

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

WITNESS

Leanne Campbell.

The CHAIR: Leanne, how this will work—it is really a very informal conversation, and so we would love to give you the opportunity if there is anything you would like to tell us about your lived experience of organ and tissue donation. And then we might have a few questions, just following on from what you have told us, from the Committee Members if that is okay with you.

Leanne CAMPBELL: Yes, that is fine. Yes, absolutely.

The CHAIR: Great. We have got our Hansard team here as well, who will be transcribing today.

Leanne CAMPBELL: I will try not to mumble.

The CHAIR: Just on that, all the evidence that you are giving today is protected by parliamentary privilege, but comments repeated outside this meeting may not be protected by this privilege.

The Secretariat will provide you with a proof version of the transcript for you to have a look through, and you can advise us as well if you are comfortable for the Committee to decide for it to be made public—or public with your name and any identifying details removed to keep it private. The Secretariat will be in touch with you after today's meeting just to have a chat about that. So rest assured that, you know, if you do want to keep some things confidential, we can absolutely do that as well.

Leanne CAMPBELL: Thank you.

The CHAIR: Leanne, my name is Ella George, and I am the Chair of the Committee. I am the state Member for Lara, which is in Geelong's northern suburbs. And we might just go around the table now and introduce ourselves. Annabelle.

Annabelle CLEELAND: Thanks, Leanne. I am Annabelle Cleeland. I am the Member for Euroa.

Meng Heang TAK: Heang Tak, Member for Clarinda.

Chris CREWOTHER: Chris Crewther, Member for Mornington.

Cindy McLEISH: Cindy McLeish, the Member for Eildon.

Chris COUZENS: Chris Couzens, the Member for Geelong.

Leanne CAMPBELL: Nice to meet you all.

Gary MAAS: And over here, Gary Maas, last but not least.

A member: We always forget Gary.

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

Cindy McLEISH: The important one.

Gary MAAS: That is it.

Chris CREWOTHER: Save the best till last.

Gary MAAS: It is on Hansard now.

The CHAIR: Leanne, thank you again so much for your time in speaking with the Committee today. We thought it was really important to hear from people who do have lived experience of organ and tissue donation, so we are really grateful for your time. I would love to hand over to you now if there is anything you would like to share from your story.

Leanne CAMPBELL: Okay. I will try not to get emotional. Gee, I thought I would be good at this.

The CHAIR: Please take your time, Leanne.

Leanne CAMPBELL: It is the sitting for 40 minutes that did it. Thank you for the opportunity to speak. I think it is really important that the donor family voice is heard. I would like to take a moment for us all to reflect on our donor loved ones and the gift of life they gave to others and on the people who died waiting for a transplant. I think it is really important that within this discussion we put some humanity back into it. I think we remove that too much, and I do not think that is a good thing.

Okay. I do not know if any of you have read the submission recently about Brett's story. He was a 21-year-old young man away on holidays with his mates, having a damn fine time and drinking up along the Murray River. And one of his mates decided it would be fun to ride a pushbike down a boat ramp and knocked him over at the bottom. We received a wake-up call at 1:30 in the morning to say that there had been an incident but everything would be fine and that we would hear from the hospital. At about 3:30 we got a call from them saying no, it was not good at all. I think you have to be very mindful that in a regional setting a hospital like Echuca is very, very small, and certainly the population probably more than doubles in summer with lots of things. There were really only two emergency beds as such. They were just brilliant at the hospital, but over the phone the doctor did the 'Er, ah, um', to which I said, 'You're going to ask about organ donation, aren't you?' It is definitely not the ideal situation to have that presented to you over the phone, because you do not actually have any clarity of the true medical situation then, you know.

Cindy McLEISH: Was that at 3:30?

Leanne CAMPBELL: In the morning.

Cindy McLEISH: That was that second phone call.

Leanne CAMPBELL: The second phone call. The first phone call was from the boys to say there had been the accident, and the first phone call we knew was at 3:30 in the morning to say that his life was not going to be, you know, sustainable. Of course at this point we had not actually been to bed from the night before—we had been awake this whole time. We had to wake our other two children up, and we drove to Echuca. They were fantastic at the hospital there. They had obviously had a battle, you know, to maintain his life and had done a lot of liaising with the Austin Hospital staff for that to happen. He was then transferred by air back to Melbourne, but we then had to turn around and drive back. We were not able to go with him. We did receive a phone call to say that he had arrived back in Melbourne, because they were not sure whether he would actually survive the flight. I think the context of this in terms of our donation experience is that it is now 13 years since Brett passed and much has changed. The system that we went through was the old DonateLife coordinator role. There were no hospital-based people as such at our time, so we did not have a nurse donation specialist to walk us through it.

