TRANSCRIPT

LEGISLATIVE ASSEMBLY LEGAL AND SOCIAL ISSUES COMMITTEE

Inquiry into increasing the number of registered organ and tissue donors

Melbourne—Tuesday 25 July 2023

MEMBERS

Ella George—Chair Gary Maas
Annabelle Cleeland—Deputy Chair Cindy McLeish
Chris Couzens Meng Heang Tak

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WITNESS

Professor Gregory Snell, Medical Head, Lung Transplant Service, Monash University and Alfred Hospital, and Chair, Lung Transplant Sub-committee, Victorian and Tasmanian Transplant Advisory Committee.

The CHAIR: Good afternoon. We will now recommence the public hearings of the Legislative Assembly's Legal and Social Issues Committee's Inquiry into increasing the number of registered organ and tissue donors.

My name is Ella George, and I am the Chair of the Committee. I am joined today by my colleagues Gary Maas; Meng Heang Tak; Deputy Chair Annabelle Cleeland, who will be with us in a moment; Cindy McLeish and Chris Crewther.

I welcome our next witness Professor Gregory Snell, Medical Head, Lung Transplant Service at Monash University and Alfred Hospital, and Chair, Lung Transplant Sub-committee of the Victorian and Tasmanian Transplant Advisory Committee. Thank you very much for joining us here today.

All evidence given today is being recorded by Hansard and broadcast live. While all evidence taken by the Committee is protected by parliamentary privilege, comments repeated outside this hearing may not be protected by this privilege.

I invite you now to make a brief opening statement of 5 to 10 minutes, and this will be followed by questions from Members. Thank you.

Gregory SNELL: Thank you for the opportunity to speak. As you mentioned, I have been in lung transplantation for 33 years, and my main thrust of that has been looking at extending the organ donor pool to maximise the number of transplants and the outcomes from transplants. I am a world expert on donation after circulatory death, which I will be talking about a bit. One of the main points I wanted to bring to your attention is that all organ donation is really for transplantation. It is not sufficient to just collect them and put them in a corner; it is getting organs that we can use and using them efficiently. There are three themes I was going to talk about: the current logistic issues with donation and transplantation; some of the new ways beyond the Ngamuru and EY reports that we can talk about for lung and indeed heart assessment and resuscitation; and expanding the DCD, donation after circulatory death, categories to novel and underused organ pools and indeed, as we heard before, some other populations that perhaps do not understand what we are talking about with traditional organ donation.

First of all, the current logistic issues are very real. The system we are in has been built around donation and not around transplantation or retrieval. We can get up to four retrievals at the same time, and we do not have the teams and the resources to do all four at the same time. If they would talk to one another, that would help so that we are able to schedule them. Even in talking to one another, with the current practice of the way the organs are retrieved in different units in different hospitals, there is a bit of a competition to fit into the operating room schedules at the different hospitals. The heart and lung guys want to go in the morning; the liver guys want to go in the evening so that they can then machine perfuse until the next day. So there is some competition with that that leads to inefficiencies, and it blocks the use of resources in doing standard heart operations or standard lung or kidney operations. The daytime operating that is being pushed often stretches things such that the organs do not make it to the next sort of morning block, and at the same time you then push some things into the evening. It used to be that they were all around the clock. We are using busy theatres for organ transplants during the day that could be done at other hours.

Donation after circulatory death currently involves organ donors that die in a prescribed 90 minutes after withdrawal of treatment, and you get 66% of your organ donors that way. So 66% of those will convert that way, in the 90 minutes, but if you wait 12 hours or 8 hours, you can extend that out to 90% of the organs that you set up—consented donors that everyone has agreed we are going to use. But we do not because of, again, the teams on stand-by and the resources available to do that. There are, as I will talk about, ways that machines can be used to run longer. This also fits for distance. We have got Albury–Wodonga, we have got Mildura and we do Tasmania and that as well, where we do not go to consented organ donors because of the perception of staffing and transport. We had a donor recently where we were not able to agree on a transport mode to get there to potentially retrieve organs. It recognises that DCD is less efficient, but if we were able to wait longer, it is highly predictable that the person will have a cardiac arrest eventually, and that is typically sort of within 6, 8, 12 hours or so.

