's mostly in  
25 good health now. She can't – she doesn't understand stranger danger anymore because she's still a little uncertain about who she might have known or might not have known, whereas before she was totally solid with stranger danger, so she was safe on public transport. She – for example, if a bus came along, she may not be able to make a decision quickly enough to actually enter the bus. She would know it's a  
30 bus, but it would take too long and the bus – so there has been quite a lot of change. She's a little quieter, she's a little more self-contained, but she's still a person, and she's certainly a very different person from the person we were told to expect at the stroke.

MS EASTMAN: But you say in your statement that her energy continues to sustain you, and you don't see that because you think she's inspirational because she has  
35 Down syndrome - - -

MS REGAN: No.

MS EASTMAN: - - - but she's inspirational because she has prevailed against the naysayers, and you've been very impressed by what she has achieved. And you say there's a lot that we can learn from people with intellectual disability. And I'm just –  
5 in paragraph 89 I think is very important, about when we're born we rely on instinct and intuition. And you've got a view from what you've learnt by parenting and living with Erin about how her skill in that area has developed. What can you tell us about this?

10 MS REGAN: I've given this a lot of thought, but I don't – I'm not pretending to be an expert. It's just my opinion, but it's something that I've observed in my daughter and in friends of mine who also have an intellectual disability, but particularly from Erin. It strikes me that when you're born you rely mostly on instinct and intuition to navigate your life, and then as we get older we learn logic and reasoning, and we use logic and reasoning to make decisions, and we start to not rely so much on instinct  
15 and intuition. What I found with Erin – and some people like her but with Erin – she hasn't had the same access to logic and reasoning as others do. So she has continued to sharpen and hone her instinct and intuition, and I have come to rely and trust on Erin's instinct and intuition because she picks things up in human relationships and in situations.

20 MS EASTMAN: I think we've seen this today, haven't we?

MS REGAN: That I – I wouldn't be aware of or wasn't as cognisant of because I  
25 logicked it out or I reasoned it out when I should have possibly gone with my feelings. And in some other situations where I have had mentors – three I can think of – who are wise people with intellectual disability, they have that skill in spades, and it's something that I need to continue to learn.

MS EASTMAN: All right. Next you talk about being an advocate for Erin. And,  
30 as you say in your statement at paragraph 91, the quality of care for Erin has been so variable that many times that we've been to hospital for choking, seizures and other health issues, you say, "I believe that it comes down to doctors making social decisions for us rather than medical decisions," and that sometimes doctors cannot see past Erin's Down syndrome. And so this has caused you to have to be constantly on guard.

MS REGAN: Absolutely. In my statement I talk about how important our GP has  
35 been to us. She has been a godsend. And she ended up being the stroke coordinator because we asked her to be, and give me advice when I had conflicting specialists' opinions on what Erin should do. One thing, though, is I found that doctors have made a decision about Erin's worth to society, and given us advice shrouded in medical opinion that is really a social decision that has nothing to do with them. I rely on doctors for their medical opinion, for their understanding of medicine and  
40 understanding the body and all of that that I have no access to. That's their knowledge and expertise. I do not rely on doctors for their social opinions of what Erin should do and how she should be, because unless they have had some kind of

experience of Erin as a real person rather than the grief of an initial diagnosis of disability which is all they often see, then they've always got a negative or low expectation of people with disability, and particularly an intellectual disability.

5 MS EASTMAN: Okay. So the final bit I want to turn to is some of your suggestions for change and some outcomes that you'd like to see the Royal Commission consider. So one is the need for research. And you deal with this at paragraph 94. And you say before Erin's stroke she was prescribed a low-dose contraceptive pill.

10 MS REGAN: As many young woman were, for all the same reasons.

MS EASTMAN: And this is something that you've reflected on over the years because you are now aware that there are a number of young women with Down syndrome who are taking a low-dose contraceptive pill who have also had a stroke like Erin. So you're not saying that there's a connection, but you're saying there  
15 may be a need for some research about the impact of medication, or specifically a low-dose contraceptive pill for young women with Down syndrome. So what do you want to tell the Royal Commission about what you have discovered, but why, rather than just jumping to the conclusion, you want there - - -

MS REGAN: Yes.

20 MS EASTMAN: - - - to be some research in this area.

MS REGAN: Erin has Trisomy 21 Down syndrome. That means that every – every cell in Erin's body has an extra chromosome. She has got extra than us. So in lots of ways she should be more. That – it makes sense then that maybe medications affect her or impact her in a different way, but we're only just discovering that now. It  
25 seems to me that I should not know of 10 young women, all in their mid to early 20s on the low-dose contraceptive pill who have Down syndrome who have had massive strokes. That's statistically significant. So I thought, "If the low-dose pill is not indicated in women like Erin, then we need to know and not put more women at risk."

30 I did contact a Professor of intellectual disability at Queensland University, with whom I was connected, who said he would follow it up. He was in contact with a researcher in Spain. The research did not proceed. There was no money and no outside interest in progressing that. I suspect that's just the tip of the iceberg with some of the impacts of medications on various people with various conditions.

35 MS EASTMAN: Now, final thing is you've made some suggestions for change at paragraph 97 and following. So I'm not going to ask you any more questions. I'm going to hand over to you, and you can tell the Royal Commission for the matters that are set out there, what would you say are the key changes that you think need to be made.

MS REGAN: I could say that I think all doctors need to be trained. And I understand that whether or not that's realistic, but I do think that doctors need to be trained in the difference between medical decisions and advice and social decisions and advice. I would like to see very much exposure to different types of people as  
5 part of mandatory learning for doctors, rather than an experience they pick up on the way. I would also like to see support for doctors by experts, experts with lived experience of disability. Not me sitting here talking about Erin, but Erin's experience and others like Erin sharing their experiences.

Also, I would like to see a system of mentoring, of access to expert advice, of  
10 supervision as part of a medical professional's regular working life. But also, expert opportunities for centres of expertise where they can go for information. I'm very aware that if we expect doctors to know everything they've got to know, it's simply impossible. But knowing that you can go somewhere for information and having an attitude that includes everybody, are two things that you should start with, and that's  
15 something that should be expected of a doctor, a specialist, a GP at the very least. And in my statement I've set out how hospitals could – suggestions, very high-level suggestions about how hospitals could change some of their approaches to people with intellectual disability, and it should not depend on someone who happens to have a sister or a brother with an intellectual disability so you get a better deal. It  
20 should be just the same as any other citizen but with a little extra support, like everybody else gets at times.

MS EASTMAN: Can I ask you a question. You've said that it's important that we hear from Erin, and in this environment in the Royal Commission it's a fairly formal environment and we wanted to include Erin. How can we do that better?

MS REGAN: There's all sorts of ways. I know that you are speaking to some  
25 experts with Down syndrome who will be able to share things with Down syndrome, information, advice, suggestions, recommendations, about people with Down syndrome. But by that, I also mean other people with intellectual disability, people with cognitive disability, brain injuries, etcetera. The thing that I have benefitted  
30 from which I consider an absolute privilege in my life is having spent time with people. And that is invaluable. And it doesn't take a lot. It's just a matter of getting to know a person who looks different or acts different or thinks differently, as a person first, where you start to see how much you have in common. And then you can understand the difference that disability makes rather than looking at the  
35 disability, looking at the face or looking at the hands or looking at the body, because that's not what separates us. But it's what people make decisions based on, whether or not they're medical. We've got to relax that.

MS EASTMAN: Thank you very much for your evidence. The Royal Commissioners may have some questions.

40 COMMISSIONER GALBALLY: I would just like you to elaborate a bit more about the medical and your view about doctors sticking to the medical and the social

and, you know, thinking about – I thought you might have been thinking about advice on housing or advice on education.

MS REGAN: This is where I think the centres of expertise are critical. And thank you for the question. My GP has learned to speak directly to Erin even when she  
5 knows Erin might need support to provide an answer or maybe Erin will defer to me, because then Erin feels completely involved in her life regardless. Erin’s GP also knows that she doesn’t know everything and does not give advice on education and housing, etcetera, but can point me to where I need it, advocates, or can point me to other people who could provide that advice in a much more expert way.

10 Just like when you go to any service provider, they should not make a decision about who you are before they provide that decision to you – that service to you. They should provide the service to you that you’re requiring like any other person. Our GP can do that by opening up. “I’m not sure where to go with this. You have these options on the table. If you want my recommendation, I suggest this, but for these  
15 reasons, how do you go forward?” And it becomes a conversation rather than, “You should do this. You should do that. I’m a specialist, I’m a doctor, this is what I’m telling you to do.” It’s exclusive. It’s quite often wrong. It might be based on flawed experience, and it does not involve experts.

I just need to say Erin has taught me a lot about Erin and about intellectual disability,  
20 but I don’t consider myself an expert. And the reason I don’t consider myself an expert is because I don’t know what’s in Erin’s future life, and there are experts who know what to – what to know about, what to think about for a young woman like Erin in her future life and as she matures. And I will need that expertise from people to say, “These are some things you might be facing in the future. Have you thought  
25 about helping Erin to consider blah, blah and blah?” I don’t know what those are. I rely on people who have gone before us and who have that expertise. That’s the kind of access to expertise that I’m talking about.

The difference between the social model and the medical model, I rely on doctors to know what they do best. They don’t know about my life and they don’t know about  
30 Erin, but they might know about Erin’s body and they can give us that advice because I don’t know it. For social decisions, I might go to another set of experts. I might go to my family, I will first ask Erin, but I might also talk to other people who have experience with Down syndrome or who work with Down syndrome or are family members, or who know what’s in Erin’s future, and I might then consider,  
35 with Erin, what decisions confront us, present to us. That’s a social decision, a decision about Erin’s life separate from Erin’s medical. Is that clear?

COMMISSIONER GALBALLY: Yes, thank you.

MS REGAN: Oh, good.

COMMISSIONER SACKVILLE: I know you’re speaking in your personal  
40 capacity and not in your role as the State Director for NDIS Quality and Safeguards

Commission, but I notice that your statement and evidence hasn't referred to the NDIS. Has that played any role?

MS EASTMAN: No, I've – I've – sorry, I've been quite deliberate in relation to not covering that issue because Ms Regan is only speaking in - - -

5 COMMISSIONER SACKVILLE: I understand that.

MS EASTMAN: - - - her personal capacity.

COMMISSIONER SACKVILLE: I understand that. But isn't it a matter for Ms Regan to determine?

10 MS REGAN: I – I can – I can say, separate to my role, my daughter does use the NDIS.

COMMISSIONER SACKVILLE: Yes.

MS REGAN: And I love to think I was part of the campaign to bring in - - -

COMMISSIONER SACKVILLE: I was more interested in any difference it has made to - - -

15 MS REGAN: Oh.

COMMISSIONER SACKVILLE: - - - her life is what I'm really asking about.

MS REGAN: Absolutely.

COMMISSIONER SACKVILLE: Yes.

20 MS REGAN: The difference is – and it's really clear – we – years before the NDIS we decided that we needed an independence worker. And some of that was as part of Erin's recovery, someone who wasn't us, who could get to know Erin, same age as her, who would separate what her family thinks she should do from what Erin as a person thinks she should do. As a mother, I think I'm pretty groovy and sophisticated, but you don't want your mother to do your life plan, you want to do  
25 your own, you're different. We wanted a way for Erin to find her voice. So we employed privately, for only a short time because we couldn't afford it, an independence worker. And she was the one that suggested Erin loves coffee shops. And we would never have thought of that, and it opened up lots of doors. Since the NDIS, we had always planned Erin would move into her own place and be  
30 separately supported before we came to too late in life and that became a tragedy. There is no way prior to the NDIS that Erin would have had access to supported accommodation, despite the fact that I'm now in my early to mid-60s, and I didn't want a tragedy to befall Erin and suddenly she not only would lose the people that

she's most familiar with but also her environment, and we don't expect that of anyone else but we still do that to our people with disability. And so that has been opening up, as well as other opportunities like now an independence worker who can work with Erin on her own independence in a way that doesn't involve her family.

5 It's so critically important. And those are just two of the things that the NDIS has offered us and how it's enhanced our life.

COMMISSIONER SACKVILLE: Thank you very much for that. You have caused me to incur the wrath of senior counsel, but I will have to manage that with as much fortitude as I can muster.

10 MS EASTMAN: Well, for that purpose, it might be appropriate if we adjourn for 20 minutes.

COMMISSIONER SACKVILLE: Yes. I know Erin is not - - -

MS EASTMAN: And thank you, Mrs Regan.

15 COMMISSIONER SACKVILLE: Erin is not here at the moment, but I would like, on behalf of the Commission, to thank her for coming to the Commission and letting us share her life experiences and her achievements. So would you pass on to Erin - - -

20 MS REGAN: I will. And one thing I didn't say at the beginning, if I may, I have asked Erin's consent to share the story. Some of these parts belong to me, so I didn't need it, but most of that is Erin's story, and we agreed what I could share before we wrote the statement.

COMMISSIONER SACKVILLE: And I would like to thank you on behalf of the Commission for both your statement and coming and giving the evidence which I can say resonates with us and is extremely important for our work. Thank you very much.

25 MS REGAN: Thank you. Thank you for having me.

COMMISSIONER SACKVILLE: We will now adjourn, and I will face the wrath of Ms Eastman.

30 <THE WITNESS WITHDREW [11.13 am]

ADJOURNED [11.13 am]

RESUMED [11.39 am]

COMMISSIONER SACKVILLE: Yes, Ms Eastman.

MS EASTMAN: I think I had failed to formally tender Ms Regan's statement, and I think I mentioned it would be marked exhibit 4.11. So if I can formally do that.

COMMISSIONER SACKVILLE: All right. I will forgive you if you forgive me.

5 **EXHIBIT #4-11 STATEMENT OF CHRISTINE REGAN DATED 13/02/2020  
(STAT.0059.0001.0001)**

MS EASTMAN: Thank you. Of course. But more importantly, Lorraine Clark is the next witness. So she's going to give her evidence now. If she could be sworn.

10 COMMISSIONER SACKVILLE: Thank you very much.

**<LORRAINE GAYE CLARK, SWORN**

**[11.40 am]**

**<EXAMINATION BY MS EASTMAN**

15

COMMISSIONER SACKVILLE: Please sit down. Thank you very much.

MS CLARK: Thank you.

COMMISSIONER SACKVILLE: Ms Eastman will now ask you some questions.

MS CLARK: Thank you.

20 MS EASTMAN: So your name is Lorraine Gaye Clark.

MS CLARK: That's correct.

MS EASTMAN: And you're an event manager for the Festival of Sport for the Special Olympics in New South Wales; is that right?

MS CLARK: That's correct.

25 MS EASTMAN: And you prepared a statement for the Royal Commission dated 12 February this year.

MS CLARK: Yes.

MS EASTMAN: And the contents of the statement are true and correct?

MS CLARK: They are.

MS EASTMAN: And you've come to give evidence in relation to your daughter, Gabrielle.

MS CLARK: Yes.