We had only very recently, only two weeks prior—which is just freaky—had the discussion about organ donation with Brett. I think if you have read the submission, typical boy, he said, 'Well, if I am dead, they're no good to me,' shut the fridge door and walked out of the house. So while we knew his wishes, that in no way prepared us for what we were about to be thrown into. I think the thing I find hardest with the campaign to register, register, register and the anecdotal stuff that 'It is only a minute—it's really easy,' is there is no context that you have to have talked or the importance of talking to your family. It is not enough to say, 'I want to be an organ donor.' If I was to look at how many of you—if any of you are registered—what was the discussion you had with your family? 'I want to be donor'—that is it.

We did not know the different types of death. We did not know how that would impact on us. We were not aware that by law they have to get consent for each organ. Obviously back then they were not particularly well trained with how that was presented, so it felt a bit like a shopping list, you know, bit of paper—'Heart, kidneys and a lung?' I am sure they do it much, much better now. There is also a whole list of questions that are asked of you, obviously very pertinent to what is going on in terms of medical things, but you are asked about their sex life—had he been with a sex worker? Was he a drug taker? Obviously this is in relation to potential HIV, hep C—totally understand that—but why don't we divulge these questions to the public? Why is this a hidden thing? Why do we have to wait until we are in this critical point before we educate people that this is what happens? I suppose the narrative of what we see out in the community is always brain death. If it is ever portrayed in a movie or something, that is what it is—it is around brain death. But in Brett's case, he still had some blood flow to his brain, so we had to go through cardiac death. That brings in a whole other new complexity to the thing in terms of dying. Obviously our process was not well handled, and as a result of that

we have a lot of grief, so the importance of having really well-trained nurse donation specialists and clinicians that are good on the floor is imperative.

During the process, while he was off to have some testing, we got left in a room for two hours and forgotten. We actually had to come out after two hours and say, 'Well, can someone tell us what's going on?' Being mindful of the fact you are in a large ICU with other critically ill people and their families, you do not want to just go barging back in. Someone said, 'Oh, he's been back for ages'—oh, well, that is really nice, you know, that we were considered. It was interesting reading back through some of the other submissions and the transcripts, the clinicians saying that they understand that that process is hard and the time frame factor is—there is no infinite time to it. In some ways I compare it to a birth. You can have a quick birth, you can have a long birth, and you can have one with complications. Well, donation is no different to that. It is being able to access recipients and get them into hospitals and all that, so you are there in that time waiting, I suppose, seeing what has happened.

In our case unfortunately the discussion about the organs happened in front of our other two children, which we would have preferred to have had privately ourselves, they rang a friend and said, 'Take us out of here.' So now we are stuck. Where do we go as a parent? Just be with your child that is dying or do you go to look after your other two kids that are alive? It was a really unfair situation to be placed in. Being able to see the scans and stuff I think really helped, presenting them so that you could actually see for yourself the damage and that life was not going to be sustainable.

I think the other thing that happened in terms of when I reflect on the time focus is that they had said to us that they would withdraw life support at about 9 o'clock—so of course you are obviously sitting there and you are clock-watching—and then they came to us and said, 'Oh, we're not ready; we're going to put it back 3 hours.' Thank you, we will just start that whole process again. And for us, we did not have anyone there to support us. The nurse at the bedside was a lovely young girl who spoke no more than two words the entire time we were there. She was obviously out of her depth in terms of that. And when life support was finally taken off he actually lasted 50 minutes, which was close to the critical time for the organs to still be used, so that meant they obviously take them away very quickly. Now, that nurse that was caring for Brett should have stayed with us, but she went off with the thing. We were left standing where the empty bed was, and no-one came to us. I can remember a doctor and a nurse on the other side of the room just staring at us, and we went, 'I suppose we go home.'

Because of the way he died we had made the decision to come back and see him after the donation. That was really well handled; it was in a separate room. It was very nice. We did make the decision not to look, though, at anything, because they will tell you that they do not look different, but they do. If you have had parts cut out of you and stuff like that, you look different. Let us be honest and say you are going to look like you have had a surgical procedure. I chose not to do that, because I did not want to have that snapshot in my brain.

