

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

Name withheld.

The CHAIR: Good morning. My name is Ella George, and I am the Chair of the Legislative Assembly Legal and Social Issues Committee. I open this meeting of the Committee about its Inquiry into increasing the number of registered organ and tissue donors.

I begin this morning by acknowledging the traditional owners of the land on which we are meeting, the Wurundjeri Woi Wurrung people of the Kulin nation, and I pay my respects to their elders past, present and future. I extend that respect to Victoria's First Nations people.

I am joined today by my colleagues on the Committee. I might just start with Gary, and we might move around the table and introduce ourselves.

Gary MAAS: Gary Maas. I am the state Member for Narre Warren South. Nice to meet you.

WITNESS: Nice to meet you, Gary.

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

Meng Heang TAK: Meng Heang Tak, state Member for Clarinda. That is in the south-east.

WITNESS: Excellent. Yes, I know where Clarinda is.

Chris COUZENS: And Chris Couzens. I am the Member for Geelong.

WITNESS: Wonderful. I also know where Geelong is.

The CHAIR: I am the Member for Lara, which is just north of Chris's electorate, so we are neighbours.

WITNESS: Excellent.

The CHAIR: Just to let you know: all evidence given today is being transcribed by Hansard. 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 that you can review, and you can advise us if you are comfortable for the Committee to decide for it to be made public, with your name and any identifying details removed to keep it private.

Thank you so much for making the time to speak to the Committee today. We recognise that this may be a difficult subject to talk about, but we are incredibly grateful for your time and your generosity. The Committee is interested to hear and learn about your lived experience of organ and tissue donation and what outcomes, if any, you would like to see from this inquiry. I invite you now to begin sharing your story, and if it is all right with you, following that, there might be some questions from the Members.

WITNESS: I am very, very happy for questions. Thank you for, first of all, showing an interest in this area and holding this inquiry. I would also like to just acknowledge that we are meeting on the lands of the Wurundjeri people, and I would like to acknowledge them as the traditional owners of these lands and pay my respects to their elders past and present and any other Aboriginal elders who may be present in the room or, alternatively, read the transcripts from your inquiry.

Just in terms of declarations, I have a lot of different roles but the role that I am going to speak to you from is the role of a parent today. But for the record, I work as [a senior doctor] at [a public hospital]. I am fractionally employed as a donation specialist at [a public hospital] to improve organ donation, and I have a role as a senior research fellow at [a university].

Visual presentation.

WITNESS: Okay. I have divided my talk into two—part A and part B—and there are reasons for Hansard why I have done that. I suppose I am here to talk to you about the need for transplantation. That is the sort of thing that I can perhaps be most useful to the Committee with. Just a very quick recap of my submission: when we think about the number of people waiting for life-saving transplant, we know that there are about

1,800 individuals currently waiting at the moment for a life-saving transplant in Australia, and about 460 of them live in the state of Victoria. To put it into perspective for you, if you all sat at the one time in the Legislative Assembly, we could fill the Legislative Assembly five times over with the number of people who are requiring a life-saving organ transplant. When we think about those more than 460 Victorians awaiting it, about 360 of them are awaiting a kidney transplant. But for every one person who is awaiting a kidney transplant, there are 10 other people who are on kidney dialysis therapy, and every single one of them would benefit from a kidney transplant. They are just not on the waiting list, and the Committee needs to think about why that might be.

This is what having kidney dialysis looks like. This gentleman is strapped to a chair for many hours a day, three days every week, to stay alive. If he does not do this, he will die. While there is a human story behind this, you are also the custodians of public resources, and there is a cost argument here as well. Keeping somebody alive with single organ failure is expensive, and we can do that when it comes to renal failure by giving them a kidney transplant or by dialysing them. If we look at the first year, a kidney transplant is expensive too. It costs about \$100,000. But that is roughly the same price as keeping somebody alive for a year on dialysis. However, the year after we transplant somebody it becomes a lot cheaper to maintain their transplanted organ. There are just some medication costs—popping in and out for a few hospital clinic visits—whereas it is still the same cost for dialysis. Because today if we transplant a kidney, the average duration is 20 years and the cost saving is really significant over that period of time. So we talked a lot about kidneys, and kidneys are something that we have a machine that can sort of do the job—not as well, but sort of do the job. But we do not have a machine for liver transplants. If your liver suddenly stops, we can only keep you alive for 24 to 48 hours and then you die. We have seen that perhaps recently in the news.

