

TRANSCRIPT

LEGISLATIVE ASSEMBLY LEGAL AND SOCIAL ISSUES COMMITTEE

Inquiry into increasing the number of registered organ and tissue donors

Melbourne—Friday 25 August 2023

MEMBERS

Ella George—Chair

Annabelle Cleeland—Deputy Chair

Chris Couzens

Chris Crewther

Gary Maas

Cindy McLeish

Meng Heang Tak

WITNESSES

Anna Gillard,

David Gillard, and

Cynthia Caruana.

The CHAIR: Today is really just an opportunity for a bit more of an informal conversation with you. We are so grateful for your time today. My name is Ella George, and I am the Chair of the Committee. We might just go around the table of Committee Members for everyone to introduce themselves to you. I am the state Member for Lara, which is in Geelong's northern suburbs.

Annabelle CLEELAND: Annabelle Cleeland. I am the state Member for Euroa in regional Victoria, and I am Deputy Chair.

Meng Heang TAK: Heang Tak, Member for Clarinda.

Chris CREWETHER: Chris Crewther, Member for Mornington.

Cindy McLEISH: Cindy McLeish, Member for Eildon.

Chris COUZENS: Chris Couzens, Member for Geelong.

Gary MAAS: Gary Maas, Member for Narre Warren South.

The CHAIR: Once again, thank you so much for appearing before us today.

Just to let you know, all the evidence being given today is transcribed by our Hansard team. It is protected by parliamentary privilege, but comments repeated outside this meeting may not be protected by this privilege.

You will be provided with a proof version of the transcript to review and advise us whether you are comfortable with it and whether you are comfortable for the Committee to decide if it will be made public. It could be public with your name or any identifying details removed to keep it more private. So the Committee Secretariat will be in touch with you after today just to have a conversation about that, but we are really in your hands with that one.

We are incredibly grateful that you have appeared before us today. We have spent the morning already—you will notice the tissues around and some red eyes—speaking to people who do have lived experience of organ and tissue donation. For us as a Committee they were really important voices to hear. It is really important that we hear the human side of this inquiry too, so once again we are incredibly grateful that you are here.

I would like to now hand over to you if there is anything you would like to share with the Committee about your own stories and your own experiences. Then following that we might have some questions from the Committee Members, if that is okay.

David GILLARD: Our son Rhys—we lost Rhys just over two years ago—was 17 years old. He died when he was nearly 18. He died suddenly, unexpectedly. We still do not know what the cause was. It is being put down to a –

Anna GILLARD: Sudden cardiac arrest.

David GILLARD: Yes, so the assumption is that his heart just stopped.

Anna GILLARD: He had an arrhythmia.

David GILLARD: So, yes, that was the Thursday morning. He was a fit and healthy athlete. You are invincible as a 17-year-old. We were totally devastated obviously. On the day he passed we were out with my parents. We went for a walk in the park during the day. We were in the car on the way home and had a phone call from, as it turned out—I cannot remember the lady's name, but it was the nurse –

Anna GILLARD: Janine.

David GILLARD: Janine, from the tissue bank, and that was after Rhys had been taken to the coroner's. She started talking about the possibility of him being a tissue donor. I think at the time we said, 'Oh, we can't talk now because our other two sons are in the car.' But then we spoke to her later and had just an amazing conversation with clearly a highly trained individual who talked us through the options for Rhys. Organ donation was not an option because they still had to go through a process of investigation, but he was a prime

candidate for tissue donation. We thought, 'This is what Rhys would want.' You know, his whole life was about sharing and giving, so it was kind of perfect for that. So the machine kicked in, the process went through. Later on we found out that he donated corneas and skin, and over time we found out that all of his donations were successfully—I do not know what the word is—not transplanted but gifted, and it gave us a lot of comfort knowing that he had helped other people. And I think from a lot of conversations that Anna has had, parents in a similar position who for whatever reason did not have that opportunity –

Anna GILLARD: I will go through that.

David GILLARD: feel cheated, in a way, that they did not have that opportunity. So in hindsight it is a powerful comfort to know that that happened.

The CHAIR: Thank you, David.

Anna GILLARD: I will just speak a little bit as well. I wrote a few things down, so I might refer to my phone if you do not mind.