I am just thinking what else was here that I was going to say. Anyhow, if it comes back to me, I will do that.

The CHAIR: That is okay. Leanne, initially I would just like to say thank you so much for sharing your family's story and your son's experience with us. We are incredibly grateful. I think when you first started speaking you were talking about the importance of the human stories, and you are completely right. It is really important as a Committee that we remember—that we do not get caught up in the clinical side of things or the numbers and statistics. It is so important to remember the humans behind this and why this is so important as well. Thank you. It is a great reminder for us as well, so thank you. Would any Committee Members have any questions for Leanne? Christine.

Chris COUZENS: Thanks so much, Leanne, for sharing your story, the reality that you experienced. We really do appreciate it. And thank you for your submission and being here today. It is fantastic for us, and I think Ella just made the point as well. What outcomes would you like to see from this inquiry? What recommendations do you think are really important ones?

Leanne CAMPBELL: I think maybe if I take a little bit of a step back and I go through how I came to be in the position I am. I suppose because of our negative experience I did not want another family to have to go through what we went through, so I decided to step forward and see what could be done. I originally became involved with Transplant Australia. I found that they said they had a focus on donor families, which I later

came to find they do not; it is a very small part of what they do. I attended my first Transplant Games—it was only six months after Brett had passed—and that was at the unveiling of the donor quilt that Transplant Australia had done. I soon came to realise that in the whole structure around donor families and recipients there was this huge, I don't know, big box—that they should be kept separate, that they in no way should interact. It was a very unnerving experience as a donor family to place myself in that environment. Within the Transplant Australia committee they are a fantastic group of people, and through Donor Families it was actually the first time I got to meet a recipient face to face. I got to meet them and learn about their journeys and how hard their things had been. Transplant is not a cure. They are still going to have medical—and the drugs and stuff they take can be very hard. I have made lifelong friends through that, which has been a wonderful experience. The Victorian committee in particular were very, very supportive about trying to emphasise the donor family voice.

I went to my next transplant games with an intention of trying to encourage recipients to say thank you. It was something that was not happening a lot within our space, and I think there was a lot of healing to be done on both sides—from donor families getting a thank you; from the recipient just acknowledging their gift and in some ways talking about the opportunities that they hoped to have for life. We were encouraging within Donor Families Australia to have a donor family's right to ask recipients how they are going as well, so that it can be a two-way street. We worked extensively on the thank you letters.

I did the community engagement training through DonateLife, and I spoke to a lot of clinicians about my experience to try and help improve it. I think it is important within the medical profession, and it is there every day. 'Complacent' is perhaps not the right word. But it is their normal, so I think it is important to be able to speak to them to share our stories. I remember one nurse asking me, if she shed a tear, would that be seen as unprofessional, and I said, 'No, it just shows you've got empathy.' But it is that feeling that we have to make sure that is comfortable.

In 2013 I actually was part of the inaugural committee for Donor Families Australia. Part of that came out of meeting a recipient at the transplant games who said, 'There's this man in WA I think you need to talk to.' I met Bruce McDowell, and with Graham Harrison and Holly Northam we formed Donor Families Australia. There was no advocate group. There is no-one out there for donor families. Once you leave that hospital you are on your own, pretty much. You get a contact from DonateLife perhaps a month after and get a letter saying where the organs have gone and that and a phone call, but after that, that is it. I think we need to recognise that there are two parts to the grief. It is not just the grief from losing your loved one. It is the grief from the actual process or the need to understand.

If I go back to our process, we had not been to bed from the night before, we spent five hours in the car and later that night we were being asked to make this decision. If I was to sign any other contract, I would be advised not to, because with the lack of sleep you have got the brain capacity of being .05, yet the expectation is that you will sign that form, you will be happy with everything and you will understand it. Your body produces cortisol as a way of fight or flight to try and calm your body down. But it also puts you in this fog, so how much of it do you actually retain? I think a lot of donor families talk about months or years later really wanting to go back, process what actually happened and clarify some of the things that they still have doubts about. One of the hardest things to do as either a grieving person or a donor family is to reach out to someone to ask for help, so I think there should be able more points of contact coming from people. Obviously when they ring, often it is a phone call out of the blue. You could be having a shocker of a day on the day they ring or you could be in a headspace that turns you off, so that is just something.