In terms of heart transplants, we have a machine that can pump blood around your body, but it has got all sorts of complications, and we know for children who are on the heart transplant waitlist which we connect one of these machines to, one in four of them will die before they get their heart transplant. And lungs—well, we have got a ventilator, but in fact you get pulled off that lung transplant waiting list if you are on a ventilator, because you are deemed too sick. Speaking of lungs, you might think, ‘Oh, well, lungs—somebody’s made a poor choice to smoke.’ But if you think back to your workplace, the Legislative Assembly, we know that four of your members will, statistically, be carrying the cystic fibrosis gene—four of them in the house will have the gene. They probably do not know that they have the gene, but they have the ability to go on to have children who will have cystic fibrosis. We know in Victoria more than 30 babies are born each year with cystic fibrosis, and all of them will benefit from lung transplantation.

You may say, looking at death on the waitlist, that the current one in 131 people awaiting kidney transplant die on the waitlist—you might go, ‘That’s pretty good. That’s a pretty low chance of dying.’ But that is not the real story. The real story is that one in three people who get listed for kidney transplant will actually come off the waiting list and not get their kidney transplant. Why do they come off? They come off because they are too sick to proceed. They have run out of time, they are too sick and they get withdrawn. So the real number is one in three, and the numbers for the other organs are also not very good. So from part A of my opening remarks, I would just say that this is my sort of final thought: we know that 81% of Australians, Victorians, support organ donation. We do not need to convince the other 20%. We just need to get that 80% to go and register so that when we are talking to their loved ones, it is easier for everyone.

This is part two of the talk—probably the part that will be redacted. I work, I believe in public service, I vote, I pay tax, I am a parent, and potentially I have a lot of things in common, because of those things, with you guys. And briefly I am going to tell you my daughter [name withheld]’s story. This is the first photo I took of [name withheld] when she arrived into the world. It is black and white; it is nicer than the colour version. You know, the best thing that has ever happened to me in my life is being a parent—awesome. Obviously, in your role as a parent, you want to take care of this little life that has arrived, and that was my absolute plan and mission. This is the first photo that I took of her when it was just me and her, when her mum was—she was delivered via caesarean section and I was ushered away, and we were just in this room. It was just me and my daughter, like ‘Oh, this is weird—responsibility.’ But I thought she was super cute. She turned a little bit yellow, but lots of kids turn yellow in the first few days after they are born; it is a normal thing. But unlike most normal kids, her yellowness did not go away. She had a condition that involves her biliary tree, called biliary atresia. The biliary tree is the green thing in this diagram, and it is the tubing that drains bile from the liver. We know that in [name withheld]’s condition, it all gets scarred and destroyed. We do not know why it happens at all, but it occurs in

about one in 15,000 children, and that means that the Children's Hospital sees about 10 kids with [name withheld]'s condition every year, 10 new kids.

There are no fancy tests we can do, no risk factors we can modify and no known cause. It is just one of the things that happens. We got diagnosed at about six weeks of age, and we got told—we knew that basically if you do not do anything, all of these kids die by two years of age. 100% chance of death—you cannot live without a liver. You can do this surgery, and the idea of the surgery is it just sort of tries to extend the life of the liver you have got. It is good, but it is not great. About a third of the time it works really well, about a third of the time it partially works and about a third of the time it does not work at all. And even if you have the surgery, your kid still dies, three-quarters of the time, by 10 years of age, and the only way that you get your kid to live is to have a liver transplant.

This is a picture of a kid about [name withheld] age when she had her liver transplant—and it cures her condition; it does not come back in the liver that is transplanted. Livers are like these magical organs that tolerate being transplanted into other people really, really well. The liver lasts in the recipient for a really long time, and this condition that [name withheld] has, called biliary atresia, is in fact the commonest cause for liver transplant in kids.

So at six weeks of age we heard that our daughter could die. If she did not have surgery, she was definitely going to die. The surgery needed to happen right now at six weeks of age to extend the life of the liver that she had. There was a one-in-three chance that it would fail and she would require a transplant by two years of age, and regardless, at some stage, for any sort of significant longevity in her life, she would need a liver transplant.

This is her at six weeks of age and she is prepping for her surgery, which she had. She is a tough kid and she pulled through that. It was a big surgery—a really big surgery. She pulled through that, and that is her recovering. Initially the surgery looked like it went well, but over the next few weeks to months it was clear that the surgery did not go well and we were the one out of three kids where it did not go well—not within our control.