The CHAIR: Please. Of course.

Anna GILLARD: When we got that first call and during the day when we spoke to Janine a few times, it just kind of gave us something to focus on. I think for both of us, we did not know Rhys's wishes but there was a gut feeling that he would have wanted to help people, so I think we did not have to think about it long. And then, when they did let us know that Rhys had donated—the corneas had to be donated in the first month, so they both were donated to different individuals. And then they let us know. The phone call was, you know, quite emotional, but it was so nice to hear that that had happened. The skin graft took a bit longer because they had to do some testing, and that can last five years I think. I think he helped five different people with that, which again was amazing.

The CHAIR: Incredible.

Anna GILLARD: Again, to be in the loop and have those conversations was really special. Also, for us, I know the tissue bank does the leaf ceremony. I am not sure if you went to it. But in 2021 it was COVID, so it was not going to happen. But we went in for a meeting to meet with the forensic pathologist, which was in the next building, so we called Janine to see if we could actually go and have a look at the *Tree of Life*, and we got some leaves with Rhys's name on it and chatted to Janine about it all. That was a really special experience, as well as going to the DonateLife Victoria event, which was in December last year. That is wider than just the tissue bank, but it was such a safe space to be with lots of people grieving, freshly grieving. I think I just cried the whole 2 hours we were there. But it was just beautiful to hear the stories, and it was just a safe space to share that emotion. So to be provided with that as well by the organisation was really lovely.

As David touched on, I have got four friends who I have got to know through the Compassionate Friends. All of their children were around the same age as Rhys and died within the same year, but none of them had the experience that we had. One of the mums called the tissue bank to see why they were not called, and she was told that it depended on the actual day and that because her daughter died on the Friday night during the weekend the staffing was not necessarily trained to speak to grieving parents. I just thought I would bring that up today as well, because I just thought everyone gets called, but we then realise how special it was that Rhys did get that opportunity.

The CHAIR: Thank you, Anna.

Anna GILLARD: Thanks.

Cynthia CARUANA: Me?

The CHAIR: Yes, please. We would love to hear from you.

Cynthia CARUANA: I prepared something earlier because I did not want to forget anything.

The CHAIR: That is great. Thank you.

Cynthia CARUANA: You will just have to bear with me if that is all right.

The CHAIR: Absolutely. We are in your hands.

Cynthia CARUANA: Cool. Good morning, everyone. Thank you for giving me the opportunity to speak about my experiences with organ and tissue donation. My name is Cynthia, and my family consists of my husband Martin and my sons Mason and Myles. My journey with this topic started many years ago. You see, my father's family suffered from a disease called polycystic kidneys, and five out of nine children were affected. For many years my aunts and uncles controlled their condition with medication, but they all deteriorated to a point where it did not work and the only option was organ donation. I am happy to say that they all had successful transplants. What is important here is the difference that it made to the quality of life that they had thereafter. From being hooked up to a dialysis machine 7 hours a day, three days a week, to having no treatments at all, it gave them the freedom to enjoy life with their family and friends again. We had a special uncle and aunt we stayed with when we were in Sydney. When my uncle was not on dialysis, Myles would spend time with him, asking questions about the procedure and the outcomes. Like most children, there was no conditioning about what may or may not have been improper questions. Many years later my uncle told me how much he appreciated the interest and how much in awe he was of this child, who seemingly had no fear of the process and his condition, as in his experience even most adults shied away from the topic. I believe that it was this experience that made Myles aware and shaped his outlook on organ donations.

It was about four weeks after Myles was born that we started to notice that his skin was becoming quite red and raw, and it soon developed into what we can only describe as a gravel graze all over his body. He was diagnosed with eczema and had to continually be wet dressed, with the bandages being changed every 2 hours. A few months later, when introducing him to solid food, we noticed there were times when his eczema would be much worse. After many visits to doctors, specialists and numerous tests, he was diagnosed with life-threatening allergies to eggs, nuts and dairy. All those years ago there was no access to the variety of alternative foods that we have today. Fast-forward 18 months and we were faced with another medical condition, asthma. I have to say that his eczema had almost cleared up at around two years of age, and his immunologist at the Children's Hospital did advise that, because his eczema was so bad, he would probably suffer from either life-threatening food allergies or asthma, but it would be rare to have all three. We never did expect that he would have had all three in such a severe manner.

