

# 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** *(via videoconference)*

Robert Manning.

**The CHAIR:** My name is Ella George, and I am the Chair of the Committee. I am joined by the full Committee today, which is wonderful. Annabelle Cleeland is the Deputy Chair. And I might just ask everyone to go around the table and say hello and introduce themselves.

**Meng Heang TAK:** I am Heang Tak, the Member for Clarinda.

**Chris CREWETHER:** Chris Crewther, Member for Mornington.

**Cindy McLEISH:** Cindy McLeish, Member for Eildon.

**Chris COUZENS:** Hi, Robert. I am Chris Couzens, the Member for Geelong.

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

**Robert MANNING:** Excellent. Nice to meet you all.

**The CHAIR:** Thank you so much for being here today. Just to let you know, the evidence being given today is being transcribed by the Hansard team. They are in the background here. It is protected by parliamentary privilege, but comments repeated outside of this meeting may not be protected by this privilege.

**Robert MANNING:** I fully understand.

**The CHAIR:** Great. 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—public with your name on it—or if any identifying details are to be removed to keep it private. The Secretariat team will have a chat to you about that following today's conversation, but rest assured, you know, we can have a conversation about anything that you might like to keep private as well.

**Robert MANNING:** Thank you. All right. I appreciate that.

**The CHAIR:** Robert, thank you so much for taking the time to speak to the Committee today. We are really interested to hear about your own lived experience of organ and tissue donation and also what outcomes, if any, you would like to see from the work that we are doing on this inquiry. So I might hand over to you now if you would like to share a little bit with the Committee, and following that the Committee Members might have a few questions for you if that is okay.

**Robert MANNING:** Yes. Thank you so much, and it is a real privilege to be here. I realise I am not a constituent of Victoria, but I am one of the luckiest people alive who got to spend a lot of their life working in Victoria in various roles that I have had. In fact for a four-year period I spent five days a week in Melbourne. I have probably been one of the most frequent visitors of the Sofitel down there on Spring Street and Collins Street.

Today actually is a very special day for me because it is 600 days since I woke up from a two-week coma. On 26 March 2021 my wife, after some persistent reminders, got me to go and see a GP. I had not seen a GP in the 20 years since our son was born, and he was about to turn 21. She said, 'Rob, go and see the GP, please.' So I made what I thought was a valiant effort to go and see a GP. I walked into the doctor's surgery and asked the receptionist whether I could make an appointment to come back and see a doctor, and she said, 'Take a seat, there will be one with you shortly', which caught me a bit by surprise because everything I had seen in the media said that it takes weeks to get an appointment to see a doctor.

So I sat in reception, and within a few minutes a small Egyptian man walked out of the doctor's surgery and said to me, 'Rob Manning?' and I said, 'Yes.' As I stood up and started to walk towards him, he said, 'You're a very sick man. Why are you here?' I said, 'Well, nice to meet you too, Doc, but I am here because my wife said "Go and see a GP. You haven't been in 20 years."' He said, 'No, you are very sick. Why the fat belly, and what's that spot in your eye?' I said, 'I probably eat too much, drink too much and don't exercise enough. The spot I can't explain.' He took less than a few minutes to point me in the direction of a nurse, who took six vials of blood on the Friday afternoon. He got me back in on the Saturday for an MRI and an ultrasound on my stomach. When I got a text on the Monday to come in and see him about my results, I rang him and said,

‘Look, I can come and see you on Thursday, because I’m actually in Melbourne on Tuesday and Wednesday.’ He said, ‘Robert, you don’t understand. I need to see you today. We’re off to the Royal North Shore Hospital.’

And that Monday afternoon on 29 March I was admitted into Royal North Shore Hospital and spent two weeks there while they did various tests and that sort of thing, and then asked me to come back on a weekly basis to the liver clinic while they did blood tests each week and were looking to try and find out what was wrong with me. They eventually did a biopsy, and on 9 July that year, 2021, I sat in a specialist room and they said, ‘Rob, you have end-stage liver disease and if we can’t get a transplant to you within 12 months, you will be dead.’ And I said, ‘But I don’t feel sick.’