Her liver started failing. And as it fails, you try and do more things to support it. You need your liver to absorb vitamins, so we had to start pouring vitamins in the top end, but you also need your liver to absorb fat, so we needed to give her very special formula that was really high in easily absorbable fats. Our house turned into this sort of children's pharmacy full of these medications, all these different vitamins, iron, special milk formula, special fats—all of this was going in on a regular basis. Then by about six months of age she really could not—she had stopped gaining weight and she needed to be continuously nasogastrically fed. This is to compare her to a kid her age in our mothers group. She is the one on the left of the screen. You can see a sizeable difference.

She developed all the complications that people with end-stage liver disease get, and things that you would only think that adults get we were seeing in our daughter. She needed to have regular admissions to hospital to top her up with albumin. Her belly became really big like a beer gut, a big belly, and because of that she could not crawl or learn to walk. She developed big varicose veins in her oesophagus that were at risk of rupturing, and the problem when you are that small is that if they start bleeding, you cannot fix them because you cannot fit any of the equipment down inside her mouth. When you are a bit older you can try putting a scope down to fix them, but little kids—cannot fix them. In fact she started bleeding from her gut, and one night before work I was changing her nappy, and her nappy was full of blood that she had passed from her stomach. This was her on her first birthday, and the wheels are really falling off by this stage; she was not gaining weight and she was looking really unwell. She could not eat, she could not crawl, she could not walk, she had not eaten solid food by 12 months of age and she was continuously nasogastrically fed. She developed severe osteoporosis, or what we call 'osteopenia', which you would think is like an old lady's disease, but this was happening in my one-year-old. One night when I picked her legs up to slide the nappy underneath her, her thigh bone broke. And she developed multiple crush fractures of her spine just from the weight of her body going and squishing her spine that was not strong anymore.

At 13 months we noticed that she was developing a temperature and we went back to hospital. Her liver had turned into this sort of Swiss cheese thing, where all of these holes had developed in her liver, and they had filled up with pus because the bile could not get out, so it had sort of backed up in these big collections inside her liver. Over the next 30 days she had a fever continuously and her liver failure got much, much worse. This is what it looks like to have end-stage liver failure when you are young. We know that there are 10 kids every

year that get seen at the Children's Hospital, that look like this. She had to have a special tube into her vein, just under her collarbone there, to give her intravenous fluid, because all of her veins were damaged through repeated blood-taking and intravenous access.

I have got a little video, and then we will have a chat.

Visual presentation.

WITNESS: All right. If you get this right, if you work out how to do this as a Committee, that is what you get. I am happy for questions.

The CHAIR: Thank you, [name withheld]. I think we are probably all a little speechless at this point in time. I guess the first thing I would like to say is thank you so much for your generosity in coming today to share your story and [name withheld]'s story. It is incredibly important that we hear about the lifesaving impacts of organ and tissue donation. I think it is very easy sometimes to get caught up in the statistics or the numbers or the clinical side of things, but what you and [name withheld] have shown us today is the human side, and personally, I am incredibly grateful for that.

WITNESS: No worries.

Gary MAAS: I will go first, if you –

The CHAIR: Thank you, Gary.

Gary MAAS: No, that is okay. Thank you so much, [name withheld]. We are incredibly fortunate on this Committee to have someone of your background and your skill set as well as someone who has lived experience as well, so thank you so much for your insights today. It demonstrates to me two things: firstly, the power of medicine and just how fortunate we are to have generations of knowledge that has built up over time and for the fact that as humans we have the ability to accomplish this—but we only have the ability to do that if we get the decisions correct. Secondly, it demonstrates to me the power of story. Thank you for sharing your journey and your story with us. It is really very important. Thank you.

WITNESS: That is okay.

Gary MAAS: Your presentation was put to us in two parts. If I could take us back to part A while most of us dry our eyes, we will go back to that part of it.

WITNESS: Sure.

Gary MAAS: You spoke to us about the numbers on the waiting list, particularly with kidney transplants, and you talked to the numbers that are occurring with kidney transplants. You then also posed a rhetorical question for us as to why so many are on kidney dialysis, and I think it is really important for the record that we get an answer to that rhetorical question. Are you able to let us know why there are so many—particularly when you took us through the quantum of statistics, the economics of it all as well—over the 20-year time horizon?