MS EASTMAN: And we might start with Gabrielle, if that's convenient. So  
5 Gabrielle is your youngest daughter.

MS CLARK: Yes.

MS EASTMAN: And she has lived with you at home until January last year; is that right?

MS CLARK: That's correct.

10 MS EASTMAN: Gabrielle is 44 years old.

MS CLARK: Yes.

MS EASTMAN: And she lives with Down syndrome.

MS CLARK: She does.

MS EASTMAN: So we're to talk about Gabrielle's current circumstances and her  
15 experience with the medical and hospital systems. But before we do that, I want you to talk a little bit about Gabrielle. She is a very strong advocate for people with Down syndrome but quite a talented athlete in her own right.

MS CLARK: Yes.

MS EASTMAN: Is that right?

20 MS CLARK: Yes, she is.

MS EASTMAN: Tell us about Gabrielle. And we've got some photographs. So you let me know when you would like any of the photographs to come up.

MS CLARK: Gabrielle has always been an intuitive young woman, I guess I could say. When she was born we were a little bit taken aback, but nevertheless we  
25 celebrated her birth and I – my – my husband had a meeting with all our friends – excuse me.

COMMISSIONER SACKVILLE: Take your time.

MS EASTMAN: Do you want me to jump in a little bit here?

MS CLARK: Yes, please. Yes.

MS EASTMAN: Okay. So when Gabrielle was first born, you were a little taken aback.

MS CLARK: Yes.

5 MS EASTMAN: And your husband said, "Right. Well, this is the situation", and he gathered all your friends together and he said, "This is Gabrielle. She's our daughter. This is how we want you to treat her."

MS CLARK: Yes.

MS EASTMAN: "And we want you to support us."

MS CLARK: That's right.

10 MS EASTMAN: "She's part of our family, and this is what it is." So something like that. I think I've - - -

MS CLARK: Absolutely.

MS EASTMAN: - - - probably paraphrased. But it was this sense that immediately after her birth, is that notwithstanding the shock and surprise to you, this is your daughter, she's central, part of your life and part of your family and part of your broader community.

MS CLARK: Yes.

MS EASTMAN: Is that right? So Gabrielle has been a very strong person since the beginning. I think when she was born the first thing she did was poke her tongue out.

MS CLARK: That's right, at me. Yes.

MS EASTMAN: At you. And so you said, "Right. This is the beginning of - - -"

MS CLARK: Yes.

MS EASTMAN: "Of a very strong person who is going to be a very strong young lady."

MS CLARK: Yes.

MS EASTMAN: So can I just ask you a little bit about Gabrielle's early life.

MS CLARK: Yes.

MS EASTMAN: So she was sick for a long time, wasn't she, after she was born?

MS CLARK: She was. She had – she had a lung condition, and she got – I think she got croup six weeks – not – whooping cough, I’m sorry, six weeks after she was being – had been vaccinated against it which kept her in children’s hospital for quite some time. And she had numerous bouts of pneumonia, and bronchitis, and, you  
5 know, croup. And she also had facial cellulitis which was, you know, was very, very hard to – to manage and required a lot of IV antibiotics. So, yes. But - - -  
MS EASTMAN: She had a pretty good paediatrician you say in your statement.  
MS CLARK: She had an excellent paediatrician. And he was very concerned about her taking so many antibiotics so he referred me to an iridologist and naturopath,  
10 which I was a bit taken aback with, but nevertheless we went along and she made up this – it was a potion of minerals and vitamins for Gabrielle and it absolutely reeked, it stunk. It was the worst thing I’ve ever smelled in my life and – but Gabrielle – we said, “You have to take this because this is going to be good for you and you’re going to get better.” So she just skolloled it like it was a good shot of whiskey, but - - -  
15 MS EASTMAN: And it did the trick, so to speak.  
MS CLARK: It did the trick. It did the trick. The iridologist interesting – showed me a photo of her eye where she had all these dots around her eyes and she said, “Well, that’s all mucus. But after you’ve taken this medication for a while, that should move”, and those dots are no longer in her – her eyes these days.  
20 MS EASTMAN: So before Gabrielle started school - - -  
MS CLARK: Yes.  
MS EASTMAN: - - - you had a number of friends who were teachers.  
MS CLARK: Yes.  
MS EASTMAN: And Gabrielle became a little bit of their project, but she learnt to  
25 read before she went to school; is that right?  
MS CLARK: She certainly did. She did.  
MS EASTMAN: And when - - -  
MS CLARK: We had – we had sight cards. So if Gabrielle wanted a cup of water, she would say, “Can I have a c-u-p, cup, please.” And so everything around the  
30 house was identified by Gabrielle spelling it out first, and – and that’s how she learnt to – to read.  
MS EASTMAN: And to the best of your knowledge, she became the first person living with Down syndrome in Australia to go to a mainstream public school.

MS CLARK: That's correct.  
MS EASTMAN: So she started at Collaroy Plateau Public School.  
MS CLARK: She did.  
MS EASTMAN: And she was just over five years old.  
5 MS CLARK: That's right, she – yes.  
MS EASTMAN: And as far as you're aware at that time when she started school,  
that it was usual for children with Down syndrome to either go to a special school or  
be home-schooled; is that right?  
MS CLARK: That's correct.  
10 MS EASTMAN: But you were fairly keen for Gabrielle to go to the local primary  
school.  
MS CLARK: Yes, and I - - -  
MS EASTMAN: And not only that, she had to walk to school every day with her  
sister; is that right?  
15 MS CLARK: That's correct, yes.  
MS EASTMAN: So no special treatment in terms of - - -  
MS CLARK: No.  
MS EASTMAN: - - - special schools or how she got to school.  
MS CLARK: No.  
20 MS EASTMAN: Is that right?  
MS CLARK: And she was very well accepted at school. She got special treatment  
at school because the teachers thought she was so cute they let her do whatever she  
wanted. So sometimes she was teaching.  
MS EASTMAN: All right. And Gabrielle's early life was one very much focused  
25 on sports.  
MS CLARK: Yes.  
MS EASTMAN: So she did Little Athletics.

MS CLARK: She did.  
MS EASTMAN: And she joined the local surf club.  
MS CLARK: Yes.  
MS EASTMAN: So she did nippers.  
5 MS CLARK: Mmm.  
MS EASTMAN: She became a cadet.  
MS CLARK: Yes.  
MS EASTMAN: She swam in the surf races every Sunday.  
MS CLARK: Yes.  
10 MS EASTMAN: And she had a deal of success as a swimmer; is that right?  
MS CLARK: That's correct. She's actually – Gabrielle has competed in swimming  
at Pan Pacific Games and won quite a lot of medals over the years at swimming.  
She's ventured on from swimming to ten-pin bowling, and – and then golf. And she  
– she's travelled overseas playing golf.  
15 MS EASTMAN: Can I put some photos up of Gabrielle?  
MS CLARK: Yes, sure. Thank you.  
MS EASTMAN: With some of her medals.  
MS CLARK: Yes.  
MS EASTMAN: And I think you've got a photo you've given the Royal  
20 Commission of her bowling.  
MS CLARK: Yes.  
MS EASTMAN: All right. So she's got a few medals around her neck there. Can  
you tell us what they are?  
MS CLARK: Yes, that's – that's her – when she came back from the Pan Pacific  
25 Games where she represented in New South Wales in swimming and athletics.  
Those medals are all from swimming. Two gold, a silver and a bronze.  
MS EASTMAN: All right. And then the next photo is a photo of Gabrielle in  
action bowling.

MS CLARK: Yes.

MS EASTMAN: Is that right?

MS CLARK: She's got a great style. And she gets lots and lots of – knocks over what she calls strikes and turkeys.

5 MS EASTMAN: Right. Okay. You might have to explain that to me later.

MS CLARK: A turkey is if you get three strikes in a row.

MS EASTMAN: Okay. So Gabrielle's early life at school was school plus athletics and sports.

MS CLARK: Yes.

10 MS EASTMAN: And when she was eight, her school changed; is that right? She went to a special boarding school.

MS CLARK: That's right. When she went into – when she went into – was due to go to primary school – because Collaroy Plateau School did not have a vacancy for her in primary school. It was a higher level. So she went – she started at Narrabeen

15 Lakes Primary School, but the headmistress there wasn't very keen on Gabrielle because Gabrielle looked different to all the other children that were in the support class. So she – after six weeks she said, "I think that you need to find a better school for Gabrielle to go to."

MS EASTMAN: So Gabrielle then went to the local high school.

20 MS CLARK: She went to Kingsdene Special School for – for primary, and then she was at Kingsdene – she would live in – Dad would – Jon would drive her to school on Monday and bring her home Sundays. And – and then – sorry, and bring her home Fridays. And she was there until she was ready to go into high school, and the headmaster approached Jon and I and said that he thought that Gabrielle should

25 actually go to mainstream high school. So she was enrolled at Freshwater High.

MS EASTMAN: And that's where she completed her high school years, is that right?

MS CLARK: Yes, she – she – she did. She got a certificate of attainment for a high school certificate, and she got her school certificate.

30 MS EASTMAN: And you say in the statement that she didn't experience any bullying when she was at school; she was accepted.

MS CLARK: Not at school. She – she – she was very accepted. And I think one of the reasons that Gabrielle was accepted more so is because she was very, very

socially aware. She's a very socially aware young woman, and she participated in sports and she was a great sportsperson and she held her own and she – and people thought that, you know – that she was pretty good, and so did we.

5 MS EASTMAN: She did training every day. So she was a very fit young woman, wasn't she?

MS CLARK: Yes, she is, extremely fit.

MS EASTMAN: But when she was 13, a health issue arose which made some changes for her in some respects. So when she was 13, she started to gain some weight.

10 MS CLARK: Yes.

MS EASTMAN: And she was diagnosed with Hashimoto's disease; is that right?

MS CLARK: That's correct, yes.

MS EASTMAN: And you say in your statement that that's a condition where your immune system is attacked through your thyroid.

15 MS CLARK: Mmm.

MS EASTMAN: And that can lead to an underactive thyroid.

MS CLARK: That's correct, yes.

MS EASTMAN: Right.

20 MS CLARK: And she – she – she gained a lot of weight and that was troublesome for her. She didn't – she didn't like the fact that she had to put so much effort into the work she did. She tried very hard to lose the weight, and we were backwards and forwards to the endocrinologist for quite some time before they were able to get a positive – apparently he said it was very hard to pick up the thyroid inaction in people with Down syndrome, and so she had to go backwards and forwards to have  
25 lots of different blood tests at different times of the morning and on fasting and all that sort of thing. So it was about three months before they actually got a proper diagnosis.

MS EASTMAN: Okay. And before Gabrielle was 13 and the diagnosis of Hashimoto's disease occurred, how had Gabrielle's health been before that? And I  
30 might, just before – if you can slow down a little bit.

MS CLARK: Sorry.

MS EASTMAN: Just so that the interpreters can keep up with us.

MS CLARK: Okay. So Gabrielle had, as I said before, she had flus, she had a little bit of facial cellulitis, but, basically, she had just a few sniffles. She had been in hospital with pneumonia on several occasions, as – as I said before. But because she was training and she was – her swimming all the time, her – her lung capacity

5 developed much, much better. And she still, to this day, has a lot of scarring on the left side of her lung, but that's from the pneumonia, but it doesn't impact on her breathing or anything like that. I – I would say that her health in her teenage years was probably the best it's ever been, except for the Hashimoto's.

MS EASTMAN: And then when she finished school, she went on to get a job; is

10 that right?

MS CLARK: Yes, she did. Yes, she did.

MS EASTMAN: And so she held the same job for about 14 years.

MS CLARK: She did.

MS EASTMAN: And that involved setting up computers, meeting, greeting clients

15 and performing administrative duties.

MS CLARK: Yes, she worked for a payroll computer company, and so they had clients that would come in and do the training, so Gabrielle would set up the training rooms, turn the computers on, meet and greet clients. She did a little bit of admin work on reception, answering the phone, and she also helped out her – her

20 responsibility was also keeping the staffroom clean and tidy.

MS EASTMAN: And after – I think there might have been a new boss coming into the business.

MS CLARK: Yes.

MS EASTMAN: She had a few issues in her workplace, and that really dented her

25 confidence a little bit; is that right?

MS CLARK: It did. She – she – she had a really great relationship with everybody at work, and when she went to this company she was actually head-hunted by the managing director who had seen her speaking at a forum. And they – they brought her in and she was trained and she had a wonderful time there. She worked five days

30 a week, from 8.30 till 11.30, and she had a great rapport with everybody that she worked with. But a new lady came along, and she was the new manager, and she made it very, very obvious that she really didn't understand Gabrielle, but also that she didn't particularly want to work with Gabrielle.

MS EASTMAN: So Gabrielle made the decision that she'd had enough, and she

35 decided - - -

MS CLARK: She did.  
MS EASTMAN: - - - to resign.  
MS CLARK: She – she was bullied for six months. She went away to the National Games in Adelaide to – to compete in golf, and when she came back she decided to –  
5 she went – she told Jon and I, she came home and said, “Well, I’ve done it. I’ve resigned. I’m leaving.”  
MS EASTMAN: That’s a decision she made?  
MS CLARK: She made that decision. She did.  
MS EASTMAN: All right. So on more positive news for Gabrielle, while she was  
10 working she was also doing a lot of work as a volunteer.  
MS CLARK: Mmm.  
MS EASTMAN: She was an ambassador for the Special Olympics here at Homebush.  
MS CLARK: Yes.  
15 MS EASTMAN: Was that in 2000?  
MS CLARK: Yes.  
MS EASTMAN: And she’s also spent many years of her life being an Australia Day ambassador.  
MS CLARK: That’s correct, yes.  
20 MS EASTMAN: And in terms of all of the events that she needed to go to, all her speaking engagements, she did all of that independently; is that right?  
MS CLARK: Yes, she did. She used to travel for – we live at Narrabeen. Gabrielle used to catch the bus to Wynyard, and then she would catch the train and another train to get out here and work out here at Homebush.  
25 MS EASTMAN: And so she has often given speeches to support and to advocate on behalf of people with Down syndrome; is that right?  
MS CLARK: She has. Gabrielle has had a very active role in World Congresses for people with Down syndrome.  
MS EASTMAN: So we - - -

MS CLARK: And she was invited by the Minister for Disability in Israel to go there and speak at a conference. She has spoken in Paris, London, Madrid, New York, Florida. She's – she's been an avid advocate for people with Down syndrome, and she used to talk about – she's written a paper that has been published on – in several  
5 languages on the social image of the person with Down syndrome, and she says in her words that people with Down syndrome are human beings. "We're just like everybody else. We laugh, we cry, and we love life."  
MS EASTMAN: So I think we've got a photo of Gabrielle in action giving a speech. Do you remember what this was about?  
10 MS CLARK: Gabrielle - - -  
MS EASTMAN: Maybe you didn't go to that one.  
MS CLARK: Yes. No, no. She spoke at a – I did. I was at – it was Sydney Convention Centre, and there were about 1800 delegates in the room, and she spoke and she got a standing ovation.  
15 MS EASTMAN: You're very proud of Gabrielle, aren't you?  
MS CLARK: I'm extremely proud of her. I'm very, very fortunate to have Gabrielle in my life, yes.  
MS EASTMAN: So I want to now move to some issues which I know are distressing, and if you need a break at any time or you would like me to read any part  
20 of the statement, just let me know.  
MS CLARK: Mmm.  
MS EASTMAN: So we're going to move to 2013. And in that period, 2013 to 2015 there are a few health issues that arose for Gabrielle.  
MS CLARK: Yes.  
25 MS EASTMAN: These are in your statement starting at paragraph 31. And so Gabrielle was doing some work in her ambassadorial role, and she had done an event with one of the television stations in the morning, and then while she was doing, I think, one of her speeches, she collapsed while making the speech.  
MS CLARK: Yes.  
30 MS EASTMAN: Is that right?  
MS CLARK: This was – in 2013 the Asia Pacific Games for Special Olympics were held at Newcastle, and Gabrielle was involved as an athlete leader, and she was up there with a couple of other athletes. They were welcoming all the overseas

delegates that came in, and – and delegates from around Australia. She worked at the Healthy Athlete Program. They do a lot of promotional work in Newcastle leading up to the games. And then she was – worked with Peter Overton in welcoming people to the games. And they didn't get home until really late. It was  
5 very, very hot in Newcastle as well that time of the year, because it was December, and Gabrielle had to be at – on the Young Endeavour at 7.30 the next morning to meet and greet clients, and she was – not clients, sorry, guests – and she was delivering a speech when she passed out, fell backwards, and ended up in John Hunter Hospital.