At no stage during that two- or three-month period between April and July did I ever once feel that I was sick, but being told that you have less than 12 months to live is a very confronting experience. So I went through the process of being assigned to the Royal Prince Alfred Hospital here in Sydney and going through various tests for Wilson’s disease, hepatitis, fatty liver, cirrhosis caused by alcohol—a whole number of things. It was eventually on the last day of a two-week stint at the end of November and having had four stents put into my heart and been treated for kidney deterioration and liver failure that they did a lupus test to see if that was what was causing the organ failure.

I was released from hospital on the Friday and then on the Sunday woke up not feeling quite right. My wife said, ‘Look, if you’re not going to take your medication and you’re not going to eat, then I’m going to take you down to Sydney and get you to the clinic as fast as possible.’ She went to put petrol in the car, and when she came back I was standing in the doorway. She said, ‘Are you okay?’ I said, ‘I can’t get my shoe on.’ She said, ‘But, Robert, you’ve got no pants on.’ And at that stage I realised that I was in a bad way, she realised I was in a bad way, and she put me in the car and drove me straight to the Royal Prince Alfred. I was admitted there on the Sunday night, 19 December. Then as far as I knew everything was normal, but what I did not realise was that by 6 o’clock that night I was on life support in intensive care having had massive organ failure. That kind of lasted until I woke up on 2 January 2022, and I had a new liver and a new lease on life. From that moment I started wanting to give back. I realised that I was probably the luckiest man alive. When everything had gone catastrophically wrong for me, it went miraculously right, to the point that I have an O-type liver and I am an A-positive blood type. I realised that I had to get back—I had to make sure that I did everything I could within my power to make sure that every Australian got the same opportunity and the second chance that I was given.

It was probably spurred on because when I was in the coma, as I said, I did not realise I was in a coma. If you have ever seen that Jim Carrey movie *The Truman Show*—I felt everything was going along normally. I was talking to the doctors and the nurses. I was saying, ‘My name is Robert James Manning. I was born on 6 January 1967, and I am here in the Royal Prince Alfred Hospital for a liver transplant,’ because that was the process that I had gone through for the previous two weeks. Every time I had my blood taken or medication given to me, I had to verify who I was. So I thought that was happening still on a regular basis. I also thought that my wife was coming to visit me and we were talking about what was going to happen when I got the transplant and how I would get better. The thing that surprised me was I had a visit from my dad. He said, ‘Robert, you’re not 6 foot tall and bulletproof like you thought you were. When you get out of this, son, and you will, you’ve got a job to do. If you’d seen your GP earlier, you wouldn’t be in this situation now. So when you get out of here, go and tell everyone that you know, everyone you’ve played sport with, everyone who you went to school with, everyone who you’ve ever worked with—tell them to go and see their GP and get checked out, because the sooner you find a problem, the better.’ Then he said, ‘The other thing you have to do is talk to the politicians and get them to change the legislation, the education and the communication around organ and tissue donation, because the system is broken.’ So when I woke up on 2 January I told my wife, and she said, ‘Robert, you do realise your dad’s been dead for six years?’

At that moment I realised I had a calling, and that calling was to do whatever I could to improve organ and tissue donation in Australia. I started by writing to Minister David Gillespie, who was the assistant minister for organ and tissue donation and regional health, and I told him my story. I also wrote to politicians around the country in the state and federal parliaments explaining that we need harmonised legislation across Australia. We need to do things differently to how they have been done, because in Australia we have been told that we operate on an opt-in system. The reality is we do not. We are an opt-out system as of today. In 2022, as an example, 454 amazing donor heroes’ families said yes to organ donation, and they saved 1,224 lives. The sad part about that is only 170 of those 454 people were registered on the organ and tissue donation registration list, which is quite phenomenal.