WITNESS: Sure. So first of all, I should say that I am very happy to answer that question, but we all have our subspecialty areas of knowledge, and I am not a renal transplant physician, although I have had the pleasure of working closely with a number of them. And I know that you have spoken to John Whitlam previously, this Committee, who is a lovely gentleman and also an expert in this area.

What I would say, though, is that—and I have spoken to Greg Snell about this as well; I know that you have spoken to Greg—there are some people for a variety of reasons who just, even if you put them on the list, never get to the top of it. They might be older. They might have some other illnesses, comorbidities. And it is not that they would not benefit from a renal transplant, it is just that the actual real queue that we do not measure, the real need that nobody actually has numbers on, is so big that you do not put people through it. You do not dangle the carrot of life-transforming transplantation, because it is sort of cruel. If you know that you have only got X number of donors, it is cruel to dangle a transformative intervention to a whole group of people who will realistically never get the opportunity to access that. With kidneys, that unmet need is a lot easier to quantify because we have this other modality which is dialysis to measure what the ratio of listed to unmet need is,

whereas we just do not have that for any of the other organs. We do not have a realistic measure of how many people are not listed for lung transplantation, but it is very sizeable. It is many multiples of the people who are formally listed.

Gary MAAS: Okay. Thank you. For my second and my final question, I will go to part B. Just given your experiences, do you have any personal views that you could share with us about how we might improve that rate? You talked about the 81% that are already across the line in wanting to be organ donors. If you were on the other side of the table, so to speak, what would you say would be factors to help improve that?

WITNESS: I am speaking on behalf of me and not of all of the other different affiliations that –

Gary MAAS: Yes. Okay.

WITNESS: I think it was potentially a mistake to move away from the drivers licence registration model, and I think it would be useful to look at re-engaging in a frictionless way with that. I do not think that an opt-out solution is the solution for the problem. If you want radical ideas, you know, I think that as a society we should thank people who sign up, like actually thank them. What does that look like? I do not know. We know that it saves society hundreds of thousands of dollars if not millions of dollars for every person who becomes an organ donor in terms of the life transforming effect that they have on multiple recipients. Most organ donors do not donate one organ; most organ donors donate three or more organs on average and up to seven to individuals. I cannot even put into numbers the societal benefit that that produces. Maybe we say as a token of our appreciation, you know, when you are going for your registration again, maybe you get a 2% discount—a tiny little thing that just says we acknowledge that you are paying forward by going to the effort of enrolling. Or maybe we promote a free concert in the Sidney Myer Music Bowl for people who have got a donor card. They just get to go in for free and listen to free music—just as an acknowledgement that goes, ‘Thanks for taking the minute of your day to go and sign up.’ Just thank you. Because I am very thankful.

Gary MAAS: I did say that was my last question, but there was something in there that I just want to follow-up on and –

WITNESS: I have got all day.

Gary MAAS: It was just on the part about your view about it not being opt-out. Why do you say that?

WITNESS: One of the hats that I wear is as a medical donation specialist. When we go to sit down with a family who is in a really bad headspace, their loved one has just died, and we say, ‘You know your loved one had gone to the effort of registering as an organ donor’, I think that holds very significant weight. And therefore we know that in the sort of high 90s people will agree with whatever decision their loved one has made. I am not sure that if we were to go to a family and say, ‘What we do know is that your loved one hasn’t withdrawn consent’—the reverse, opt-out situation—I am not sure that that will hold the same weight in terms of empowering the family to—it is much more likely that they will turn around and go, ‘Oh yeah, well, there are a lot of things they didn’t get around to doing’. It is devalued, and it devalues people who register, who go to the effort of registering. Whereas if it is an active thing, where you are actively registering, it translates to families in a powerful way. I hope that makes sense.

Gary MAAS: It does. Thank you. No further questions. Thanks, Chair. Thank you.

The CHAIR: Just a brief comment: that is certainly something we have heard a lot about throughout the process of this inquiry, the importance of those family conversations. I think probably almost every witness has come to us and said just how important that is. Annabelle, do you have a couple of questions?

Annabelle CLEELAND: I will pull myself together now, do some deep breaths. Thank you for the music, just add a little bit more emotion. [Name withheld]’s story is obviously extraordinary. I have got a couple of young children, so I find it extra hard to even comprehend what you have gone through as a family and how brave you are as parents to have dealt with that. You mentioned the Royal Children’s dealing with 10 children a year with a similar condition. How many children are not fortunate to have [name withheld]’s experience, do you know, by any chance, of those 10 children?