10 MS EASTMAN: She had to be taken to hospital. She was there for one week.  
MS CLARK: She was. She was in the cardiac unit because her heart rate was fluctuating between 37 to 45 over - - -

MS EASTMAN: And the result was that the doctors recommended that she may need to increase the dose of her thyroid medication.

15 MS CLARK: Yes. They said that it – it – after all that time that they didn't think it was her heart, that they thought it was her thyroid.

MS EASTMAN: And so once the medication dosage had increased, you say in your statement at paragraph 34 that there was a change in Gabrielle's personality.

MS CLARK: There was.

20 MS EASTMAN: And that she had anxiety, panic attacks, self-doubt, depression, and she was withdrawn.

MS CLARK: She had all of those. All of the above. She also seemed to lose a little bit of her confidence. She wasn't as confident. She was more – wondering if she was going to pass out again, and wondered – she would say, "Sometimes people look  
25 at me differently, you know", and we would just put that down to her just being a little bit anxious, but her anxiety also, at times, stopped her from doing the things that she – she loved doing, or – and more about – it was more about her not wanting to embarrass her friends or make her friends feel bad if – if something happened to her.

30 MS EASTMAN: All right. And then this resulted in her being prescribed some antidepressant medication, and your view was things were worse.

MS CLARK: It – she was prescribed – she was put on an antidepressant, and it – it changed her. I didn't notice the change so much in the beginning. I thought it had just calmed her down. I know – and there were a lot of things going on so I thought,  
35 "(a) you're not working in the environment that you – you love so much and, you know, you – you sort of – you're getting a little bit older and, yes, this Hashimoto's and all these drugs are sort of having a diverse effect." That's what I – I thought.

We spoke about them and – to the doctor and our family doctor is very, very supportive, and she would have blood tests and – and having blood tests for a lot of people with Down syndrome is very, very difficult because they have very, very small veins, and it's – it's a bit of a process in trying to get the blood.

5 So Gabrielle just wasn't herself. We – you know, we didn't – we were concerned. We took her to counsellors, we took her to other specialists, but it was the anxiety and the panic attacks. She would just, for no reason, decide that she wasn't going somewhere, which was just completely alien for – for Gabrielle.

10 MS EASTMAN: Right. Then in your statement you talk about her health during the period 2015 to 2017. But in late 2017, she was eased off antidepressants and you say in the statement she came good.

MS CLARK: Yes.

MS EASTMAN: But in September 2017, she collapsed in her bedroom.

MS CLARK: Yes.

15 MS EASTMAN: And you took her immediately to the Mona Vale Hospital. So she was admitted there.

MS CLARK: Yes, we – we – we called the ambulance. We had to call the ambulance because she actually passed out.

MS EASTMAN: And she was examined by a neurologist; is that right?

20 MS CLARK: Yes. Yes.

MS EASTMAN: And there were some CT scans done.

MS CLARK: Yes.

MS EASTMAN: And the issue there was whether or not she had developed epilepsy; is that right?

25 MS CLARK: When – when she first went to the hospital, they thought that, again, it was the – the heart because of the – the low heart rate. But they said that they wanted us to see a neurologist. They thought that there could be a possibility that it – it may have been a seizure. However, it was a drop and what they called a hypoxic state because her blood pressure was 80 over 40. And they hydrated her through a drip for a few days and then discharged her. So – but we did go and – and consult  
30 the neurologist. Jon and I took Gabrielle to the neurologist, and he said that although the CT scans were clear, there was a fifty-fifty chance that she would develop epilepsy.

MS EASTMAN: Epilepsy. And that then led to a discussion about what medications she might take, and you received a five-page printout listing possible side effects, and you decided that you were not going to put this out.

5 MS CLARK: Well, to this one medication. He – he – he – he said he wanted her to start on Lamictal, and that it was a fairly new drug but there were some side effects, and he wanted us to read them. And I said to him, “What’s the worst side effect?” And he said, “Oh, well, if she gets a bad rash, you have to stop because it could – you know, it could cause further implications.” And one of those implications was possible death.

10 MS EASTMAN: And so a decision was made not to put her on the medication; is that right?

MS CLARK: Jon and I read the – the paperwork over and over again, and we were firmly convinced that it wasn’t a seizure, and I have in – in working with athletes with disabilities witnessed grand mals and petit mals and myopic seizures. And there was – there was none of that. When Gabrielle dropped, she just passed out. There was no incontinence, there was no seizure, there was no – no, you know, pulse – thrashing around, I’m sorry, on the ground. It was just Gabrielle’s eyes would go back into the back of her head and she would go to sleep.

MS EASTMAN: And Gabrielle is still living with you at this stage?

20 MS CLARK: No, Gabrielle is not living with - - -

MS EASTMAN: Where was she – no, no, at this point in time.

MS CLARK: Yes, yes, yes.

MS EASTMAN: Back in - - -

MS CLARK: Yes.

25 MS EASTMAN: - - - 2017.

MS CLARK: Absolutely.

MS EASTMAN: She’s still living with you?

MS CLARK: Yes, she was.

30 MS EASTMAN: All right. So after that admission in September 2017, she came back home and then she had a further bad drop in February 2018; is that right?

MS CLARK: That’s correct, yes.

MS EASTMAN: So she's at home with you and, again, you call the ambulance and take her back to Mona Vale Hospital.

MS CLARK: Take her back to Mona Vale Hospital, and - - -

5 MS EASTMAN: All right. And this time, what happened in terms of any testing and any diagnosis?

MS CLARK: Well, they – they – once again, they did a CT scan. This time they did with dye. Doctor told Jon and I there was no impairment on her brain, that there was a tiny little spot that – the size of a pin head at the back of the brain, the bottom part, and that that was like normal, a lot of people have that. It's like a calcification.  
10 So he wasn't perturbed about that at all and – but he did say, "I think the time – you have to go back to the neurologist."

MS EASTMAN: So that then resulted in a trial of the medication for a period of time; s that right?

MS CLARK: It did. It did.

15 MS EASTMAN: And that resulted in Gabrielle's personality changing completely. You say - - -

MS CLARK: Absolutely.

MS EASTMAN: - - - she became aggressive. It was like she had Tourette's, and - - -

20 MS CLARK: Yes.

MS EASTMAN: - - - she started to swear frequently, and you've never heard her say or behave this way.

MS CLARK: No.

MS EASTMAN: So that caused you real concern, didn't it?

25 MS CLARK: It did cause me real concern because she absolutely – she lives – my – my two grandsons live with us, and she absolutely adores them, but she got very, very aggressive, not only to them. She – she was aggressive towards me. She punched me in the face one day and broke my glasses, and I ended up with a black eye, and she would go hysterical, and the only way that you could calm her down  
30 was I would – Jon or I would just hold her and reassure her. She would cry. She would say, "I'm sorry, I'm sorry", and just lash out.

MS EASTMAN: And from this, then, a month later there was another grand mal seizure.

MS CLARK: Yes, there was.  
MS EASTMAN: And that resulted in another hospital admission - - -  
MS CLARK: Yes.  
MS EASTMAN: - - - and a change of medication.  
5 MS CLARK: Yes. The - - -  
MS EASTMAN: But still even with the change of medication, Gabrielle was still  
angry and aggressive.  
MS CLARK: Yes.  
MS EASTMAN: Is that right?  
10 MS CLARK: Yes. Yes.  
MS EASTMAN: So then a third medication was trialled, and that had similar side-  
effects as well. So this was - - -  
MS CLARK: It had more – she became a little bit psychotic, and, you know, had  
rages where she would scream, but she also would go and she would shoot hoops for  
15 three hours in the backyard, just continually shooting hoops because that was the  
way that she could keep herself calm.  
MS EASTMAN: You say in paragraph 51 of the statement that Gabrielle became  
psychotic.  
MS CLARK: Yes.  
20 MS EASTMAN: And you say it was horrific.  
MS CLARK: It was.  
MS EASTMAN: I had to hold her to stop her from harming herself or anyone else.  
MS CLARK: Yes. Yes.  
MS EASTMAN: And you spent most of your time with your arms wrapped around  
25 her rocking her back and forth and telling her she would be okay. So was Gabrielle  
really frightened at this stage for herself?

MS CLARK: She was frightened, and she didn't understand what was happening to her and, you know, it – it scared her. And it scared her how she was reacting to the members of the family who she loved dearly.

5 MS EASTMAN: So what – just pausing, looking at this period of time and you – and she's prescribed a range of different medications – what advice or information did you have about side-effects of medication, particularly for a young woman with an intellectual disability?

10 MS CLARK: Well, we would ask the question. Jon and I would go to the specialist with her all the time, and we would ask the question, "Is this a side-effect?" And we would get, "Well, yes, it – it could be. It's been known to do that so we will just change her and put her on – on another one." But the trouble is when – with epilepsy medication that we found out that you can't just stop taking one and go on to the next one. There is an ease-off and an ease-on. So you're taking a mixture of two drugs in – in – and it's usually a three to four-week period that the next drug kicks in and you completely come off the other. So you have to cut the dose down. It depends on  
15 what the dose is. And Gabrielle was on 250 micrograms of a morning and 250 micrograms of an evening.

So they start off changing – cut it back by 50 micrograms, and increased the other one by 50 micrograms until you build up and you – you know, you come down completely. It's – it's a long, drawn-out process, and I don't know that, in my  
20 opinion, looking at her, she ever had a period where – during all this transitional process that she had a period where she wasn't confused.

MS EASTMAN: So by September 2018, Gabrielle had had an MRI.

MS CLARK: She had.

25 MS EASTMAN: And that showed no signs of scarring or damage to her brain.

MS CLARK: Yes.

MS EASTMAN: And so after discussions with your family doctor and one of the neurologists, you decided to ease her off all medication; is that right?

MS CLARK: Yes, absolutely.

30 MS EASTMAN: And by October, you started to see a great improvement in her and she was once again able to engage with everyone at home.

MS CLARK: Absolutely. And she – she would want to be involved, where before she would be quite happy to just sit in her room or sit out on the back balcony looking at the lake, and just drinking her water and flicking pages after pages in her  
35 book. So she actually would come downstairs and she would want to be engaged, "Can I set the table?", she – you know, when she asked me if she could do that after

the period that we had been through, I think I had to sit down and catch my breath, and I said, “Absolutely. Absolutely.”

MS EASTMAN: And so Christmas 2018 was a pretty important Christmas for you and the family.

5 MS CLARK: It was.

MS EASTMAN: It was a good Christmas. Gabrielle had a beautiful smile on her face and was fully engaged with the family.

MS CLARK: Absolutely. And she – she posted on her Facebook page a photo of her with a Christmas hat on wishing all her friends merry Christmas and saying, “The  
10 good news is I’m off the epilepsy medication. And I’m doing good. And I know that 2019 is going to be my year.”

MS EASTMAN: Yes. All right. So we get to 2019. And we’re pretty close into the early days of 2019 - - -

MS CLARK: We are, yes.

15 MS EASTMAN: - - - on 6 January.

MS CLARK: Yes.

MS EASTMAN: Tell me if you need a break - - -

MS CLARK: I’m fine.

MS EASTMAN: - - - at all.

20 MS CLARK: I’m fine.

MS EASTMAN: So on that day, you and Jon were woken up by Gabrielle crying.

MS CLARK: Yes.

MS EASTMAN: And you went into her room and you found her slumped over her bedside table, and she was wet - - -

25 MS CLARK: Yes.

MS EASTMAN: - - - shivering and she had a bruise on her eye.

MS CLARK: Yes.

MS EASTMAN: And she also had an injury to her head.

MS CLARK: That's right. She'd obviously – well, we think that she had a seizure, and she fell over her bedside table. She was – wasn't aware of what had happened. All she was aware of was that she had wet herself in the process and she was deeply humiliated and very cold. So I put her in the shower and warmed her up. And then I  
5 said to her, "Would you like to get into my bed?" And she got into my bed and she went back to sleep. She woke up. I gave her something to eat. And then we – I said to her, "Would you like to watch – your favourite show is on television, which was The Mighty Ducks. And I said, "Would you like me to put your show on?" And she said, "Yes." So she was watching that and – I thought she had thrown her head back and was laughing, but she had thrown her head back and she was – she was having a  
10 massive seizure.

MS EASTMAN: You were very distressed.

MS CLARK: I was hysterical. I - - -

MS EASTMAN: You put – had to put her in recovery position.

15 MS CLARK: I put her in the recovery position. I kind of know, you know, the basic human – the basic first aid. I put her in the recovery position. I picked up my phone, and I rang my husband and said, "You have to come home straight away. Gabrielle's had another seizure."

MS EASTMAN: But on this day you decided that you didn't want to take her to the  
20 hospital.

MS CLARK: Yes.

MS EASTMAN: That you thought you would be able to manage at home.

MS CLARK: Yes.

MS EASTMAN: And so she – but she was aware of what was going on.

25 MS CLARK: She was.

MS EASTMAN: She was saying to you, "I'm sorry, Mum. I'm sorry."

MS CLARK: Yes, over and over and over. But she got up and had dinner. She came downstairs and had dinner that night. And we were going to see a cardiologist that we had an appointment with for months and months. We were seeing him first  
30 thing the next morning, and that probably impacted on my decision-making skills by not taking her to the hospital. I said to Jon, "Look, you know, let's see how she goes." We got her up the next morning. She was very agitated. We took her to the cardiac specialist and he took one look at her and he said, "I just want to – I want to give her an ECG." And he said, "I need you to take her up to Northern Beaches  
35 Hospital straightaway." He said, "Her heart rate is really, really low and she needs to

be in hospital. We need to have that looked at.” He said, “I’ve got rooms up there. You take her up there, and I will ring the hospital.”