The reality in Australia is if you die in the right circumstances, which is on life support in a hospital, the first thing as part of the process that happens is the hospital will check the organ and tissue donation register. They are not looking to see if you are a registered organ donor; they are looking to see if you have registered your intent not to be an organ donor and at that point if your name is on the list having ticked the box, which is now still on Medicare express and used to be on the drivers licence registration—‘Do you want to be an organ donor, yes or no?’ On the current Medicare express it is, ‘Do you wish to be an organ donor of all of the above, some of the above, or do you want to register not to be an organ donor?’—you can tick one of three boxes. When New South Wales handed over their drivers licence registration list in 2011, 40% of the registered people on that list had registered not to be organ donors. So when you die in the right circumstances, your family will be asked one of two questions. The question will be, ‘Robert is not coming home, but he was a registered organ donor. Will you consider organ donation?’ The other question might be, ‘Robert is not coming home. We’ve identified that he is a potential organ donor and his organs could potentially save other people’s lives. Will you consider organ donation?’ They are the only two questions that get asked, because if your name is on the list as not an organ donor, your family do not get asked.

In 2022, 1,400 individuals were identified as potential donors across hospitals around Australia; 1,300 families were asked whether they would consider organ donation. So that means 100 of those deceased persons and their families could not be asked either because the families could not be identified, or the person had registered no, they did not want to be an organ donor. Of the 1,300 families that were asked, 701 families said yes; 599 sadly said no, and days after saying no they had regretted their decision and wished they had said yes, but obviously timing is critical when you are on life support and being considered for organ donation. So the reality is we can talk about opt-in and opt-out, and we can talk about how we register more people, but one of the things I was amazed about is that Victoria has the lowest rate of registration, at 21%, but your state is still one of the most generous, because you have 50% of families saying yes. So that means that a lot of families who did not know that their loved one was an organ donor, or had not registered to be an organ donor, still say yes in Melbourne. You have got wonderful families.

I believe you have already spoken to Allan Turner from Zadie’s Rainbow Foundation. I work here with the Gremmo Foundation. Nathan Gremmo was a young New South Wales boy who was hit by a car on a Thursday night, declared dead on the Friday, but organ and tissue donation could not take place until Monday. His family agreed to keep him alive across the weekend so that he could go on and become a donor hero, and that family now run a program called Jersey Day.

The most important thing that Zadie’s Rainbow and Jersey Day do is they encourage families to have a conversation—because right now around Australia, every day, there are about three families that are not going to know when they woke up this morning that their transplant journey is about to start. So you will get a situation where you are going about your day as normal, and a phone call will come that someone who you love is now in a hospital, potentially on life support—they could be in an emergency ward—but their life is hanging in the balance, and by the time you get to the hospital, you might find out that their mortal journey has come to an end. In the time that that is happening, the hospital will have done the various tests they need to do to identify if it is a cardiac or brain death, and they will have checked the register to see if the person had registered their intent not to be a donor. If they do not find a name on the list or if they find a name on the list that says they had been a registered donor, then the family will be asked. Every family has to give consent. There is nothing that happens from the point of view of a registration that confirms when the deceased can become an organ donor. It can only happen with the express consent of the senior next of kin. Your legislation says it—also in New South Wales, Western Australia and South Australia. In fact in every state around Australia organ and tissue donation can only happen with family consent. If there was anything that I would recommend that needs to be changed is the education and the communication around the important role that the family plays in this process.