The second point was in terms of assessing the quality of the organs. Machines exist that can evaluate the organs and see what they are really like for hearts and lungs, and we can potentially buy more time to rearrange

the logistics of the other organs that might come along. But these machines are expensive—they require resources, they require staff, they require space—and this is true for hearts and lungs.

The third point was about expanding the DCD categories to the novel and under-utilised organ pools. There is a Maastricht classification of five different types—which you are probably aware of—of donation after circulatory death. We typically do category 3, but with the category 1s and 2s, where someone has a cardiac arrest in Fawkner Park and is taken to the Alfred, it is possible to particularly retrieve lungs, where they can sit even for hours—no cessation, no ventilation—and potentially be used, but again you have got to have the space, the staff and the timing. But the technology completely exists to do that.

At the other end of the spectrum you have got the Maastricht 5 category, which is our voluntary assisted scheme here in Victoria. It is established, and it is turning over—quite a lot of people are coming through it, and as they choose to make donations to the Lost Cats Home, they can potentially make choices about what they might want to do with their organs. There is the opportunity again to swing this in using the same type of spacing of withdrawal of life, perhaps in the administration of the end-of-life medications within the hospital system in an appropriate environment, and organs can be taken. We have got more time than we ever realised after the circulation stops. A space near the ICU for people with neurological conditions in one of the three major transplant hospitals would work fine. Currently they go through the Peter MacCallum system in many cases. The same is true again for the different religious groups for DCD, the different cultural groups—we can use time to smooth out some of the gaps, some of the rushes, some of the unseemliness of pushing to get organs fast. Certainly lungs can be done that way, and that, as I said, applies to the country hospitals.

In summary, I think that it is about transplantation, not the number of organ donors. It is the actual number of quality organs that we use that is important. It is about using the existing organs more efficiently. We can expand donation after circulatory death. There are a number of different ways we can do that, and the voluntary assisted dying one is perfectly organised legislation; it sits perfectly against the existing legislation that we use for DCD. And finally, I think the Ngamuru and EY reports, which overlap with this, can be updated to include some of these new technologies and new ideas that we have had over the last few years since they were put together. Thank you.

The CHAIR: Great. Thank you. Would you like to start?

Meng Heang TAK: No.

The CHAIR: Okay. I might start with a question then, if that is all right. Thank you very much for both your written submission that the Committee has received and for your presentation. One of the things we have been hearing a lot about is the importance of conversations between families and clinicians about end-of-life wishes and opportunities for organ and tissue donation. Obviously there are some people who are registered on the Australian organ donor register, but then there is another cohort of people who are not registered but still end up making a donation. I am just wondering, in your clinical experience, if you can tell us a bit about the differences between the two. Essentially, how important, in your view, is registration in terms of ensuring that organ donation process takes place?

Gregory SNELL: They have proven that the conversations that occur through any mechanism that has family aware that someone is interested in organ donation do translate to more organ donors. I think there are ways, though, that we can look at organ donors that people do not talk about because it is not known that we can use organs hours after the heart has stopped. It does not come up. I think there is a need to sort of say these are broader topics about end of life. And almost when you get there in five years time, the technology might actually be applied differently. If you ask that question, then do not be limited to the current, or in some cases the old-fashioned, paradigms about where organs come from. But I think that understanding at a grassroots level, at a hospital level, is very important.

The CHAIR: We are certainly learning about the rapid pace at which technology has developed in this space over the recent years, particularly with regard to the perfusion machines that you mentioned. We have heard from experts working in liver and kidney transplants, and they use the machine, but we have not to this date heard about machines used to support lungs, so that is great evidence that you have provided us as well with regard to that. Cindy, would you like to continue with some questions?