MS EASTMAN: So you and Jon got in the car, went straight to the hospital. But Gabrielle was able to walk into the hospital that day, wasn’t she?

5 MS CLARK: Yes, Gabrielle walked into the hospital. She certainly did.

MS EASTMAN: And that’s a matter of significance, isn’t it, that - - -

MS CLARK: Yes, it is a matter - - -

MS EASTMAN: - - - she could walk into the hospital?

MS CLARK: Mmm.

10 MS EASTMAN: And she answered all the questions she was asked on admission.

MS CLARK: Yes.

MS EASTMAN: And the nurse said to you, “We’re going to admit her. I’m going to take her straight up to the ward. We think that she might be having a myopic seizure.” Is that right?

15 MS CLARK: That’s correct, yes.

MS EASTMAN: So she went up to the ward, and during this time she appeared fine and she was aware of where she was, and she was communicating.

MS CLARK: Yes.

MS EASTMAN: She told you that she had a headache and she didn’t feel well.

20 MS CLARK: That’s correct.

MS EASTMAN: So the nursing staff suggested that you and Jon go and have a coffee while some tests were run.

MS CLARK: They were just going to do some blood tests, yes, that’s right.

25 MS EASTMAN: Okay. And so you said to them, “Well, look, you might have trouble finding a vein in Gabrielle. I just want you to be aware of that. Her right arm’s better than her left.” Is that right?

MS CLARK: That’s correct.

MS EASTMAN: And you were told it was under control, “Go and have coffee. This has been a bit traumatic for you.” So you remember that.

MS CLARK: Absolutely.

5 MS EASTMAN: So you went to have coffee. Gabrielle was asleep when you saw her again, so you went home.

MS CLARK: That’s correct.

MS EASTMAN: Okay.

MS CLARK: And – and they said that they would call us if there were any changes, that they would run some more tests. They should have the – the blood results back

10 and they would run more tests the next day.

MS EASTMAN: Did you leave the hospital confident that Gabrielle was going to be okay?

MS CLARK: Well, we were concerned, but she was settled and she was sleeping and she seemed to be all right.

15 MS EASTMAN: All right. So we get to the next day. So you and Jon went back to the hospital early in the morning.

MS CLARK: Yes.

MS EASTMAN: You’re about to go in to Gabrielle’s room and a nurse said to your husband, “You can’t go in. They’re doing something to Gabrielle.”

20 MS CLARK: That’s right.

MS EASTMAN: And you were there and you said, “What do you mean?”

MS CLARK: No, Jon was there first.

MS EASTMAN: Yes.

MS CLARK: I – I went up to the nurse station when they said that. I went up to the

25 nurse station.

MS EASTMAN: Okay. So Jon said, “We can’t go in. Something’s being - - -”

MS CLARK: Yes.

MS EASTMAN: And you said, “What’s happening?” So Jon said, “There’s a male nurse in there trying to change her or do something like that.”

MS CLARK: Absolutely.  
MS EASTMAN: Okay. But you then went into the room; is that right?  
MS CLARK: Yes, because Gabrielle was screaming, “No.”  
MS EASTMAN: Okay.  
5 MS CLARK: “No.”  
MS EASTMAN: So you could hear that outside.  
MS CLARK: “Don’t. Don’t. No.” Yes.  
MS EASTMAN: All right.  
MS CLARK: Yes.  
10 MS EASTMAN: So this is paragraph 65 of your statement, and if at any time you want to read this, you’re very welcome, but I’m happy to go along this way. So you went in. You saw a male nurse trying to adjust Gabrielle’s catheter; is that right?  
MS CLARK: That’s correct.  
15 MS EASTMAN: And the location of the catheter was in a very sensitive part of her body, and an area where no male person had ever touched her - - -  
MS CLARK: Absolutely.  
MS EASTMAN: - - - is that right?  
MS CLARK: Yes.  
20 MS EASTMAN: And Gabrielle’s a very modest young woman.  
MS CLARK: Mmm.  
MS EASTMAN: And so was it your impression that Gabrielle felt quite distressed in terms of that?  
MS CLARK: She was distressed. She was trying to pull it out.  
25 MS EASTMAN: And you asked the nurse to stop.  
MS CLARK: Yes. I did. I asked him to – he – he was actually bathing her. I asked him to stop. He said, “I’m doing my job.” I said, “I know that, and I really

appreciate what you're doing. However, Gabrielle needs a female to be here. I will stay here." He – he went and another female nurse came back, but Gabrielle was - - -

MS EASTMAN: So just pausing there – so when you asked him to stop, he did stop.

5 MS CLARK: Yes, absolutely. Absolutely.

MS EASTMAN: Yes. All right. And then – and then he organised somebody else to come in and to attend.

MS CLARK: Mmm.

MS EASTMAN: And this was a female nurse; is that right?

10 MS CLARK: Two female nurses then came in, yes.

MS EASTMAN: Okay. Now, you've said in paragraph 67 of the statement that you think just that having the male nurse attend Gabrielle in that way and based on her reaction, that this has had a real consequence for Gabrielle. So - - -

MS CLARK: I think she has.

15 MS EASTMAN: - - - would you tell the Royal Commission about that?

MS CLARK: I – I've thought about where Gabrielle is now and what Gabrielle went through and what was the trigger. I don't understand what the trigger was. I don't understand why my daughter's personality changed so diversely as it did from when we had left the night before to when we got there. And I think it was like 7  
20 o'clock in the morning when we were there the next morning. And Gabrielle was screaming, "Don't. No. Don't. No." They're her favourite words now. She just – every time someone went to touch her. And then Jon and I actually got her up and put her in the wheelchair and took her in and showered her, because she wouldn't let anybody touch her, and then we put her back into bed. But she was sobbing, she was  
25 traumatised, and she did not want any of the medical staff to come anywhere near her.

MS EASTMAN: So you think it might be that in relation to the insertion of the catheter or changing of the catheter, that maybe no one explained to Gabrielle in a way that was - - -

30 MS CLARK: No.

MS EASTMAN: - - - able for her to understand what was going on.

MS CLARK: And I – and I would have thought that I would have been consulted as to the fact that they were going to do that procedure. They did say that they were

going to test to see whether she had a urinary tract infection because they – they said sometimes that – you know, that could be an underlying problem. But that was the day before, the night before when we left, and they were waiting on tests coming back.

5 MS EASTMAN: Okay. So Gabrielle remained in Northern Beaches Hospital for a while.

MS CLARK: Six weeks.

MS EASTMAN: She received a diagnosis of rapidly advancing Alzheimer's.

10 MS CLARK: After they had done all these tests, yes, they said, "Oh, yes, well we – she's got what we call rapidly progressive Alzheimer's."

MS EASTMAN: That was a real shock to you and Jon, wasn't it?

MS CLARK: It was a real shock.

MS EASTMAN: And you said, "But, look, we had an MRI back in September and the MRI says that her brain and functioning is completely clear."

15 MS CLARK: Yes, that's correct.

MS EASTMAN: And the medical practitioner said to you, "That's my diagnosis", and then there was a discussion about who did the MRIs, and the content of the MRIs.

MS CLARK: Mmm.

20 MS EASTMAN: Was that quite confusing to you, having had the MRI and supposedly an all-clear in terms of any damage back in September, to, by early January, now being told that there was a significant problem for Gabrielle and damage to her brain?

25 MS CLARK: Yes. The – the neurologist was a lovely doctor, and she was obviously quite distressed in delivering that sort of news, but I argued that I felt that if someone had rapidly progressive Alzheimer's, that it would have shown up in the MRI. And when I told her who had done it, she said that – the name of the radiographer, she said she would check on them – check with them and get the results. And we never saw her again.

30 MS EASTMAN: Okay. So with this diagnosis of Alzheimer's, that had some consequences for what was going to happen to Gabrielle after she left the hospital - - -

MS CLARK: It did.

MS EASTMAN: - - - is that right?

MS CLARK: It did.

MS EASTMAN: And you make the point in your statement that the staff at the hospital were very helpful, to a point.

5 MS CLARK: Yes.

MS EASTMAN: And that you had both some good experiences and experiences that could have been better; is that right?

MS CLARK: Yes.

10 MS EASTMAN: And you also had the assistance of some social workers and nurses, but you got the impression that you felt that – they felt that Gabrielle shouldn't be staying at the hospital long-term.

MS CLARK: We - - -

MS EASTMAN: And it was time for her to move on.

15 MS CLARK: They called Jon and I into a couple of meetings where they said that – they brought the physiotherapists in and the physiotherapists said, “Oh, what we need to do is get Gabrielle up and walking. We feel that she can't – if she – if she can't get up and walk and we've used a hoist to get her out of, and she resists and” – you know, as soon as they try to touch her she would push herself back and start screaming, “No, no, no”, so they said, “We're going to try one more time, but in the  
20 meantime we want you to go and have a look at some aged care homes.”

MS EASTMAN: Was there any advice about any options other than an aged care facility?

25 MS CLARK: No. We were not given any other options. They said – they said we could look at veterans – War Veterans at Collaroy Plateau, Seabeach Gardens at Mona Vale, and the only other option was a nursing home at Bexley.

MS EASTMAN: And it was just not possible for you and Jon to have Gabrielle at home because of her needs and the lifting; is that right?

30 MS CLARK: Because of her needs, because the house is – is two storey, her bedroom's upstairs. They said, “We can make a – we can make a hospital room out of your front lounge room.” And I said, “There's no bathroom. There's no bathroom down there. There's no – you know, we'd have to rebuild the whole of downstairs.” But more importantly, I said, “I'm 71 and my husband's 70. And we can't lift her. She's just – she's just too heavy. She – she won't stop pushing back. Every time anyone touches her, she pushes away.” So they said, “Well, you know,

the option is that she will have to be lifted by a hoist and she will have to go into nursing”, and then the next thing we had someone from aged care coming to do an assessment.

MS EASTMAN: And so she now resides in an aged care facility; is that right?

5 MS CLARK: She certainly does.

MS EASTMAN: Do you want me to put the photo up?

MS CLARK: Yes. Yes.

MS EASTMAN: So this is Gabrielle shortly after she’s moved into the aged care facility; is that right?

10 MS CLARK: Yes. Yes.

MS EASTMAN: And that was that in terms of just appearance, a very different young woman - - -

MS CLARK: It is.

MS EASTMAN: - - - to the woman who walked into the hospital; is that right?

15 MS CLARK: She was very, very ill. I – I don’t believe that she was ready to be transferred to the nursing home at that stage because she was ill. I think that she needed further medical treatment, and I think it was an impost on the staff at the nursing home to have to nurse her through that very, very difficult period. She then got flu and bronchitis. She – she was riddled with gout. She had gout in her arm and  
20 her leg. Her knee was three times the size it should have been, and, you know, that’s – that was my opinion.

MS EASTMAN: You – since Gabrielle’s been at the nursing home, you’ve questioned the diagnosis of Alzheimer’s; is that right?

MS CLARK: I have. I have.

25

MS EASTMAN: And you’re not entirely sure that that might be the correct diagnosis because you think if her condition was as grave as the condition described that she probably would have died by now.

30 MS CLARK: I – I can remember on probably five occasions between March and August where Jon and I were planning her funeral, because her health was dire.

MS EASTMAN: And there had been occasions where sometimes she hasn’t recognised you; is that right?

MS CLARK: There have been during – at that period, yes, there were.

MS EASTMAN: And this is – what supports have you and Jon had during this year?

MS CLARK: I've had – I have some amazing friends who – who go out and feed  
5 Gabrielle some days so Jon and I can sleep in at the weekends, because Jon and I are  
at the nursing home – I'm there every morning from 8 o'clock till half past 9. I've –  
I'm happy to say that I'm the first person that Gabrielle sees when she wakes up and  
I get a beautiful smile and a kiss, and give her her breakfast because she's unable to  
feed herself. She's unable to go to the toilet, she's in nappies, and that, to her, is  
10 really, really distressing. I – I go home - - -

MS EASTMAN: Okay. Part of the distress is to see Gabrielle in an aged care facility.

MS CLARK: That's - - -

MS EASTMAN: Her roommate is 95 years old and she's the youngest person there;  
15 is that right?

MS CLARK: Yes. Her roommate is 95, and she is the youngest person there, I was  
told the other day, by 35 years. She quite – the residents there love Gabrielle. They  
all – she goes into the room – she's now in a wheelchair, so she's got her own  
wheelchair that was provided for her by the NDIS, and the NDIS are paying for her  
20 physiotherapist and her speech therapist. And Gabrielle goes into the general room  
or the dining room or the common room and all the ladies say, "Hi, Gabrielle, how  
are you?" Or call her Gabbi, those of them who can remember her name. And there  
are a lot of ladies there who have Alzheimer's who have these – they're like life  
babies that give them comfort so they carry these around. And Gabrielle – Gabrielle  
25 looks at that as if to say, you know, "They've got babies. Is that normal?" And I go  
to her, "No, they give them – they help the ladies. They give them comfort." "Oh,  
okay." There's a lot of yelling and screaming that goes on in an aged care facility for  
women with dementia and Alzheimer's, and that's really, really sad, and that can be  
very, very upsetting for people that are there, and I find myself continually reassuring  
30 Gabrielle that it's okay, one of the ladies doesn't like having a shower, she doesn't  
like the water on her, and – and so I just take the time to explain those things to her,  
and that settles her. But there are days when Jon and I go out there that she's  
agitated and we don't know what it is – you know, we don't know what – what that's  
about, but we spend a lot of our time reassuring her.

MS EASTMAN: You still want her to have a quality of life; is that right?

MS CLARK: Absolutely. I do.

MS EASTMAN: So you still take her to the beach.

MS CLARK: I do. Gabrielle loves the beach. The first thing we did the day she got her wheelchair was we took her down the beach, because we're only a block away from Mona Vale beach. Gabrielle when she was younger if she wanted to solve problems or wanted to think about things she would always gravitate to the

5 roof of the surf club and sit out there and watch the waves, or down the bottom of our street where the lake is, and – so we get down to – she was, “No, no, no,” all the way down in the wheelchair, because I'm a shocking driver, so I'm told.

MS EASTMAN: There's a – I think we've got the photo of her going to the beach in a wheelchair.

10 MS CLARK: Yes. And she's got a smile on her face, and that's because – she had the tear rolling down, because she saw the ocean and she just said, “I can see the sea. I can see the sea. I love it. I love it.” But - - -

MS EASTMAN: You say in paragraph 94 that you don't know what Gabrielle's future holds, “but as long as Gabrielle has a smile on her face, we're happy.”