As a recipient, I know how lucky I am, and my story has been read into the New South Wales Parliament, the Western Australia Parliament and the federal Parliament—as a recipient who understands just how critical the role is that families play in organ and tissue donation. Until such time as we as a nation understand the role that family plays and are honest with the Australia people—that there are no religious blocks to becoming an organ donor and that it is an altruistic gift, given when all hope is lost in a personal situation, when somebody’s mortal journey has come to an end, there is some relief and some hope that is gained. All you need to do is talk to some of the probably close to 600 donor families that I have spoken to. Many of them become passionate advocates, like Allan Turner, like Michael Gremmo, like Bruce McDowell and Philippa Delahoy—all of these

people who I have met. They have lost a loved one, and that loved one has gone on to give hope. At the recent world games, we had a young lady stand up from the Dunn family network from the UK. She said, 'The decision was easy for us when it was asked because we had talked about it. But I think even if we hadn't talked about it, we realised that we could prevent four or five more funerals happening as a result of our daughter's death if we could say yes. So we said yes, because it meant that there only had to be one funeral.'

Many people die on the waiting list for reasons, whether it is the guidelines set for hospitals with things like vaccinations or existing conditions, quality of life et cetera. But if you think of the 701 families that said yes, only 454 went on to become organ donors, because there were 247 deceased persons' families who had said yes but for medical or logistical reasons—and the logistical reasons and medical reasons are a term used by the Organ and Tissue Authority to cover up things like not enough taker-outers, which are the retrieval teams, and not enough putter-inners, which are the transplant teams, to facilitate the transplant of organs from deceased persons to living persons.

The Organ and Tissue Authority claim things like, 'Register today. It takes 60 seconds, and you could save up to seven lives' or nine lives, depending on which campaign they are running, and at the end of it they will throw in the throwaway line, 'Remember to tell your family.' But it does not bode well, because telling your family you have become a registered donor does not change their ability to say no. The reality is, if you look at the organ and tissue donation rates where there were 454 donors but only 1,224 transplants, the average deceased person only contributes to saving about 2.98 or let us round it out to three lives, so there is a lot of work that needs to be done on the clinical processes and the reporting situations within hospitals.

Every hospital has a different way of identifying potential donors and then matching them with potential recipients. There are logistical issues of moving organs from hospital to hospital and then state to state. New South Wales is a net importer of organs because of the money that they have to facilitate that. You have situations where there is the tyranny of distance, whether it is remote regional Victoria into the major cities where the transplant can take place or the ability to get a team to a remote hospital or get a person who is on life support into a facility where the retrieval can take place. So there are lots of things that need to be addressed, but the number one thing that will change is the identification of potential donors by making sure that families understand their role and the importance that the family plays in organ and tissue donation.

For the last 18 or 19 months I have worked in South Australia to introduce legislation into their parliament for posthumous recognition of deceased donors and the change in their legislation to allow families to tell their story, the deceased's families. In Western Australia I had the Chief Health Officer send a letter saying that there was no public interest in prosecuting families under their *Human Tissue and Transplant Act*, the HTTA. Basically we need to, I think, look at different ways of communicating with people, and drivers licences are not the way to do it because of the time that it would take to get your population to understand the importance of registration. Even getting them to register with the life cycle of drivers licences would be a long period of time when you have got an app, which is the Service Victoria app, where you have got a digital application.

In New South Wales we have trialled it twice, once in 2022, when we did four weeks in November and we had over 60,000 people interact with the registration process. We actually saw a spike in consent rates in New South Wales from 53 up to 55% for the year last year over a very short period of time. November and December had a significant increase in consent rates, and we are just waiting on the results of what happened during DonateLife Week when it was run again here in New South Wales. Digital services and providing as much information and education to the community about the importance that families play and the way in which it can improve lives, I think, are the things that need to be identified. Unfortunately, I can talk for a long time, so you just have to interrupt me and say, 'That's enough, Rob.'

**The CHAIR:** Well, firstly, can I just say thank you so much for that. That was an excellent presentation and you have given us a lot of things to think about. You have definitely touched on some key themes. One of the things we have heard from so many witnesses is that importance of the family conversations and just how important that is. Do any Committee Members have any questions of Robert? Yes, Chris Crewther.