There were many visits to both the Sunshine and Royal Children's hospitals, at times resulting in stays in intensive care. Specialist visits were spaced out every six weeks, and his medications were an integral part of his life. After his second respiratory arrest, he was placed on long-term cortisone, and the lasting effect of this was osteoporosis in his spine. For this he had to have bisphosphonate infusions every three months, and he had to give up the one thing he really loved, gymnastics, because of the hard landings for his spine. In true Myles style, he took up golf instead. I have always marvelled at his determination to keep going despite all the hurdles, and again, he made my job so much easier. As a child Myles never complained about what he could have or not have; rather he just got on with life. I just realise now how much of a blessing that was. He had absolute faith in himself. He knew he had the love of family. I remember at one camp, the very, very first one I did not go to, he came to the car and said his teacher would like to see me. Surprised? Certainly. In any case, I was told that Myles was rolling a billiard ball on the floor that had bounced up and shattered a window. Apparently in his usual calm manner he owned up to the mischief and told the teacher, 'Don't worry, sir, my mum will pay for it.' I remember many instances like this, and I am so grateful that he had that love and certainty to hold onto. I believe that it was his life experiences with his conditions that gave him the empathy and the compassion for others who had a similar medical or challenging condition, but for the most part he was such a happy child, and we nicknamed him 'Myles and miles of smiles'.

It was after one visit with my uncle and aunt that Myles had the conversation with us about organ donation. He explained that when his time came, he would like to be a donor, and this would be the ultimate form of recycling. At the time we took it all in, marvelled at his insight and realised that this was a worthwhile process. Little did we realise how soon that time would come.

Myles had many hospital admissions for his asthma and food allergies, ending up in ICU on three occasions. We knew the nurses by name, and even the cleaners would come and say hello to him. Myles had a cardio respiratory arrest on 6 March and was admitted to Royal Children's Hospital intensive care. There were many tests in the week after, with the result being brain damage from some of the arrests. Myles was in ICU until

23 March 2006, when he was transferred to the adolescent ward. Unfortunately, he never woke up and continued to deteriorate until he passed away peacefully on 26 March. He was 15 years old.

It is important to note here that it was from all the conversations that we had as a family that we were fully aware of his wishes, which made it easier to fulfil when his time was here. It is crucial for a person's loved ones and next of kin to be aware of their wishes. If not, the additional shock at a time of such grief and sadness is almost overwhelming for families to take in, and the decision, with such a small window, is sometimes lost. Apart from his tissue of skin, heart, valves and corneas, Myles has made a difference. After his passing many of his school friends had the conversations with their parents, and one has even become a paramedic.

I believe the current process which allows the next of kin to overturn a person's wishes is cruel, because it comes down to their outlook and their values, which might not match the initial decision that was made by the person. It is important to get the message out there, and I believe the younger generations who are considering things like climate change at an earlier age are seemingly more aware of cause and consequence and are more open to the process of organ and tissue donation. I have spoken on many occasions on behalf of the Victorian Institute of Forensic Medicine, but I think the message needs to go out to a wider audience, most of whom would not think about tissue donation or organ donation until it directly affects them. Mostly, at that time, it is too late. TV programs which deal with difficult issues, for example, *Insight*, might be valuable in targeting this audience. Signing up to the donor registry should be legally binding, but I admit that this is problematic without familial discussion.

I thank you for your patience and your time in listening to my family's story. It has been my absolute pleasure to share a small snippet of my Myles's life.

The CHAIR: Thank you so much, Cynthia and David, for sharing your stories and your families' stories with us. We are incredibly grateful that you felt comfortable to share that with us. Like I said earlier, it is so important that we remember the human side of why we are doing this inquiry as well. Again, thank you so much.

Cynthia, you spoke a little bit about the importance of those family conversations, and that is something that we have heard from a lot of witnesses. Something that the Committee is thinking long and hard about is those family conversations and just how important they are. Now I would like to open it up to Committee Members if you would like to say anything or ask any questions. Cindy, would you like to start?