15 MS CLARK: Yes. That's true. We are. We want her – you know, we want her engaging when - - -

MS EASTMAN: Right. There's – I think we've got a photo of Gabrielle and you, so this is the importance of the smile - - -

MS CLARK: Gabrielle celebrated - - -

20 MS EASTMAN: This is her 44<sup>th</sup> birthday.

MS CLARK: Yes.

MS EASTMAN: Okay.

MS CLARK: 44<sup>th</sup> birthday that she celebrated in the nursing home with all the residents. Yes. She's wearing her pearls.

25 MS EASTMAN: They're very nice pearls. Can I ask you now about being an advocate for Gabrielle? And you talk about this in your statement, that you're an advocate for Gabrielle, but you also think it's very important for you to also be an advocate for people with Down syndrome generally; is that right?

MS CLARK: Absolutely, yes. Yes.

30 MS EASTMAN: And it can be difficult at times. And you've asked yourself this question: are you really advocating for your feelings, or are they her feelings? And that you always want to ensure that your advocacy is for Gabrielle; is that right?

MS CLARK: Yes.

MS EASTMAN: Can you just explain that a little bit to the Royal Commissioners.

MS CLARK: Well, I think, you know, like, in my current situation, I know what I want for Gabrielle, and I am very emotional about it, as you can see. And so I think I have to try and put a lid on those emotions and put myself in Gabrielle's position, and knowing her as well as I do, but I always have to try and find a way in her current state of explaining to her, you know, what's happening, why it's happening, and is she okay with that.

MS EASTMAN: Now, you in your statement make some suggestions for positive change. Can we turn to those matters now? So this is paragraph 98.

10 MS CLARK: I'm a long way behind you. I think it's about - - -

MS EASTMAN: So the first one was your suggestions for change are doctors and nurses should be aware of the potential misdiagnosis of Alzheimer's or dementia for people with Down syndrome.

MS CLARK: Yes. Yes.

15 MS EASTMAN: And I think you said you were here yesterday when Professor Trollor was giving evidence about this issue as well. So you have got some strong views on this, don't you?

MS CLARK: I do. I think - - -

MS EASTMAN: So what are your suggestions?

20 MS CLARK: I think – and it's been on the topic of many Down syndrome Congresses over the years where people have said, you know, “Of course people with Down syndrome age more rapidly than other people”, and that 98 per cent develop dementia or Alzheimer's, and I question that because I think that a lot of people with Down syndrome do have thyroid problems, and the thyroid causes a lot of things to go wrong as well. It – and hormonal things that you can take into consideration. But I also think that sometimes people with Down syndrome get to a certain age in their life and they become a little bit more sedentary, and people don't challenge them. I think the – the most important thing for people – all people, not just people with Down syndrome – is that, you know, cognitive development goes on, you know, reading, using your brain, being engaged, having social interactions, and being physically active and have – have a fitness program. I think that goes without saying. And I – and I've met people with Down syndrome who are in their late 80s, so I know. But this – this terminology that they use all the time in saying that, you know, 98 – I – I don't see any evidence of data that sort of supports that. I think that in my understanding of Alzheimer's is it can only be conclusively confirmed when a person has an autopsy, and I don't know many people with Down syndrome that have passed away that have had autopsies to confirm that.

MS EASTMAN: One of the other issues you raise is the importance of health care professionals being appropriately and properly trained and having education in intellectual disability. And so this is the example that you give of people needing to know who Gabrielle is and her achievements, rather than just see her Down syndrome - - -

5 MS CLARK: Absolutely.

MS EASTMAN: - - - is that right?

MS CLARK: Absolutely.

MS EASTMAN: And you think doctors and nurses should listen to parents and carers.

10 MS CLARK: Yes.

MS EASTMAN: And you've got a very firm view that younger people should not live in aged care facilities.

MS CLARK: I certainly do, and I've always had that view, and I understand the limitations and the fact that – the residential needs. But I have to tell you, it's – it's very boring. I always say beige is boring. But, you know – Seabeach Gardens where Gabrielle is, I've actually decorated Gabrielle's room. I've got pictures and photos and palm trees and flowers - - -

15 MS EASTMAN: Bit of Elvis Presley, I think.

MS CLARK: Elvis Presley. She's fanatical about Elvis Presley. And she has always had – this – a friend of my husband's gave us an Andy Warhol Elvis Presley portrait which is on the wall and has always been on Gabrielle's wall, so that takes pride of place out there. And because of that, the residents always ask to put on Elvis movies for Gabrielle.

20 MS EASTMAN: What is your hope for Gabrielle from hereon in?

MS CLARK: I – you know, I have – I have reservations. I – I can't say – speak highly – more highly of the nurses and the people who look after her at Seabeach Gardens. They treat her with utmost respect. They talk directly to her. They ask her questions. And they wait very patiently for her to think about it and answer. And I –

30 I tell myself I – that she – she needs to be with a lot of younger people, and I believe that, because she gravitates towards all the younger nurses who work there, and they gravitate towards her too. But I think that she needs to be in a facility where there's lots of colour, lots of action, lots of things going on, music. There's a complete – there's just such diverse differences between her needs and the needs of the aged

35 care residents in – in that hospital.

The downside to me would be that she would have to move away from Mona Vale, move away from a place where she's very, very comfortable, and, you know, I don't even see that there's a – there's a future there because no one's talking about having any facilities like that. And I've met other mums of people with intellectual  
5 disabilities whose children are in nursing homes because they've got higher support needs or because they've been put in an aged care facility because that's the only place that can look after them.

MS EASTMAN: Thank you, Mrs Clark, for your evidence. And thank you very much for sharing this aspect of Gabrielle's life and also the photos that you brought  
10 with us.

MS CLARK: Thank you.

COMMISSIONER SACKVILLE: I would like also to thank you on behalf of the Commissioners for your statement and coming and giving evidence and sharing your experiences and those of Gabrielle's. Thank you very much.

15 MS CLARK: Thank you.

**<THE WITNESS WITHDREW**

**[12.29 pm]**

MS EASTMAN: Commissioners, the evidence can be found – the statement at part  
20 A of the tender bundle behind tab 26. And if it could be received into evidence and marked exhibit 4.12.

COMMISSIONER SACKVILLE: Thank you.

**EXHIBIT #4-12 STATEMENT OF LORRAINE GAYE CLARK DATED  
25 12/02/2020 (STAT. 0056.0001.0001)**

MS EASTMAN: I'm conscious of the time. Mrs Creevey's here to give her evidence. I just wonder whether it's convenient and not too much disruption to those who manage the logistics of the Royal Commission if we adjourned early for lunch  
30 and perhaps resumed as 1.30.

COMMISSIONER SACKVILLE: Certainly. All right. Thank you very much. We will resume at 1.30.

**ADJOURNED**

**[12.44 pm]**

35 **RESUMED**

**[1.33 pm]**

COMMISSIONER SACKVILLE: Yes, Ms Eastman.

MS EASTMAN: The next witness is Kim Creevey, who is sitting here ready to go.

COMMISSIONER SACKVILLE: Good afternoon.

MS CREEVEY: Good afternoon.

5

**<KIM LETITIA CREEVEY, SWORN**

**[1.34 pm]**

**<EXAMINATION BY MS EASTMAN**

10 COMMISSIONER SACKVILLE: Thank you very much. Please sit down. Ms Eastman will ask you a few questions.

MS CREEVEY: Yes.

MS EASTMAN: So you are Kim Letitia Creevey.

MS CREEVEY: Yes.

15 MS EASTMAN: And you're a teacher.

MS CREEVEY: Yes.

MS EASTMAN: And you live in Queensland.

MS CREEVEY: Correct.

20 MS EASTMAN: And you've prepared a statement for the Royal Commission dated 7 February this year.

MS CREEVEY: Correct.

MS EASTMAN: And the contents are true and correct.

MS CREEVEY: Yes.

25 MS EASTMAN: And the evidence that you wish to give to the Royal Commission today is about your son, Harrison.

MS CREEVEY: Correct, yes.

MS EASTMAN: Known as Harri.

MS CREEVEY: Yes.  
MS EASTMAN: And Harrison died at the Mater Hospital on 1 October 2015.  
MS CREEVEY: Correct, yes.  
MS EASTMAN: And you want to talk about Harrison's life - - -  
5 MS CREEVEY: Yes.  
MS EASTMAN: - - - and also to talk about the circumstances leading up to his death.  
MS CREEVEY: Okay. Yes.  
MS EASTMAN: You might have to keep your voice up a little bit.  
10 MS CREEVEY: Okay. Sorry.  
MS EASTMAN: Just so we can hear you. If at any time you want a break or if at any time you want me to read part of the statement, just let me know.  
MS CREEVEY: Okay.  
MS EASTMAN: And your husband, Matthew, is here today as well. Let's start  
15 with getting to know Harri a little bit.  
MS CREEVEY: Okay.  
MS EASTMAN: And you have talked about him in your statement. So he, as you say, was a normal boy. He liked to play and climb trees.  
MS CREEVEY: Yes.  
20 MS EASTMAN: He liked to challenge the limits of your ability and also of your rules. And he rode motor bikes, horses, ran in the fun runs, he was a fun-loving person. What else would you like to tell us about Harrison? And we do have some photos.  
MS CREEVEY: Yes.  
25 MS EASTMAN: If and when you would like us to put them up, let me know.  
MS CREEVEY: Whenever you feel.  
MS EASTMAN: Okay. Shall we put one up now?

MS CREEVEY: So, yes, you can put them up now. Yes.

MS EASTMAN: Okay.

MS CREEVEY: Yes. Harri was a quietly determined little boy. He was quite comfortable in his own abilities. A couple of his sayings were “me too”, as we all  
5 do, but there was also the one of “me do it meself.” So if you tried to help him do something, he was like, “Yeah, no, stay away.” He had a wicked sense of humour. He would understand things and giggle at them before we’ve even understood what was going on, especially after his injury. He just wanted to participate in life as much as he could. He – in the same way that he would laugh before we would laugh,  
10 he would also cry. So many a time he was taken out of the movies because he was crying before – like the music would come on, he knows where the story is going, so he would cry, so we would have to take him out.

He loved to push the limits of adrenalin-type rides. So when we would go to theme parks, he would – they would see the wheelchair, we’d – they – the attendants would  
15 come over and put him at the beginning of the line and he’d get on and then he’d come around and they’d say – ask him whether he wanted to go again, and he’d quickly put his thumb up and give them a big smile and – so they wouldn’t make him come off. So there Harri and Matt would be going round and round on the roller coaster until Matt called it quits and – because he couldn’t stand it anymore and –  
20 yes. He loved music, even if he had to go with his parents to the concerts. He – yes.

MS EASTMAN: He was a champion ten-pin bowler.

MS CREEVEY: He was, yes. He went to the – represented Queensland in the national championships in – in Tasmania.

MS EASTMAN: He loved the Gold Coast Titans, didn’t he?

MS CREEVEY: Yes. Yes, he chose them when they first started. Probably their  
25 only fan, but anyway. And, yes, I guess after he got sick, we’d been very blessed with friends and family that saw Harri as Harri, not Harri with a disability. So anything that the other kids did, we just modified it so that Harri could do it. And what always interested me is that people would say, “Oh, what are you going to do –  
30 what would you do if he fell off? What would you do if he –” you know, and we’d say, “Oh, take him to the hospital.” “What would they do? What would you tell them?” “Oh, he fell off”, you know, or he – you know, whatever happened, we tried to modify it so that Harri could participate.

So, like, on Christmas Day there was a spot that Harri sat in, and even to this day if  
35 you get out – if your ball goes that way, you’re out because Harri would have caught it. But he was in a safe spot that it was, you know, very unlikely that he was going to get a ball come at him at a fast speed. So things like that, yes, we just tried to make his life and everybody around us tried to make his life as normal as possible. Yes. And, you know - - -

MS EASTMAN: So he was a – you know, he was a person first and foremost - - -  
MS CREEVEY: Yes. Yes.  
MS EASTMAN: - - - as you say in paragraph 15.  
MS CREEVEY: Yes.  
5 MS EASTMAN: But Harri wasn't born with a disability.  
MS CREEVEY: No.  
MS EASTMAN: He contracted Murray Valley encephalitis.  
MS CREEVEY: Yes.  
MS EASTMAN: And the result of that was that he was then having a – he was a  
10 spastic quadriplegic. Is that - - -  
MS CREEVEY: Yes.  
MS EASTMAN: - - - the right expression?  
MS CREEVEY: Yes, non-communicative.  
MS EASTMAN: And that happened when he was about three and a half years old.  
15 MS CREEVEY: He was, yes.  
MS EASTMAN: So it meant that in terms of his day-to-day life, much of that was  
spent using a wheelchair; is that right?  
MS CREEVEY: Correct, yes. He was left with spastic – I can't say it now, but he  
20 was also non-communicative. So we relied on him doing the thumbs up or smiles  
initially. And then as he got older, he realised he had choices and they weren't  
always yes and no. And we made it a little bit interesting for a while there. But, yes,  
he – yes, he relied on us to do everything for him.  
MS EASTMAN: Well, you provided his primary - - -  
MS CREEVEY: Yes.  
25 MS EASTMAN: - - - care at home.  
MS CREEVEY: Yes.

MS EASTMAN: And so that you would use the medical system if and when needed; is that right?

MS CREEVEY: Correct, yes.

MS EASTMAN: And what you sought to do was to make his life at home as  
5 normal as possible.

MS CREEVEY: Correct.

MS EASTMAN: There were occasions where Harri did have to have short stays in hospital.

MS CREEVEY: Yes.

10 MS EASTMAN: And some of these occasions you've dealt with in the statement, but they've caused you, I think, to say right at the outset of your statement that your experience of these occasions was one where you saw what you've described as unconscious bias inaction.

MS CREEVEY: Bias. Yes, correct.

15 MS EASTMAN: So can I ask you to give a few examples. The first one in paragraph 11, I referred to this in the opening address back on Tuesday when the Royal Commission public hearing commenced. But now you're here, I want to ask you some questions so that we understand - - -

MS CREEVEY: Okay.

20 MS EASTMAN: - - - the context of that comment. So you had to take Harri to the hospital because he was suffering an undiagnosed breathing issue.

MS CREEVEY: Correct.

MS EASTMAN: And you went to see a paediatrician in hospital; is that right?

MS CREEVEY: A paediatrician came to visit us in the hospital.

25 MS EASTMAN: And you say in the statement that the paediatrician had been very quick to suggest that the anomaly, that was the breathing issue, was due to his underlying disability.

MS CREEVEY: Correct.

MS EASTMAN: And that the paediatrician on that occasion didn't pursue any other  
30 differentials.

MS CREEVEY: No.

MS EASTMAN: Okay. So at that point you had a conversation with the doctor. Can you remember how that went?

5 MS CREEVEY: He was very quick, like I said, to point out it was Harri's disability. It wasn't anything else. Couldn't possibly be anything else. And while he was standing over Harri's bed, who can understand and hear everything that's going on, he – he said, you know, "How much more money are we going to spend on him keeping him alive? You know, do you have an end-of-life plan for him?" He was quite quickly moved out into the hallway, because that wasn't an appropriate  
10 conversation to have over someone who can't ask any questions, and asked not to come back. And that – that had other consequences by way of we couldn't go back to that hospital because he was the paediatrician that would have been allocated to Harrison. Yes, and then we had to spend a lot of time talking Harri through what he'd actually said.