**Chris CREWETHER:** Unless you want to go first?

**The CHAIR:** No, please. Go for it.

**Chris CREWITHER:** I was just interested in your views on absolute consent, and I am wondering if you can elaborate on your views and recommendations regarding absolute consent.

**Robert MANNING:** Absolute consent is an issue that I started writing about probably in October of last year. I think I raised it here in New South Wales, saying that absolute consent is like when you have a last will and testament. The reality is absolute consent still has issues. Once again, it will take time to move a large population from intent to absolute consent, and like a last will and testament, it still could be challenged. The main feedback I have had from a lot of people around organ and tissue donation when it comes to families is they do not like the word ‘harvesting’, which is a word used predominantly by clinicians and the Organ and Tissue Authority—that organs are harvested. Absolute consent will always be challenged by a family. No medical procedure can take place without authorisation. As I said, my recollection of when I was in the coma was telling them my age, my date of birth, my place of birth and where I was, so making sure that I could identify myself. ‘Robert, we’re about to give you 100 milligrams of mycophenolate. Are you okay to take this medication?’ I would say yes.

If you introduce absolute consent and you say to a family who is in grief—they have just found out that their loved one, their child, their daughter or their son, who was bright and bushy-tailed this morning, is now not coming home—‘Well, we are an opt-out system, so unless you tell us otherwise, we’re going to retrieve the organs, or harvest the organs,’ or if you are the parent of a 21-year-old who is still living at home and they are in a car accident and you say, ‘Look, they signed absolute consent to say they’re going to be an organ donor,’ you are in a moment of grief. It is a really difficult thing to argue with a family that there is going to be good coming out of it when they are grieving the notice that their loved one is not coming home. So I think using the legislation in that way is going to be a challenge and will complicate things.

One of the frustrations I have at the moment is the way in which organ and tissue donation has been hijacked by vaccine warriors on either side—the vax versus non-vax. Organ and tissue donation should not have any part in vaccination. The guidelines that hospitals write when you go into a transplant list are that you need to be in the best possible shape to survive a transplant. Every transplant has risks.

Absolute consent—I was a fan of it at one stage, saying that it is a way to get around it, but the more donor families you talk to, the more pushback you are going to have in that hospital situation. There will be challenges. We had a situation in the UK with young Archie, who was declared dead, and his family petitioned the courts to keep him on life support. It is just a sad situation. With the right education and the right communication to families and their understanding, we do not need to force people into this. I think we can bring the community on a journey and just help them understand that family will always have to give their consent for the handling of a body. When my dad passed away I had to authorise them to cut his wedding ring off and what was going to happen with various other parts. The family will have to get involved, so you cannot remove the family from the decision. Absolute consent is not a solution, it will just raise more opportunity for people to say—right now 21% of Victorians have registered, and even if there was absolute consent, it does not change the number of transplant recipients. The only thing they can change is next-of-kin consent.

**The CHAIR:** Thank you, Chris and Robert. That is certainly something we have heard as well, the importance of family consent. It is a theme that the Committee have heard from multiple witnesses, so thank you again for raising that with us.

I am terribly sorry, but we might have to finish our conversation here, because I am very conscious of time and we have run a little bit over. Robert, thank you so much for appearing before the Committee today. We are really grateful for your evidence, particularly as somebody who has lived experience of organ and tissue donation. That is just invaluable for our Committee and our inquiry. Thank you so much again for appearing. We will provide you with a proof version of the transcript, so you will have that to review before we publish that, and the Secretariat will be in touch with you to have a chat about that.

**Robert MANNING:** Excellent. Thank you very much for this opportunity, and I wish you, with the best of intent, the best of outcomes for this Committee and inquiry. I am just so glad that Victoria is doing it, because you have, as I said, a very generous community, and I think the better you educate them, the more lives you will save. Thank you.

**Witness withdrew.**