Cindy McLEISH: Thank you everybody for coming in. It is interesting, actually, having had the family conversations, Cynthia, through the experience that you have had, and then on the other hand with Anna and David, and particularly the people in that compassionate group that you have met. I am kind of interested how the conversation went. You mentioned that Rhys was a donor, and the fact that they said, 'Why weren't we called?' They sounded obviously very open to being called and perhaps did not know anything about it. Was that your experience?

Anna GILLARD: Definitely. It was more with one friend who came for a coffee. At the time I think we were sharing Rhys's story, or the donor tissue bank was sharing Rhys's story, on his one-year anniversary. So I happened to mention it to her and did not really realise how she felt about it. She then said that she wished that she had had that call, and she wished her daughter could have helped others as well. She was actually quite affected by it, which is why she then called the tissue bank to find out why that call was not made to them. She asked some of the other members in our group whether they had had a call, because she wanted to find out whether it was to do with the day of the passing.

Cindy McLEISH: What do you think it was to do with—just the weekend?

Anna GILLARD: That was the answer she was given by the tissue bank. I know there are other circumstances when they cannot use the tissues, but she was told it was to do with the day.

Cindy McLEISH: And you said Rhys was not able to be an organ donor; I am not sure exactly why. Was Myles an organ donor or just tissue?

Cynthia CARUANA: He would have liked to have been an organ donor, but because of the way he passed—he was in ICU for nearly three weeks—there was obviously the deterioration of organs, which did not

make them viable. So then we went down the path of tissue. But our original conversations were all about organ donation because of that familial connection. But, yes, at the time we did not realise even that we would have had that opportunity and that avenue should organ donation not be viable—that we also had another avenue available to us.

Anna GILLARD: Yes. That is another thing actually. We did not know anything about tissue donation, and most people we speak to do not.

David GILLARD: Yes, organ donation is the thing. I am a card-carrying organ donor, but tissue is not really something.

Cindy McLEISH: We found the same thing.

Anna GILLARD: And they do not know that it means things like the cornea or even internal parts of the heart. Rhys passed in what we think were the very early hours of 13 May, and we found him in the morning. So it was quite a few hours by the time he got to the coroner's. As far as I am aware, someone has to pass away in hospital to be able to donate organs.

David GILLARD: Also, they were still trying to find cause of death, so they were not going to remove any organs. That is why his tissue became an option.

Anna GILLARD: And the tissue harvest—is that what it is called?—had to happen within 24 hours as well.

Cindy McLEISH: Thank you.

The CHAIR: Thanks, Cindy. Annabelle.

Annabelle CLEELAND: Thank you so much. Through your experiences—I am just going to cry the whole time now—can you advise us what you would like to see through this inquiry as potential recommendations or outcomes that may have made your experience a little bit easier?

Cynthia CARUANA: I guess for me, we did not have the shock of having the tissue bank or the organ donation people contact us. So when it became apparent that Myles was deteriorating in the ward, I made the decision to contact the institute and organise that. I am very logical: I just looked at it and I thought, 'I'm in the frame of mind to do that right now; I do not know what I am going to be like later.' I knew what the eventual outcome was going to be; I just did not know when. So we contacted them, and I can only compliment Anna in saying that, you know, I think Janine came out as well at the time, and she was absolutely fabulous. She went through the whole process, and you know with organ donation there is a very specific way and there are very, very specific terms and conditions to donating your organs. You cannot just die, you have to be on life support and a whole lot of medical things. So she explained that it would be tissue donation, and we went through the whole process. They explained everything, and I think, having had a lot to do with the institute as well over the last 15 years, everyone I have met has that same compassionate outlook in terms of knowing what they need to do, but they take on board the other person, which is really, really great.

I think the institute is really well founded in that respect—but maybe, you know, some sort of intake for the weekend or so that the opportunity is not missed. There would be far more avenues for tissue donation than there would be for organ donation, and it is sad that families who are grieving might feel left out of the process when they are open to the process. It is so hard to get people to open up to the process, so it is sad when people are open and they have missed that window—because it is a very small window. That is probably one of the things that I would take from that.