15 MS EASTMAN: And it turned out that the breathing condition was brought on by acid reflux.

MS CREEVEY: Reflux, yes.

MS EASTMAN: And that could have been readily and easily managed; is that right?

20 MS CREEVEY: He was on Nexium. He never had another problem.

MS EASTMAN: There was another occasion where Harri had a hairline fracture of his elbow.

MS CREEVEY: Correct.

25 MS EASTMAN: And what happened on that occasion? This is paragraph 13 of your statement.

MS CREEVEY: We presented with Harrison at the hospital. They acknowledged that he had a hairline fracture. They tried to put him into a sling to hold his arm like this but, unfortunately, that was his arm that if he got stressed, he would do this with it. So having it in the sling and not being able to move it made him unhappy. And  
30 the doctor came and said, "Oh, just leave it. It will heal." And then he went to the hospital with a seizure and the doctor there – this was 12 weeks later – the doctor there said, "Oh, while we're waiting for the bloods to come back, how about we X-ray it again?" And he did, and the hairline fracture had separated, and he was basically put into hospital. They pinned it. But Harri was right next to another child  
35 who had had a very similar accident that very day and was having the same procedure done.

When Harri had the cast taken off, we asked – he had two cuts on his arm. We questioned that and they said, “Oh, yes, when we took the plaster off – he – one of the screws had come out of the skin and was poking into the plaster.” We asked them whether that would have any ongoing effects, and the reaction of the patient liaison officer was, “Oh, well, he wasn’t going to play the piano anyway.”

5 MS EASTMAN: How did you respond to a comment of that nature?  
MS CREEVEY: I was just horrified. I was – yes, it was just so inappropriate.  
MS EASTMAN: Right.  
MS CREEVEY: And the fact that he would have been in pain that whole time with a – the pin sticking out of your skin on to a plaster that’s not exactly stable, yes.

10 MS EASTMAN: All right. So now I want to turn to the events of September 2015.  
MS CREEVEY: Yes.  
MS EASTMAN: And I know these are difficult issues. So if you need a break, let me know.

15 MS CREEVEY: Okay.  
MS EASTMAN: So Harri had turned 18, and just had turned 18 - - -  
MS CREEVEY: Yes.  
MS EASTMAN: - - - three days - - -  
MS CREEVEY: Beforehand.

20 MS EASTMAN: - - - before the admission to the Mater Hospital.  
MS CREEVEY: Yes.  
MS EASTMAN: And that was on 13 September 2015.  
MS CREEVEY: Correct.  
MS EASTMAN: And this is the first time that Harri has had an admission to an adult hospital; is that right?

25 MS CREEVEY: Yes, correct.

MS EASTMAN: Okay. So it came about because earlier that morning Matthew had noticed that Harri had been having shortness of breath and some distress; is that right?

MS CREEVEY: Correct, yes.

5 MS EASTMAN: So Matthew took him to the hospital.

MS CREEVEY: Yes.

MS EASTMAN: To the emergency department.

MS CREEVEY: Department.

MS EASTMAN: And at the emergency department, Matthew was told that perhaps

10 Harri had acquired pneumonia.

MS CREEVEY: Yes, community-based.

MS EASTMAN: Community-acquired pneumonia.

MS CREEVEY: Correct.

MS EASTMAN: And there was a recognition that that had the potential for Harri to

15 deteriorate.

MS CREEVEY: Yes.

MS EASTMAN: All right. So in terms of this beginning part, you were not part of the initial - - -

MS CREEVEY: No. No.

20 MS EASTMAN: So you have two other boys as well.

MS CREEVEY: I do.

MS EASTMAN: And so between Harri and the other boys, you've got three busy boys whose lives you need to manage.

MS CREEVEY: That's right.

25 MS EASTMAN: And you also work.

MS CREEVEY: Yes.

MS EASTMAN: So this is Matthew in the initial admission.

MS CREEVEY: Yes.

MS EASTMAN: So Matthew stayed with Harri throughout the day, and you came back and forth; is that right?

MS CREEVEY: Yes, I came back and forth.

5 MS EASTMAN: Okay. So later, though, that day, towards the evening, then Harri experienced a respiratory arrest and then moved to the intensive care unit; is that right?

MS CREEVEY: Correct, yes.

MS EASTMAN: And he remained in that intensive care unit for the next 16 days.

10 MS CREEVEY: Yes.

MS EASTMAN: And these 16 days were the last days of his life.

MS CREEVEY: Yes. Yes.

MS EASTMAN: You now reflect back on those 16 days and decisions that were made, and you question whether or not Harri's care in the ICU unit was influenced

15 by his disability; is that right?

MS CREEVEY: And the period – the time that he spent on the ward, on the actual ward, he was certainly a victim of unconscious bias - - -

MS EASTMAN: All right.

MS CREEVEY: - - - without a shadow of a doubt.

20 MS EASTMAN: So do you want to read any part of the statement or - - -

MS CREEVEY: I would love to.

MS EASTMAN: - - - shall we walk through part of the statement?

MS CREEVEY: Yes.

MS EASTMAN: All right.

25 MS CREEVEY: Okay. So at approximately 6 am on 13 September, Matthew took Harri to the emergency department. He was suffering with shortness of breath and distress. Matthew told me, and I believe, that the doctor who reviewed Harri in emergency told Matthew that he suspected Harri had acquired – had community-acquired pneumonia and recognised the potential for him to deteriorate. Matt stayed

with him during the day. I had to come up and go back all the time. He – the observations, when he was admitted to the planning ward, they didn't take any obs. They only took obs when he left the planning ward. So they couldn't see that his condition had deteriorated, yet he was meant to be on hourly obs during that period  
5 of time.

When we got him up to the ward, we felt that the observations were not taken frequently enough. Most of the observations were only taken when Matthew or myself specifically asked for them or asked to see a doctor. We made repeated requests to see the doctor and for observations to be taken because Harri was  
10 becoming increasingly more distressed and the alarm on his oxygen saturation machine was sounding. When the machine alarmed, the nurses – the nursing staff would come in and they would lower the parameters so the machine wouldn't alarm, basically. We found it very frustrating, myself particularly, and had to walk out quite a few times because they just weren't answering our questions, and I was going to  
15 upset Harri, which – when you've got a breathing problem, you don't need people making you get upset.

We felt that he was deteriorating and that he should have been observed more closely, but it was really difficult to get anyone to pay any attention to us. We were just, you know, crazy parents. Yes, so we felt – as Harri's primary caregivers, we  
20 knew his condition and how he responded in different situations. We felt that the hospital staff were dismissive of our concerns and treated us like they knew our son better.

MS EASTMAN: All right. So just pausing there, you go on to say since Harri's death, you've reviewed the medical records.

25 MS CREEVEY: Correct.

MS EASTMAN: And you've seen Harri's Adult Deterioration Detection Score.

MS CREEVEY: Correct.

MS EASTMAN: And reading those records have caused you also further to reflect on the treatment on – at the time.

30 MS CREEVEY: Definitely.

MS EASTMAN: All right. So what do you want to tell the Royal Commission in terms of what you feel that you've learnt having had access to the medical records?

MS CREEVEY: Records. I just think it reinforces the unconscious bias that was there. I don't – and I will never – understand why if you're given a tool to use to  
35 assess somebody, why you wouldn't use it when it clearly – and is non-subjective, why they ignored that. They ignored it on several occasions. It wasn't just once, and it wasn't just one person. It was a series of different people who made a choice for

Harri, made a choice for us, that he wasn't going to get the gold standard that everybody else would get. One of the doctors even wrote on his notes that he was peripherally shutting down, yet didn't do anything. Hadn't even contacted the respiratory specialist who was on for the weekend until he actually was at the ICU doors. Yes.

5 MS EASTMAN: So were there particular aspects of Harri's care in the ICU that caused you concern?

MS CREEVEY: Can I - - -

MS EASTMAN: And I think you have touched on this a little bit - - -

10 MS CREEVEY: Yes.

MS EASTMAN: - - - from paragraph 28 onwards.

MS CREEVEY: Can I go back to 26?

MS EASTMAN: Of course.

MS CREEVEY: Where they gave him the Midazolam. So, eventually, they called -

15 - Matt called me at home. I came up. They - they eventually called a medical. They - when they arrived in the room, two of the ICU doctors came with them, and one of them said to me - I was at the end of the bed and I was trying to keep out of the way and talking to Harri, and she said to me, "Oh, you know, what's your plan?" And we said, "To do everything you can do for him." And so she then took the time

20 to walk around and ask Matthew the very same question. And at that rate, then when that happened they - they all started - they sprung to life. Up until that point, they weren't trying to save his life. They were - - -

MS EASTMAN: This is on the first night, wasn't it?

MS CREEVEY: This was - - -

25 MS EASTMAN: Yes.

MS CREEVEY: - - - on that day.

MS EASTMAN: Yes.

MS CREEVEY: This is - this is - - -

MS EASTMAN: On the first - yes.

30 MS CREEVEY: - - - the first night he was in hospital, yes. They then gave him Midazolam to intubate him. We'd been warned that if we intubated him, we may not

get him off the breathing equipment. He – and when they gave him the Midazolam, I – they had – he went into respiratory arrest and then into a cardiac arrest. And – I knew that Midazolam, because we’d given it to him for seizures and had been told by the neurologist that he – that we would need to have an ambulance on the way before  
5 we gave it to him, that caused me great concern because I was aware that it suppresses your breathing, ability to breathe. And straight after giving that, Harri went into respiratory arrest and cardiac arrest, and they had to give him adrenalin, and it was pretty horrific.

MS EASTMAN: All right. So going back to the care during the time that he was in  
10 intensive care – so I might have jumped now to - - -

MS CREEVEY: Yes, to twenty - - -

MS EASTMAN: - - - about paragraph 36.

MS CREEVEY: 36, yes.

MS EASTMAN: There were a few issues that arose while he was in intensive care  
15 and a few aspects of his care that you were concerned about. So he did contract influenza B while in hospital; is that right?

MS CREEVEY: His influenza B – he presented to the hospital – my understanding is he presented to the hospital with influenza B, it had developed into pneumonia, and then that’s when he went into ICU.

MS EASTMAN: All right. And then contracted some secondary - - -

MS CREEVEY: Pseudomonas. Pseudomonas, yes, which is a hospital-born - - -

MS EASTMAN: While in the hospital.

MS CREEVEY: Yes.

MS EASTMAN: And what were the concerns that you had in terms of the decisions  
25 to sedate Harri or wake him from sedation?

MS CREEVEY: Okay. So the first – after about seven days in there, his – all his machines were telling us that he’d fought the – the pneumonia. And the doctor that was on, the head doctor in ICU said, “We can wean him off now.” And so we were weaning him off and he came – by about 3 o’clock in the afternoon he – his  
30 temperature started to go up, and the doctor that was on duty said, “Well, we will re-sedate him, do some X-rays and – and see what’s happening”, I think – and bloods, and they – it came back that he had developed this pseudomonas, which is hospital-based infection, I guess, and he – so we re-sedated him for another period of time. Once again, he came – all – everything said that he was ready to be extubated. But  
35 instead of weaning him, which I understand is the protocol, they just lowered his

sedation and took the tube out, and that was it. He was a happy boy, sitting up watching TV for about 12 hours.

MS EASTMAN: In paragraph 40, you talk about the night shift - - -

MS CREEVEY: The nurse.

5 MS EASTMAN: - - - on 29 September.

MS CREEVEY: Yes.

MS EASTMAN: And that caused you some concern in terms of the extent to which Harri was observed.

MS CREEVEY: Yes.

10 MS EASTMAN: And so your recollection is that you remember that there was a nurse on duty and it looked like she might be doing other work or completing - - -

MS CREEVEY: Yes, she was doing an assignment.

MS EASTMAN: An assignment.

MS CREEVEY: Yes.

15 MS EASTMAN: So that caused you some concern as to whether or not he was being properly and adequately observed - - -

MS CREEVEY: Correct.

MS EASTMAN: - - - and whether or not there was appropriate oral suctioning for Harri at that time. All right.

20 MS CREEVEY: I had to – because the 28<sup>th</sup> was the day that he'd been extubated, so that – sorry, the 29<sup>th</sup>. So that night – that night, we had to make sure that he'd slept well so that he could continue the next day, like, so that we could get him home, basically. She, yes, opened the doors. She sat outside. We spoke about the

25 assignment she was doing. And I had to keep asking her – what I wanted her to do was orally suction Harri. I didn't want her to put the tube all the way down his throat. I just wanted his mouth – because he was becoming distressed because he

had the dribble going down his face. Harri never had dribble on his face. She also – because he had to sleep – Harri sleeps better on his back, but she insisted that he had to be moved every three hours because that was hospital protocol. And I said, “Just

30 let him sleep. I'll sign anything you need.” And she just wouldn't. And then the last move she did with him, she didn't get anybody to help him.

Now, his arm was full of tubes, and when Harri – when you roll Harri, he would throw his head back. And so when – when she rolled him, he just screamed out in pain, because she had rolled him up on to his hand. Yes, it wasn't necessary.

5 MS EASTMAN: Was it the next day that you were advised that Harri's respiratory muscles were weakened to the point of not recovering?

MS CREEVEY: That was on 1 October, the morning of 1 October, yes.

MS EASTMAN: And on that day you felt that the doctors had given up on Harri.

MS CREEVEY: Definitely.

10 MS EASTMAN: And you say at paragraph 42 that you felt that you were not given any option other than to have to make a decision about whether Harri would, as you say, go with as much comfort as possible.

MS CREEVEY: Yes. They – he – the doctor sat us down, explained that Harri would have to be intubated again, that he probably wouldn't come off being intubated, that he would have to have a trachea. He would – so he would spend his  
15 life in the hospital, the last few days or however long it took for him to succumb to some other infection. We weren't – my opinion is we weren't given any other options. And after being in hospital for 16 days, you're absolutely exhausted. We never left Harri's side. Harri, in the time that he was unwell, or the time we had him, was never left by one of us. One of us – and a small handful of friends. So, yes, he  
20 just told us that we had to let him go and do it with dignity and respect. And – yes.

MS EASTMAN: You felt that after many hours of fighting, Harri did go.

MS CREEVEY: Harri did, yes.

MS EASTMAN: And he passed away - - -

MS CREEVEY: At 3.07.

25 MS EASTMAN: - - - at 3.07 on the 1 October.

MS CREEVEY: Correct.

MS EASTMAN: We are very sorry for your loss, for Harri's loss - - -

MS CREEVEY: Yes, Harri's loss.

MS EASTMAN: - - - and the grief that caused your family.