Cindy McLEISH: I would. Thank you very much, Ella. Thank you very much, Professor Snell. I am still a little unclear about the retrieval process and the skills that are required for that initial retrieval. When you were talking about Albury or Mildura or wherever, to retrieve and then bring them—transport is one issue, but who can retrieve?

Gregory SNELL: It is different for the different organs. There is basically a different team—the heart and lung person can usually retrieve both, so the Alfred's team can retrieve hearts and lungs. The liver team retrieves livers, kidneys and pancreases. You usually need two teams, and they each need a surgeon, an anaesthetist or a perfusionist and often support staff and training staff as well—you have got to be able to educate people through—and because it is the most unsociable hours, it tends to be the most junior person, and they have got to be on continuous stand-by. Again, you can have back-to-back runs where this is extremely exhausting and socially very difficult, and getting people out of bed to do this the fourth time in a week is quite problematic. They are totally different skills. Even the timing of a retrieval—the heart comes out first, the lungs come out second. If you are the heart and lung team, the clock is running and you want to be off, so you have got separate transport coming back—you have got separate requirements. The liver team can fluff around splitting livers and they can take many hours sometimes before they are ready to go, so they have separate transport. Again, when you are talking about anything out of the metropolitan area, you have got planes. We do Tasmania as well, which is a challenge for us logistically, so we again have arguments about who has got the plane. The current transport arrangements involve a nurse coordinator ringing up the jet company and saying, 'Have you got a plane and a pilot?' And you can sometimes almost imagine them looking out the window and saying, 'Well, it's raining and there's a bit of a storm', and they are negotiating on the prices of these things. It has been recognised.

Cindy McLEISH: Let us say for Mildura or Tasmania, you will fly up—there is nobody in those hospitals that can undertake that. What about for a kidney?

Gregory SNELL: Correct. For kidneys essentially the same is true. Until recently the Alfred was not even retrieving kidneys. The surgeons were from the Austin who came across to retrieve kidneys, so it is a relatively small group of people. Again, it is not seen to be exciting, it is not seen to be well reimbursed and it is unsociable. There has been a problem getting staff to do that.

Cindy McLEISH: That would be limiting, then. If I am a donor and I live in Mildura, it just may not be possible to get the retrieval team.

Gregory SNELL: Correct, yes.

Cindy McLEISH: And there is no-one locally that can do it?

Gregory SNELL: No.

Cindy McLEISH: We have to fly in that expertise. And then in terms of the transport planes, is that a special charter or chopper?

Gregory SNELL: A special charter is normally what is done, yes. We do the same interstate—it is the same. We get 70% of our lungs from Victoria, but we get 30% from other states. In the big cities they can hopefully retrieve, but not always. We spend a lot of money on jets to fly to these other places, let alone if it is Orange or Townsville or somewhere else.

Cindy McLEISH: Yes, and if I am needing the transplant and I am in hospital in Albury, then I come down to the Alfred—they bring whoever is needing it?

Gregory SNELL: Yes, and that is a challenge too, because if the organ donor is brain dead, then you have got an organ donor, so the chances are if you bring someone who is sick out of another hospital, they are going to be coming down for a good reason. If it is DCD and there is a 66% chance that we have one, there is 33% we do not—we are not going to put a sick person on a plane to potentially not have an organ for them. Again, if we could guarantee them a bit more—and we do do the lungs. We do all of Tasmania, we do southern New South Wales and we do 90% of South Australia, so we are forever having to juggle the types of donors and the air transport, and the weather—if you get a big front come through in summer, you are not going to put a small plane in the air.

Cindy McLEISH: Yes, thanks. Thanks, Chair. Thank you very much.

The CHAIR: Thank you. Gary.