David GILLARD: I would just say I think the power of personal stories is important, because as hard as that is, I think that is the only way—because we never had a conversation with Rhys about being an organ donor or a tissue donor. You do not consider that outcome, but having gone through that and knowing that that is an option and knowing how that helped us with our handling of grief and processing that, it keeps Rhys's name alive, his story alive. Knowing that he helped all those people is very, very powerful. So I think the power of personal stories is not to be underestimated, and I think that the way, particularly with tissue donation, is to get it out there so that people have somewhere in the back of their mind, 'Okay, that's an option.' It may come to them—I do not know if it will in that moment—but I think personal stories, knowing how it helps with the

grieving process, are very, very powerful, and knowing how people have felt that did not have that option is powerful.

The CHAIR: Thank you. Chris?

Chris CREWITHER: Thank you very much for your evidence today before the Committee—and particularly given your experiences as well and what you have been through. A previous witness noted that it would be good for more donors and recipients and their families to have a chance to meet more, for those who consent. And also I guess another point was about death certificates acknowledging organ donation, so in the future, when future family members look at, say, the history, they can see that that person was an organ donor and so forth. Are they the sorts of things that you would support the need for?

Anna GILLARD: Definitely. I think having it on the death certificate—because it is such an official document and you keep it—would be a really good way to remember that, like you say, for future generations as well. And the first point was that donor families wanted to meet more often—is that what you said?

Chris CREWITHER: Yes. Should there be more opportunities made to enable—for those who consent of course on both sides—recipients and donor families to meet?

Anna GILLARD: I see what you mean. Yes, it is a tricky one.

David GILLARD: I am not sure about that one. I do not know how I would handle it. I probably feel it is better to not know. The information that we were given and shared was that Rhys's skin was donated to a 35-year-old male in this area as a result of—whatever. For me personally, that is all I need to know.

Anna GILLARD: And I feel that would be different, potentially, if you donated an organ. I do not know, not having experienced that. But then it is really tricky.

David GILLARD: It is a big ask for the recipient, I think, because when we went to the—what was it called, that event that we went to?

Anna GILLARD: The DonateLife Victoria.

David GILLARD: The DonateLife. So there were stories of donors, but there was a recipient as well who came up to speak, and I thought that was one of the bravest things I have ever seen. I cannot imagine being in that position, talking to a room of families of donors. I think it is a very special thing to be able to do that. I worry that that puts the recipients in a very difficult position, but if they feel as though they can do it, and people get benefit from it—yes.

Anna GILLARD: And I know that people have the option of sharing their story on, for example, DonateLife Victoria's Facebook page and saying, 'I have received this,' and actually speaking about their feelings. Sometimes people might have connected that way.

Chris CREWITHER: Thank you. I appreciate it.

Cynthia CARUANA: I cannot remember offhand now, you know, the experience and the person that actually received them, but we did let it be known that we were open to being contacted, and I would dearly love to be able to meet with those people, if they were up to it. I take on board what David said, that sometimes it is very, very difficult. You are so grateful for that opportunity, but your quality of life has come at great cost to somebody else, whether it was expected or sudden, and I do understand that person not wanting to put more pain on the donor family. But I certainly think that if both sides were open, there should be some active encouragement, because as I said, for me personally, I would just love to know and I would just love to meet them. I do not want to have a relationship with them, but I would just love to meet with them that one time, just to see with my own eyes the difference that my son made. As a mother—and my husband is a little bit different about that—I know there is piece of him somewhere out there, I know his legacy lives on. I am very visual; I would like to see them in front of me. But that is me. I think all you can ever do in these circumstances is give people the options, and I think that is what is really important with your options, as you said. Some families not having that, I think that is the most crucial thing, because you can never go back and say you did not make an informed decision. And when you think you could have made a difference and you were not given the opportunity, I think that in itself in some ways would be equally heartbreaking as well.

Chris CREWETHER: Yes. Thank you.

The CHAIR: Unfortunately, we are out of time, so we might finish the discussion here. But following on from today, if there is anything that you would like to raise with us, please feel free to get in touch. If there is anything else you would like to add in or anything else that you think is important for us to be hearing about, please do not hesitate to get in touch. As I mentioned earlier, our discussion today has been transcribed by the Hansard team, and we will be providing you with a proof version of that, so the Secretariat team will be in touch with you to discuss that. Once again on behalf of the Committee, thank you so much for your generosity in sharing all of your stories today. We are incredibly grateful that you have taken the time to present to us and that you felt comfortable to share, so thank you so much.

Committee adjourned.