30 MS CREEVEY: Yes. Harri's passing was far from gentle. We – he had to wait for a doctor to wake up to provide him with more sedation. And then it was handed over

to our eldest boy, Jae, who's got a medical background, to tell the nurse when he could increase his – the medication he was on to make him be sedated. And since then, I've been with a family friend who passed away with respiratory issues. Harri's death was nothing like that.

- 5 MS EASTMAN: So you don't feel that even in Harri's death and passing there was any peace or - - -  
MS CREEVEY: No.  
MS EASTMAN: - - - dignity for him.  
MS CREEVEY: No. Absolutely not.
- 10 MS EASTMAN: And this has caused you ongoing distress.  
MS CREEVEY: Definitely, yes.  
MS EASTMAN: But it's also fired you up - - -  
MS CREEVEY: Yes.  
MS EASTMAN: - - - to find out exactly why and to also look at these issues, and  
15 you have taken on some advocacy - - -  
MS CREEVEY: Correct.  
MS EASTMAN: - - - on behalf of Harri since his passing.  
MS CREEVEY: Yes.  
MS EASTMAN: So that has involved getting access to relevant hospital records.  
20 You've looked at policies and practices.  
MS CREEVEY: Correct, yes.  
MS EASTMAN: You have carefully examined how other people with disability different to Harri have been treated, and you've seen that experience.  
MS CREEVEY: Yes. Yes.
- 25 MS EASTMAN: And what you want to tell the Royal Commission is that from your experience and watching Harri's fight - - -  
MS CREEVEY: Yes.  
MS EASTMAN: - - - that there are things that could be done better.

MS CREEVEY: Correct.

MS EASTMAN: So there's a number of matters that you wanted to talk to the Royal Commission about today in terms of potential changes and things that you've observed. And one of them, if we could start with this, is whether Harri's death was reportable.

MS CREEVEY: Yes.

MS EASTMAN: So after Harri had died, what happened in terms of whether his death had to be reported to anybody?

MS CREEVEY: Apparently, he doesn't fit – well, my understanding is that he doesn't fit into the reportable death criteria. My understanding of that is because on his death certificate it says ABI – his reason for dying or the – is – cause of death is ABI, so acquired brain injury. It also says seizures, and it says restricted lung disease. Then it says pneumonia, influenza B, pneumonia and pseudomonas. So because it comes up as the ABI is what he died from, it doesn't fit into that reportable death. And, yes, Harri did have all those things, but from the time he was with – the main thing being the – the restrictive lung disease, from the time that he – which essentially meant one of his lungs couldn't fill properly with air. But from the time he was diagnosed to the time that we lost him, he had not had any respiratory issues whatsoever. So you look past the ABI and you see that this person's a perfectly well child. It wasn't the ABI and it wasn't the – it wasn't his disability that caused him to die, but because they've got to put – they put that on the death certificate as the first reason, it seems to activate something that doesn't require you to be – require an inquiry.

So we tried many times, many, many times, to change that it is a reportable death but to no avail. We – you know, we can accept that Harri probably wouldn't have lived a full life, barring some sort of miracle which I was happy to have happen. He would have had a shortened life, but he didn't need to die, you know, at the hands of people that knew better than – than to let him go that way. When you look at – yes, it – when you look at Harri as an 18 year old and would have presented to the hospital with the same symptoms and then you've got Harri with a disability, nobody gave us options as to how we could treat him. Nobody said, "This is the gold standard care. This is, oh, well, he's not going to survive." They made that decision. And one – Harri's neurologist is Harry McConnell, and he was involved in a Queensland paper that was called Deaths in Care, and that showed – they presented it twice to Parliament in 2016, and the response was like, "Yes, we will just shelve that." But it shows that one person in 10 years that was in care was considered a reportable death. So that's not indicative of society as a whole, is it? It's - - -

MS EASTMAN: A few other things you wanted to raise in relation to potential changes. One is in paragraph 51. And you say, "There needs to be a concerted effort to provide substantial training and education to all medical staff about unconscious bias and the impact it might have on their decision-making about treating people with

a disability.” And you give an example there. What would you like to tell the Royal Commission about what you think could be done for training and education on unconscious bias?

5 MS CREEVEY: Well, we do – doctors already, and nurses, to my knowledge, already do, like, stints in paediatrics. They do stints in the emergency room. They do in orthopaedics. Why can’t we have one working in disability? And it would actually be – not just a – you know, a thing we watch on the TV for – on the computer for two hours and we get it ticked off. Actually have, like, six months, or whatever it is, in working with people with disability so they understand that they are 10 people, and that somebody loves them and that they’re not their disability. That – and then, like, as teachers we have to do a mandatory training every year. So that could be a tick and flick watch the video and ask questions, but it’s really not that hard to implement, I don’t think. I don’t think making that sort of change would cost a lot of money, I guess, you know.

15 MS EASTMAN: Now, in paragraph 52 you also say, “It is crucial that treatment or care expectations be established on admission rather than medical professionals asking in a moment of crisis whether treatment should be withdrawn.”

MS CREEVEY: Yes. Yes.

20 MS EASTMAN: And you want hospitals to be proactive in that area. So you give an example of what you think might be helpful in terms of having some expectation on admission as to what the care may be and not be asked these very important life and death issues in moments of crises; is that right?

MS CREEVEY: Yes.

MS EASTMAN: Okay.

25 MS CREEVEY: Yes. We were – it’s very confronting when you go to a hospital and they say, “Do you have an end of life plan?” But in reality, they need to know what that person’s life is like, I guess, whether, you know, they’re having recurring chest infections and they – you know, that maybe it isn’t a good quality of life, or – but they need to know that. And it wouldn’t be any harder than, you know, “what’s 30 your Medicare number” or “what’s your – do you have an end of life plan”, so that they know they can access it. And if they don’t, have an advocate there that can help them to fill it out. Yes, that’s - - -

35 MS EASTMAN: And having an independent advocate, particularly for people living with disabilities and their families, to be able to navigate the hospital system and advocate for the rights of people living with disability you think is a very necessary addition to a hospital setting; is that right?

MS CREEVEY: Yes. When we take – when we had taken Harri to the hospital or taken our other two boys to the hospital, it was quite frequent that a person with a

disability would arrive unaccompanied. And, you know, that's – when they first arrive is when a lot of the decisions are made because, you know, statistically marriages fail and then you add a disability on it, you've got less, you've got more single mothers or single fathers, and they may have other children. So they've got to  
5 organise where they are going before they can get up to the hospital. And it wasn't uncommon for us to see situations like that, situations where we would go and sit with a child because Harri was fine. We would just go and sit beside them and, you know, pat them or hold their hand, or whatever.

They need to have somebody that's on call but not paid by the hospital. It has to not  
10 be paid by the hospital. So that they can be there, be called on in that moment of crisis, and make sure that the child or the adult gets what they need. And then there to explain – like when Harri was – we were asked whether we wanted to let Harri go. There was no one there asking any questions. Like, we asked our questions, but there was nobody there giving us the other side of the story. And then often, you  
15 can't – you know, you can't understand what they're saying to you because it's your child and you've got the emotions behind it. If there's somebody else there clarifying what they're saying, if you need it and if you don't need it, not to be there.

MS EASTMAN: And at paragraph 54 you say that you consider it would be useful - - -

20 MS CREEVEY: Yes.

MS EASTMAN: - - - to more widely implement something called My Health Matters.

MS CREEVEY: Yes.

MS EASTMAN: And that's a folder produced by the Council for Intellectual  
25 Disability.

MS CREEVEY: Yes.

MS EASTMAN: So what would you like to say about the My Health Matters, how it works and how it would make a difference?

MS CREEVEY: We – I discovered it through doing a presentation at the Panda  
30 Conference down here and it – like, the first couple of pages are very basic, and they say things like “I communicate via” – and it tells you how they communicate or – and then, like, one example was they showed a man that went in to a hospital – to a doctor's surgery where he hadn't been before, and he handed over this document, and it says on it that he uses his mobile phone. So the doctor could ask him  
35 questions and he could just type the answer out on the mobile phone. Another example was when the gentleman that has made this document, he said – his says, “I take – I will take a moment to answer.” So in that time that you and I would answer for him or assume that he can't, he just needed to give him that extra space. It then

says things like, “I’m – I enjoy bowling or I enjoy this or that.” But then if you read through – took the time to read all the pages you would really know the person. But that first page where it asks you how you communicate I think is so essential for – well, for someone like Harrison who couldn’t take his eye gaze equipment in with him but also for people to have their own independence. You know, if you’re asking a person a question in a medical situation and you’ve got to pause for them to respond but you don’t know that, it’s very easy to assume that they don’t understand what you’re saying or that they can’t respond or - - -

5 MS EASTMAN: Yes. Did Harri have one of those folders?

10 MS CREEVEY: No, no. I only discovered it last year.

MS EASTMAN: No. And do you think it might have made a difference in terms of managing that unconscious bias for Harri - - -

MS CREEVEY: Yes.

MS EASTMAN: - - - in the course of his life?

15 MS CREEVEY: Yes. Definitely, yes.

MS EASTMAN: Right. Finally you say that you consider that where there is a hospital-related root cause analysis - - -

MS CREEVEY: Analysis. Yes.

MS EASTMAN: - - - or open disclosure process for a treatment or an event during a hospital admission where the patient dies, the hospital should be required to report the death to the Coroner.

20 MS CREEVEY: Coroner. Correct.

MS EASTMAN: And why is that important?

MS CREEVEY: Well, I think when you look at the – what the deaths in care report indicated, that they’re not being reported, they’re not being reported, they’re not having to justify why the – like Harri got that treatment because on his death certificate it said ABI, so nobody questioned it any further. So your unconscious bias, you don’t have to report to anybody, you don’t have to justify, you don’t have to, you know, if you know that they’re just going to put ABI, you know, well, no one’s going to question, you know, what the – you know, the first 12 hours of Harri’s care in that hospital was appalling when you read it. And it had to be an unconscious bias because I can’t see how anybody could have done what they did to Harri or not do what they did to Harri if they didn’t have that. You can’t – I can’t see anybody purposely trying to not give somebody medication or not attend to them in an appropriate manner. It just doesn’t seem - - -

35

MS EASTMAN: Now, I have asked you all the questions based on the statement to the Royal Commission, but you've got a few other notes, and I hope I've picked everything up along the way, but do you want to check if there's anything else in your notes that you wanted to raise with the Royal Commission that I might have overlooked as we've gone through the statement?

5 MS CREEVEY: Not really. We – I guess the only thing I – you know, we're very proud to say is that Harri did only have 18 years of life, but in that 18 years of life, in his – what we call his going home party, we put up – we had a PowerPoint presentation, and the amount of people that walked away saying, "Oh my goodness, 10 our child's 18 and they've not done half the things that he had done." So we crammed into his 18 years of life things that, you know, most of us haven't done – well, at my age. So he – yes, so he did live a full life, but that was luck more than – you know, that was just tenacious parents rather than anything else. Yes. You know, essentially Harri was going to die, but we're all going to die, and – you 15 know, so we all need to get that. You need to get the best care you can and not judge a person by a wheelchair. He was using a – the eye gaze equipment that Stephen Hawkings was using. Where would we be now if he was treated the way that Harri would be? Astrophysicist – the world's greatest. He – we had imported stuff from computer – brain to computer interfacing equipment from the States, with the plan 20 that it would help him or he would be able to control drones. So this – Harri passed away four years ago, so Matt was right up on the technology of using the drones to save people for lifesavers, for putting robots down drains rather than, you know, trying to dig up the whole drain to find out where the blockage is. We were very aware of that. And Harri was going – that was his – that was where he was going. 25 He was going to do that. Yes, he would have needed a carer to be with him, but he was going to be independent. He was going to get an income. And they didn't see that. They didn't know all that about him and no one bothered to ask.

MS EASTMAN: Ms Creevey, thank you for your evidence.

MS CREEVEY: Thank you.

30 MS EASTMAN: And once again, our condolences for the loss of Harri from your life. Thank you.

COMMISSIONER SACKVILLE: Ms Creevey.

MS CREEVEY: Yes.

35 COMMISSIONER SACKVILLE: I too would like to express sympathy of all the Commissioners for your loss and to Matthew and to your two other children.

MS CREEVEY: Children. Yes. Thank you.

COMMISSIONER SACKVILLE: And thank you very much for coming and giving evidence to us and for your very thoughtful ideas, careful ideas as to what should be done in the future.

MS CREEVEY: Yes.

5 COMMISSIONER SACKVILLE: We are very grateful to you for your evidence and for your statement and for coming in.

MS CREEVEY: Hopefully it made sense.

COMMISSIONER SACKVILLE: It made a great deal of sense. Thank you.

MS CREEVEY: Thank you.

10 MS EASTMAN: Thank you.

**<THE WITNESS WITHDREW [2.16 pm]**

15 MS EASTMAN: Commissioners, we have one final witness, but I wonder if we could have a very brief adjournment for a couple of minutes just so that we can organise things for you.

COMMISSIONER ATKINSON: Sure.

**ADJOURNED [2.16 pm]**

20

**RESUMED [2.22 pm]**

COMMISSIONER SACKVILLE: Yes, Ms Eastman.

25 MS EASTMAN: If the Commission please, our next witness is Tara Elliffe. She has come with her dad, but her dad has been asked to wait outside. And, Tara, if at any stage you want dad to come back in, just let me know. Okay. All right.

COMMISSIONER SACKVILLE: It's the sort of thing that happens to dads all the time.

30 **<TARA KATE ELLIFFE, AFFIRMED [2.23 pm]**

**<EXAMINATION BY MS EASTMAN**

COMMISSIONER SACKVILLE: Thank you very much. Ms Eastman will now ask you a few questions.

5 MS EASTMAN: Can you tell us your full name?

MS ELLIFFE: Tara Kate Elliffe.

MS EASTMAN: And how old are you?

MS ELLIFFE: I'm 30 years old.

MS EASTMAN: And what is your occupation? What's your job?

10 MS ELLIFFE: I'm doing some things at New South Wales ombudsman, presenter at Speak Up disability awareness training workshops.

MS EASTMAN: And you've got a typed written-up statement in front of you. And that's the statement you've made particularly for the Royal Commission.

MS ELLIFFE: Yes.

15 MS EASTMAN: And the way we're going to do this is that in some bits I'm going to ask you a question, and in some bits you're going to read the statement.

MS ELLIFFE: Yes.

MS EASTMAN: All right. And what would you like me to call you as we go along? Tara?

20 MS ELLIFFE: Elliffe.

MS EASTMAN: Elliffe. Ms Elliffe.

MS ELLIFFE: Yes, with an I in it.

MS EASTMAN: With an I in it. Okay. Let's start. So first of all, if you turn over to paragraph number 5. Have you got that?

25 MS ELLIFFE: Yes.

MS EASTMAN: So you want to read paragraph 5. So tell us about your role.

MS ELLIFFE: I'm president of the Speak Up at Down Syndrome New South Wales, our social group, and I am on the advisory board of Down Syndrome New

South Wales. I am on the council for intellectual disability advocacy committee and the city of Sydney inclusion committee.