WITNESS: I do not have exact numbers for you. These are sensitive conversations; it is a difficult question that you have asked. However, what I would say is that [name withheld] just has her condition and she does not have any other conditions. But sometimes when you have liver failure and you have other conditions, it is like when I explained about Greg's patients on the lung waiting list—once you start having more than one problem or other challenges, when you have got a finite resource, the clinicians are very aware that they need to get the most out of and make the most out of the resource that they have. So no doubt, difficult decisions are made. But can I give you a number? No, I cannot give you a number.

Annabelle CLEELAND: We have heard a lot about the consent and the importance of that, and the next step of that is also passing that information on to your family. Your role as the organ donation specialist—do you ever deal with paediatrics in that conversation, or is it—

WITNESS: No, unfortunately I work in an adult-only hospital. It is a hard enough conversation to have with family members of adults who have passed away. There are some very special people at the Children's hospital and at Monash Medical Centre who have difficult conversations with family members of children who have passed away, because we do have paediatric donors—they are just significantly rarer than adult donors.

Annabelle CLEELAND: Through your role as an organ donation specialist, have you seen other barriers, whether it is communications or the timeliness of that conversation, and through your own personal experience within the paediatrics space, that you think we could learn from, even just the language? Like, is there sufficient training around the language? Are there adequate specialists? Are we having the conversations at the right time, and are they always effective?

WITNESS: Yes, sure. The answer to that question has changed over the last 10 years. You are probably extremely aware there has been a bipartisan, federally funded agency, the Australian Organ and Tissue Authority—you spoke to the CEO, amongst other members, of it—and a coordinated approach. One of the big things they have done is teach communication to doctors and nurses who work in this space and in fact restrict the number of people who have conversations about this to a specialist group of communicators. I think that if you asked me 10 years ago were we identifying potential organ donors and were we having appropriate conversations, the answer would be no, whereas I know that at a state and in my hospital level our numbers in terms of identifying all of the patients that are potential organ donors sit at around 100%. Our communication style sits at more than 95% of the time we have highly trained individuals conducting those communications. The amount of gain by upping those numbers from 95 to 100% is relatively—the yield there is relatively small to further tweak that at this point in time, so I think that the hospital-based donation process in terms of communication has been optimised as much as we can.

I know others have spoken a little bit about the difficulties of logistics within the transplant sector, and it is fair to say that in 2018 we had a very busy organ donation and transplantation year and we rubbed up against the limits of what the transplant sector could do. They began to be a bit overwhelmed by the numbers, but that is not the situation, in my opinion, that we are at right at the moment. We have got a real problem with getting organ donor consent. The numbers are substantially reduced, and you know, if we can build back up to 2018 numbers through initiatives that you can think of, I would be very happy to come back in four years time and talk about the constraints that occur further down the track in terms of this flow process. Right at the moment there are not enough people that are 'coming in the door' to be worried about what the constraint processes further down the track are, in my opinion. And appropriately, the question that you have asked today is about how we get more people on the register as opposed to those down-the-track issues of constraints. Does that make sense?

Annabelle CLEELAND: Yes. So with your professional but informally personal experience, what do you hope to see come out of our inquiry from a recommendations perspective?

WITNESS: Something. In a joking sense—something. But I think, you know, the need is very significant, and we need to try—we need to change what we are doing at the moment. I am not necessarily peddling a particular change, but you have spoken to a lot of smart people, they have brainstormed a whole lot of ideas for you to have a think about. We should try some of them. You get to pick which ones we try, which is exciting. But we should try something, because there are people suffering, there are people dying, and it is worth trying something different.

From my point of view, I think that the drivers licence thing is just like a gimme. It is just like low-hanging fruit—it would be nuts for you to invest the amount of time that you have invested and not progress that as a concept.

The CHAIR: We might wrap it up there, if that is okay. I am just conscious of time, and I am hoping [name withheld] is happy to come and have a very informal chat with us as well. But on behalf of the Committee, [name withheld], can I just say thank you again so much for your written submission but also coming in today and for the time that you have taken to prepare your evidence. To hear from people who have lived experience of organ and tissue donation is invaluable to this Committee, and we are so grateful. Thank you very much.

Witness withdrew.