I put a submission in to the Victorian Government inquiry 2011–12, have taken a place on a community consultative forum run by DonateLife in regard to contact between donor families and recipients, attended the DonateLife forum in Brisbane representing donor families, spoke to the Ernst & Young review in 2017, spoke again at the 2019 Donor Families Australia conference and have spent the last 10 years lobbying for the death certificates to have our loved ones put through.

I think one of the things I would really like to come out of today is for us to finally look at our legislation and get it fixed once and for all. When we agreed to donation, we did not know we were signing away the right to control of our son's information. I do not know how aware any of you are of our wish to have their donation registered on their death certificate. I think it is a really important thing. It is their last official document. If they were the one that did it, I think in 50 years how wonderful it would be when the death certificates are finally released and someone will go, 'Oh, look, my family member was an organ donor.'

We keep hearing from, I do not know, a countless number of politicians I have spoken to before, ‘Yes, it’s wonderful,’ and they all sit on their butts and do nothing. To change this legislation is for very few words to be inserted into the tissue Act: with the consent of the next of kin. Yet why haven’t we done it? In the ACT Tara Cheyne, who is the MLA for Ginninderra, attended our conference. She was so passionate about it. She went away to look at what the obstacles were. She contacted Victoria and found out it was to do with the *Privacy Act*, so Tara, instead of going, ‘Oh, no, it’s all too hard; we can’t do anything,’ said, ‘Well, how can we work a way around this?’ She went and looked at the legislation. If the request came from the family, that was going to be okay. It would be generated by them. Subsequently, it appears that we have now come to find that the legislation across the country is a bit of a grey area in terms of consent and who can say things, so after Tara had her legislation passed, the ACT went back in and put in those words ‘with the consent of next of kin’ so that it is all open. So within 18 months the ACT had the ability to do that, and in 10 years—well, I have been at it for 10 years; Penny Napier Mitchell was doing it I think for five more—we still have not done it, the difference being for some reason apparently we do not do private members Bills in Victoria, because that is how Tara got it through in the ACT. I hope for once we can finally get that done and stop sitting on it. I think the thing you need to remember is that every time we speak to this and nothing happens, you are reinforcing that donor families do not matter. Sorry, I will just take a break.

The CHAIR: That is okay. Take all the time you need, Leanne. From what you have just said in response to Christine’s question I think you have already given us a huge amount to think about in terms of potential recommendations.

Leanne CAMPBELL: We ran our Donor Heroes Night. It was lovely that the government gave us the opportunity to get that out there. It was a wonderful thing. After reading some of the other submissions I would just like to point out that we did apply for funding through the OTA, and we were knocked back. We never got funding for that night, and when you look at some of the other funding issues, one has to query why. I think there is a bit of history behind this. I think Donor Families Australia challenges what DonateLife does, and I think sometimes the authority do not like to be challenged. I do not ever want to see it coming from an attacking point of view, but if we are going to change things and improve things, we have got to be able to raise the hard questions and have those discussions. I think it was disappointing that that could not happen. Our first year of running Donor Heroes Night I think we hit around 200,000, and our last year just gone was over 500,000. We are now getting other countries involved, so both Canada and the UK are really keen to get on board, which is a wonderful message about not only recognising donors but also promoting. It was wonderful.

I think the other thing that has been sitting on the table for a long time is the possibility of donor families and recipients meeting. When going back through some of my old stuff, I actually saw one of the slideshows that was presented in 2017 at a DonateLife forum about it. I think you will find that the ethicists have been involved in this for a long time. I think it is time we really look at that now. I think that it should probably be along the lines of how adoption works—that it is supported, it is between consenting adults; obviously children should not be involved. But I think it would be healing. On lots of the media reports you will often see a story where a donor family met a recipient, and that is wonderful and heartfelt, but we actually cannot do it.

We have a private page that was started by a recipient, Kevin Green, which is a safe space to interact between donor families and recipients, and time and time again—the page was never set up in order to find your recipient, but I think out of that, and with social media and stuff, we cannot stick our heads in the sand anymore; it is all very close. I think so far we have had about 90 matches, and we have not had a negative response. I think we should be legislating for the 98%, not the 2% and the troubles they might have. When you talk about divulging information, don’t I have the right? You are more than happy for me to sign the consent under what I would consider a lot of duress, but 10 years later I cannot make that decision as an adult now, that I would like to meet them? And it is totally up to people; there is no forcing about that at all.