MS EASTMAN: Okay. Now, you love the movies.

MS ELLIFFE: Yes.

5 MS EASTMAN: And you like hanging out with your friends?

MS ELLIFFE: Yes.

MS EASTMAN: You like drinking coffee.

MS ELLIFFE: Yes.

MS EASTMAN: Travelling overseas.

10 MS ELLIFFE: Yes.

MS EASTMAN: And sometimes visiting your nieces in Wollongong.

MS ELLIFFE: Yes.

MS EASTMAN: All right. And we're going to skip over your education because we want to talk about your employment. So if you turn over to number 10. And

15 you're going to read number 10, 11 and 12.

MS ELLIFFE: Yes, Kate:

20 *For the first two and a half years, I have worked at the Office of New South Wales Ombudsman, who helped people with complaints. I also present to people with a co-worker for Speak Up workshops. I talk to people with high and low needs support. I teach them to say, "Stop" ..... because people with a disability are often get bullied. It took a lot of courage to start public speaking. I have a colleague, Christine - - -*

MS EASTMAN: And Christine was here this morning.

MS ELLIFFE: This morning:

25 *...who helped me to do this – the workshops. We did read and review ..... and that helped us to improve our workshops.*

MS EASTMAN: Okay. And before the job at the New South Wales Ombudsman, you had a job with the New South Wales Department of Family and Community Services for over seven years.

MS ELLIFFE: Yes.

MS EASTMAN: Okay. The next thing you wanted to talk about was living with a disability.

MS ELLIFFE: Yes.

5 MS EASTMAN: So have a look at number 15. And you're going to read number 15, 16 and 17.

MS ELLIFFE: Yes.

MS EASTMAN: Okay.

MS ELLIFFE:

10 *Having Down syndrome can be fun but challenged too much too. How other people treat me can be hurtful at times. But sometimes I get uncomfortable when people stare at me, but usually smile at them. I was told by a Canada man at the Congress to think "I'm okay, but you're mean."*

MS EASTMAN: So you say that sometimes.

15 MS ELLIFFE: To myself.

MS EASTMAN: To yourself. And that helps?

MS ELLIFFE: Yes, it makes me strong.

MS EASTMAN: Okay. Number 16.

MS ELLIFFE:

20 *I like going to places overseas and visiting my cousins. I get to go to the World Down Syndrome Congresses. In 2018, I went to the World Down Syndrome Congress in Glasgow. This year, I am going to the Congress in Dubai and will meet up with lots of friends from all around and the world.*

MS EASTMAN: Number 17.

25 MS ELLIFFE:

*I may also present about involvement in the Sydney City Council Inclusion Committee.*

MS EASTMAN: Okay. So turning over the page, you also wanted to read paragraph 18, 19, 20 and 21.

MS ELLIFFE: Yes.

MS EASTMAN: All right.

MS ELLIFFE:

5 *I have also travelled to Singapore, South Africa, India and also Ireland to the  
Congresses, had holidays in Ireland and UK, and went to Fiji for a friend's  
wedding. Living with a disability doesn't stop me travelling and exploring the  
world. I have lived with my parents. One day, I would like to have a place  
close to my parents, but I want my own space. I want to be independent, just  
like my brothers. Sometimes it's hard when people put you down and say  
10 things, but never say anything. I have to hold back in myself and not get upset.*

MS EASTMAN: Okay.

MS ELLIFFE:

*Sometimes I shut down and get quiet. At those times, Mum can read me like a  
book. She will help me talk through what's happened, make sense of it all.*

15 MS EASTMAN: Okay. Thank you. Now, I'm going to ask you some questions. Is  
that okay?

MS ELLIFFE: Yes.

MS EASTMAN: So we're now going to talk about your health care. So, first of all,  
talking about your doctor. You have your own general practitioner, a GP?

20 MS ELLIFFE: Yes, I do.

MS EASTMAN: And this doctor has an interest in disability?

MS ELLIFFE: Yes.

MS EASTMAN: And she talks to you straight, not just your mum?

MS ELLIFFE: No. That's right.

25 MS EASTMAN: And this doctor has been helping you for a long time; yes?

MS ELLIFFE: Yes.

MS EASTMAN: And you've been seeing her for 10 to 12 years, and you trust her?

MS ELLIFFE: Yes, I do.

MS EASTMAN: And do you think it's been a good thing to have the same doctor for a long time?

MS ELLIFFE: Yes.

5 MS EASTMAN: And you see the doctor if you feel sick, and you also see her for routine check-ups.

MS ELLIFFE: Yes.

MS EASTMAN: At the moment, you visit the doctor every month?

MS ELLIFFE: Yes.

10 MS EASTMAN: And the doctor makes long appointments for you, not just short ones.

MS ELLIFFE: Yes.

MS EASTMAN: Before you go to the doctor, you say:  
*I prepare to see my doctor before I go for my appointment.*

MS ELLIFFE: That's right.

15 MS EASTMAN: And if you have any questions to ask, you write them down.

MS ELLIFFE: Yes.

MS EASTMAN: And you take your questions and your scripts with you when you go to see the doctor?

MS ELLIFFE: Yes.

20 MS EASTMAN: Sometimes you bring your mum, but sometimes you go on your own?

MS ELLIFFE: Yes.

MS EASTMAN: And you call your mum, and the doctor and your mum talk to each other on the speakerphone so you know what's happening.

25 MS ELLIFFE: Yes.

MS EASTMAN: When your doctor talks to you, she types notes on her computer.

MS ELLIFFE: Yes.

- MS EASTMAN: And you've started using a folder called My Health Matters?
- MS ELLIFFE: Yes, that's correct.
- MS EASTMAN: All right. Can I stop there. What's that folder? Tell me about the folder. What can you tell me about - - -
- 5 MS ELLIFFE: I just recently got it, and it might be useful to use.
- MS EASTMAN: Okay. So it helps you with your information.
- MS ELLIFFE: Yes.
- MS EASTMAN: Okay. So let's go back to paragraph 20 – number 26. So you're planning to use this folder when you go to the GP and also other doctors?
- 10 MS ELLIFFE: Yes.
- MS EASTMAN: Okay. Your doctor has a special care plan for you?
- MS ELLIFFE: Yes.
- MS EASTMAN: And you talk to the doctor about the care plan every month - - -
- MS ELLIFFE: Yes.
- 15 MS EASTMAN: - - - and check how things are going.
- MS ELLIFFE: Yes.
- MS EASTMAN: The care plan has your history, medications and all the doctors that you see?
- MS ELLIFFE: Yes.
- 20 MS EASTMAN: And you also see a dietitian, a physio and a psychologist.
- MS ELLIFFE: Yes.
- MS EASTMAN: Okay. Let's go over the page. Your doctor and you review your care plan every two years.
- MS ELLIFFE: Yes.
- 25 MS EASTMAN: Okay. Now, the next topic we're going to talk about is consent. And you know what consent means. And you would like me to read part of this.

MS ELLIFFE: Yes, please.  
MS EASTMAN: Okay. If your GP tells you that you need to take medication or have treatment or a procedure, you don't ask her any questions because she usually explains everything to you first.

5 MS ELLIFFE: Yes.  
MS EASTMAN: And you trust her.  
MS ELLIFFE: Yes, I do.  
MS EASTMAN: If she says it's a good thing for you, you generally agree.  
MS ELLIFFE: Yes.

10 MS EASTMAN: You know what consent means:  
*It means, "I'm agreeing to do something", and sometimes it means my signature."*  
That's your signature.  
MS ELLIFFE: Yes, my signature.

15 MS EASTMAN: Sometimes you need Mum or Dad to help you make decisions, but sometimes you can make them on your own.  
MS ELLIFFE: Yes.  
MS EASTMAN: Now, the next bit you wanted to read over the page, starting:  
*Usually I discuss my decisions.*

20 What do you want to say there? You were going to say something about your brothers. Can you remember?  
MS ELLIFFE: No.  
MS EASTMAN: That's okay. So usually you discuss your decisions with your parents and your brothers. And your brothers are awesome, aren't they?

25 MS ELLIFFE: Yes, my brothers are really awesome.  
MS EASTMAN: That's what you wanted to say about your brothers.  
MS ELLIFFE: Yes.

MS EASTMAN: Okay. So next is when you go to see – when you went to see a specialist for a blood clot, it was good, and he helped you understand what was going on, what happened to you, and what medications you needed to take. Is that right?

MS ELLIFFE: Yes, that's right.

5 MS EASTMAN: Okay. The next topic is specialist doctors. So shall I ask the questions on this one?

MS ELLIFFE: Yes, please.

MS EASTMAN: If you go to see a specialist, you might be meeting them for the first time.

10 MS ELLIFFE: Yes.

MS EASTMAN: And it's different to seeing the GP.

MS ELLIFFE: Yes.

MS EASTMAN: And if you go to a specialist, you always go with your mum.

MS ELLIFFE: Yes.

15 MS EASTMAN: One time, you needed to see someone called a cardiologist.

MS ELLIFFE: Yes.

MS EASTMAN: And a cardiologist is someone who looks after hearts.

MS ELLIFFE: Yes, they do.

20 MS EASTMAN: And you didn't like the first cardiologist that you saw, and you didn't like him because he didn't speak to you, he spoke to your mum; is that right?

MS ELLIFFE: Yes, that's right.

MS EASTMAN: Okay. And you remember that they talked about putting in a pacemaker, and you didn't like the idea of that. So you didn't go back to see that cardiologist; you went to see a different one.

25 MS ELLIFFE: Yes.

MS EASTMAN: The new cardiologist asked you lots of questions about your history and how your health had been.

MS ELLIFFE: Yes.

MS EASTMAN: And you didn't understand a lot about what was happening. Your mum was there, and so you had to ask her to answer some of the questions.

MS ELLIFFE: Yes, that's right.

5 MS EASTMAN: Okay. Now, the next bit that we're going to talk about is a particular experience in hospital.

MS ELLIFFE: Yes.

MS EASTMAN: And this was a bit of a scary time, wasn't it?

MS ELLIFFE: It was very scary.

MS EASTMAN: But you've decided you want to read this bit out yourself.

10 MS ELLIFFE: Yes.

MS EASTMAN: Okay. Are you ready?

MS ELLIFFE: Ready.

MS EASTMAN: Let's do it. Paragraph 36. Over to you.

MS ELLIFFE: Thank you, Kate.

15 MS EASTMAN: Pleasure.

MS ELLIFFE:

20 *One day in 2018 I was feeling unwell and had a pain in my stomach. I went to the GP with my father, but it wasn't my usual GP. This doctor asked me how my pain was, and I was feeling gentle. The doctor told me to go to the hospital. I went to the hospital with my dad. When I got to the hospital, I was a lot of pain. I was – I had to sit outside for about 10 minutes before I went in to see the doctor who I was – who saw me. I had blood tests, X-ray and scans. I saw a lot of different doctors. I felt like a yo-yo going for the test.*

25 MS EASTMAN: Okay. So you want – do you want to keep reading? If you want to change your mind, just let me know.

MS ELLIFFE: I keep reading. Thank you.

MS EASTMAN: Keep reading? Okay.

MS ELLIFFE:

5 *My head was exploding from all the noise and different people. It was building and crushing down on me. My stomach was in so much pain. It was like a jackhammer was in my stomach. The big doctor came in to tell me that I was ready to go home. This didn't look at me at all. He just looked at my dad and said, "What's her problem?" Mum asked me to point on her back where the pain was. I pointed to her shoulder. Then the doctor ordered another ultrasound. The lady who did my ultrasound was good. She explained what she was going to do and said, "Sorry if it hurts." I had an operation the next day.*

10 *After the operation, I was in hospital for what I felt like ages. It took a bloody long time to get home. Every morning in the hospital I would wake up at about 4 o'clock am in the morning because I was in pain. I would call out to Mum, "I need painkillers now." I was hurting again. I had to press the button to call the nurse, but she would not give me medication. I needed my mum and my dad*

15 *to be there to help to get the painkillers and feel safe. I was in pain, just wanted to go home. I don't ever want to go back to a hospital again.*

MS EASTMAN: Okay. So just stopping there for a minute. You have thought about what doctors and hospitals can do better; yes?

MS ELLIFFE: Yes.

20 MS EASTMAN: And you've written down what you would like to say about that. Do you want to read that part as well?

MS ELLIFFE: Yes, please.

MS EASTMAN: All right. So number 50.

MS ELLIFFE:

25 *I have a lot of things that I think doctors and hospitals can do better. Listen carefully to people with a disabilities; ask simple questions; use pictures to help people understand; answering people's questions; talk to me and not my parents; have documents in Easy Read. Also, think doctors and nurses should have disability training. Any disability training would be good, and to have*

30 *people with a disability doing same of the training. Mum has worked in hospital, so I have been to hospital before. But some people have never been to a hospital. It would be good if people with disability could have a tour in the hospital when they are well.*

MS EASTMAN: All right. And then over the page, one more bit to read.

35 MS ELLIFFE: Thank you:

*If people with a disability can have a tour of a hospital, they would know what to expect if had to go to the hospital in emergency one day.*

MS EASTMAN: Thank you very much. Can I check, is there anything else that you would like to say?

5 MS ELLIFFE: Just listen to us.

MS EASTMAN: On that note, that's the evidence, and thank you so much for coming to speak to the Royal Commission.

MS ELLIFFE: Thank you.

10 COMMISSIONER SACKVILLE: Ms Elliffe, thank you very much for coming to talk with us. It has been wonderful having you come and talk with us, and can I promise we have listened very carefully. Thank you very much.

MS ELLIFFE: Thank you so much.

COMMISSIONER SACKVILLE: Thank you.

15 <THE WITNESS WITHDREW

[2.42 pm]

MS EASTMAN: So, Commissioners, can I do a little bit of administrative work that I've probably overlooked. The first, just dealing with Tara's statement, it's behind tab 30 in part A. If that could be tendered and marked exhibit 4.14.

20 MS EASTMAN: And in relation to Ms Creevey's evidence, that can be found in part A behind tab 28 to 29. If that could be marked exhibit 4.13.

MS EASTMAN: And that also includes the photographs that were part of the evidence. I think then I've now dealt with all of the tenders if I've overlooked them during the course of the week, and that concludes the public hearings for this week.

25 And we will resume on Monday morning.

COMMISSIONER SACKVILLE: Thank you very much, everybody, and thank you for everybody who has come to listen to this hearing and everybody who is following it on the webcast. And, as Ms Eastman has said, we will resume at 10 o'clock on Monday morning next. Thank you very much. We will adjourn now.

30

**EXHIBIT #4-13 STATEMENT OF KIM LETITIA CREEVEY DATED  
07/02/2020 (STAT.0044.0001.0001)**

**EXHIBIT #4-14 STATEMENT OF TARA KATE ELLIFFE DATED  
13/02/2020 (STAT.0063.0001.0001)**

**MATTER ADJOURNED at 2.44 pm UNTIL MONDAY, 24 FEBRUARY 2020**

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