Gary MAAS: Thank you. Thanks, Professor Snell, for your contribution today and your appearance today. I think my questions will be down the voluntary assisted dying path. Firstly, would you be able to confirm for us why you think that pathway is not as enhanced as perhaps it could be?

Gregory SNELL: It has developed sort of in a cancer sense, and I think it is probably expanding itself into neurological conditions, which feed more into the organ donation side of things. I do not know that there are any or if there is one neurologist qualified to look at the prognosis. For example, if you have someone who looks at the prognosis of people with chronic lung disease, they are not eligible to make a comment on the neurological cases, so you need the education out there to the providers and need to have enough practitioners who can comment on these things and head them in the right direction and potentially head them to the hospitals. The hospitals have not been interested in the voluntary assisted dying at all. It is not well regarded by the—let me rephrase that. It is seen that it is something that should be happening at home and not within the hospital system. They have not been interested to date in the administration of the medicines in the hospital.

Gary MAAS: Is that because it is relatively new as well?

Gregory SNELL: It has been going long enough that they have got a bit of an opinion on it. I know the Alfred has softened its opinion on this and is interested in being more involved. Again, it is seen to be better if the person is in the home environment, sitting in front of their television, making the choice when they have the medicine, which could be at any time they choose. It has not really been put to patients. You would have to have some tests beforehand, but if you wanted to donate your organs, it could be done in a calm, nice manner within the hospital system somewhere, where half an hour or whatever after cardiac arrest—you would choose the time and whatever organs—you would be moved to an operating room, or you could even have this in an intensive care unit and be subsequently removed to an operating room after death. The concepts all exist; they just have not been done.

The DonateLife group was really saying they did not want to muddy the waters with donation early on when voluntary assisted dying was finding its feet. But I think there have been two cases where people have donated their organs, and they went absolutely perfectly. I think for the person who had set it up—it was their wishes; they had set it up for weeks beforehand—it all took place and was seen to be an absolutely fantastic experience as an end-of-life thing. It was celebrating an end of life—rather than nothing coming out of it, there was clearly something coming out the other side. I think it was really seen to be an extremely positive event. It was on the back of those two cases that had me thinking, 'Gee, they were so successful. Everyone was so happy about it. We should be going further with this.'

Gary MAAS: That being the case, how then can our hospitals be better supported to facilitate that?

Gregory SNELL: I think having a bigger discussion, as this Committee can do, where you are saying, 'This is something that's a reasonable concept'—to put together the existing laws, which are perfectly not in contrast with one another at all with this. And how would you do it at the Alfred? Again, if you had a room somewhere, on the floor of the operating room's ICU, and you had a comfortable chair and you could bring the family in and sit there in a calm, planned way, basically the person would do exactly what they would have done at home, or indeed for some cases injections could be given in a fashion, as is done if the person cannot take tablets, and then away things go. It is as simple as that in some ways. Rather than it happening entirely in the community and people being told, 'You can't come to hospital to have your last day,' we would encourage you to 'Think about this, and here are the steps that it would take: some medical assessment, you would need to be in hospital on that last day, you would need to be understanding that the time frames afterwards would be limited somewhat compared to what the family would get at home.' But it could all be done, and it is not mentioned currently in their remit.

Gary MAAS: Thank you. No further questions.

The CHAIR: Thank you. Chris.

Chris CREWTHER: Thank you very much. Well, firstly, thank you for your time today in giving evidence. My first question is: you mentioned that the ex-vivo lung perfusion machine is not currently being used because of a lack of space and funding. I am wondering if you can elaborate on that, if you can. Also, is there an alternative location where it might be able to operate, and if so, how much funding is required? And was there funding in place when the machine was acquired?