I think in terms of education, it is really important that all our staff are trained in it, not just those that deal particularly with end-of-life practice. I was really impressed with the submission and the transcript I read from the Alfred. I think they are really finally tackling the bigger picture. I would like to see that happen in all hospitals. I think the more we normalise death—we are not real good as a society at talking about death or dying. Often within this discussion we will be told about, ‘Oh, Spain this or that.’ But they also have a different culture in the way they celebrate their dead, the Day of the Dead. I actually put down before: I wonder how our multicultural community here would like to celebrate their dead? And perhaps that is a way of also engaging

and talking about organ donation, looking at other people's spiritual things and making it a positive thing, you know, from that life.

Also, through the other submissions I noticed the trouble we often have in maintaining experienced staff. These nurse donations—staff: it takes a long time. It is not a matter of just doing the training, it is years and years of experience, and whether it be through burnout or family circumstances, we lose those nurses or clinicians in the sector. Maybe there is a way of reutilising those that have moved on, that had previously been in the sector, with their wealth of experience, and putting them in the education: can they go out to hospitals, can they do some training, rather than having to pull out people on the floor to do these things? Maybe in some ways that might help the burnout. I think it is a very stressful area in terms of their mental health, and I sometimes think that we do not look after the mental health of our nurses and doctors as well as we should.

I know DonateLife and these ladies have been keen to get into the schools to talk about it. Having been on the school council for a number of years, I know how busy the curriculums are. I know from my own children's experience, when they had someone come to school to talk it was always the person with the lived experience that they came home and told the tale about. I remember when they had Li Cunxin—*Mao's Last Dancer*—come and speak; it really resonated then. But I think the key thing that needs to be presented is perhaps the donor family–recipient story along with the DonateLife member in terms of that discussion. But rather than having to put something else into the curriculum, there are ways of using that information that is already there. For example, I think in year 9 health it is dealt with. So there are a whole lot of areas in the health factor with organs where it could be used. But also let us look at the statistics. We can then use it in maths, we can use it in English—whether it be an argumentative essay or something like that—or we can use it in debate. It is an area of study that they are already doing, so you are not putting something extra in, and by providing that information you are actually helping the teachers and giving them some information to work with. So I think that is perhaps a way.

I do not know how much training is actually done in our universities with our nurses and our paramedics. I know from my daughter's own experience when she was studying paramedics at Bendigo, she walked out of the lecture on bereavement and said, 'Oh my God, what a waste that was.' She goes, 'That's not anything those paramedics are going to need out in the field.' It was all theory based. It was not, 'How is this person going to be feeling? What can I say to them?'—all that sort of stuff, which I think is an untapped resource that is something we could go into.

Just in terms of the opt-in and opt-out and whether you override people's decisions, personally I will never put my name on that register. I do not think people understand that actually, by the letter of the law, you are giving your formal consent. While that does not happen in reality—and I do not think it ever will because I do not think we will ever want to put a doctor or nurse in that position to fight over someone's loved one, saying that they said they wanted to donate. And even more so I think in Victoria the last thing we want is to be told by a government what we should do, after coming out of COVID; I think we have all pretty much had enough.

I think the only other thing is that the narrative is slowly starting to change in the community. I notice now in our stories—we have now got the media—if there is a story about a recipient, there will be a line in there, 'Thank you to our donor.' I think that is really important. But I think we still need to do some work about inappropriate language and how we talk about it—that we do not use 'harvest' and things like that. And we need to educate the media on that so it does not appear.

So please take action. I really do hope that this goes somewhere. I think it is important too that, while I know we are looking at what other places around the world are doing, we are Australians, and we have a different way of looking at things. We want what is presented to reflect us and not be 'If America do that, well, let's just take that on board.' I think we need to be really adapting what we are looking at that is right for us. Thank you.

The CHAIR: Thanks, Leanne. I am conscious of time, so we might wrap it up there, if that is okay. Leanne, if there is anything that you did not cover with us today, we are happy to take a further written submission from you as well. Maybe in those conversations after today's session with the Secretariat, just have a chat with Jess and the team about whether you would like to do that.

As I mentioned, we are transcribing today's conversation. You will be provided with the proof version of that to have a read through before we look at publishing it. So there will be that conversation following today's

session about that. Once again, can I thank you so much for your evidence today and for all the advocacy work that you are doing. We have really appreciated hearing your story and your experiences. You have given us plenty to think about as we move forward with this inquiry to make recommendations. Thank you so much for your generosity today.

Witness withdrew.