Gregory SNELL: It is an interesting problem. The machine is reasonably expensive and was bought with some hospital funds and some donations. Its consumables are reasonably expensive at around \$40,000 a run, so you want to be sure you have got a reasonable chance that the organs you are looking at will be usable afterwards. We have had it for a number of years. The most trained people from a technical point of view have moved on, and there have been concerns really about continuing, 'How do we train people? How do we resource it out of hours when people are already going for retrievals, doing implants and stuff?' and then 'Should we be leaving that aside and just doing the transplants rather than spending more time on the machines?' There has been a looking at resources and saying, 'This is not where people want to currently put the resources', and yet the technology for livers, for kidneys and indeed for the hearts is accelerating. We will be talking of heart machines here in Victoria pretty soon, just as has been done in New South Wales. It is an opportunity that has sort of been lost a little bit, and it is because of resources, which probably includes some staff EFT and looking at the consumables and, as I said, trying to fit it into the fabric of the lives of the people who are there. It is how to put a dollar figure on it, but again it is the ethos of it as much as anything, because it is the way to buy time to evaluate and to also resuscitate organs. The technology will significantly improve with that.

Chris CREWTHER: Thank you. This is perhaps an ethical question. Do you think that a voluntary assisted dying pathway for organ transplantation might encourage someone to pursue voluntary assisted dying when they may not otherwise, particularly if they have a family member in need of a vital organ where they may be suitable?

Gregory SNELL: That is a challenging ethical question. The person has got autonomy to make their own decisions. The voluntary assisted dying pathway has a lot of checks and balances. Their prognosis has to match, they get asked several times and it all takes many weeks—much longer perhaps than was originally intended to actually happen. I think it is not something that you could push through, and you do not have directed donation as such here in Victoria.

Chris CREWTHER: Thank you. Thank you, Chair.

The CHAIR: Thank you. Heang, thank you.

Meng Heang TAK: Thank you, Chair. Thank you, Professor Snell. This inquiry is more about exploring how to increase people making donations. If there were more, would the hospitals, as you can see, cope with that?

Gregory SNELL: The hospital could handle more. I think there is still scope in the system where essentially you are hopefully taking out sick people and putting well people back in, albeit the surgery and medical adventures to get there. But I think you also would have the opportunity to get your timing right, because if organs came in in a timely fashion, even if we did not use every one of them, we could at least choose the best time and avoid the disasters. What you do not want is sick people sitting in intensive care waiting for organs. We recently had someone who waited nearly six months in intensive care on ECMO perfusion for organs. It would have been very, very expensive, and if we had been able to get timely organs earlier, it would have been a better outcome for the patient and a better outcome for the community and dollars. I think the choice of organs, the timing of organs would all be better. They are not all the same size, they are not all the same quality, they are not all the same blood group, so yes.

Meng Heang TAK: Thank you.

The CHAIR: Annabelle.

Annabelle CLEELAND: Thank you, Professor Snell. I have spoken to some of your colleagues as background for this inquiry. It is amazing knowledge that you have had in this space for a very long time. I just

wanted to ask: have you been a part of either an inquiry or department report in this space in recent years, like the last decade?

Gregory SNELL: Yes. In February 2020 there was the Ngamuru report, which I put a 60 or 70-page submission to, which we are still waiting to be released.

Annabelle CLEELAND: Do you have copies of that submission that you would be able to share with the inquiry?

Gregory SNELL: It is a Victorian Government inquiry document. I did a review of the final document before it was submitted to Parliament, so it was said to be confidential at that point.

Annabelle CLEELAND: That has not been released publicly, but would you be able to share your submission?

Gregory SNELL: If that is appropriate, given the confidentiality clause that was signed.

The CHAIR: We would be happy to seek some advice around confidentiality and provide that to you.

Gregory SNELL: Yes. The other one was the Ernst & Young report from 2017, which has been released in various iterations—but there was a submission to that as well.

Annabelle CLEELAND: Are they the two major ones?

Gregory SNELL: That I can think of, yes.

Annabelle CLEELAND: Yes. No worries. Just following on from Chris's questions around the lung perfusion machine, if it was operational and staffed and resourced, how many more transplants annually would it increase—like, if we try to quantify it a bit?

Gregory SNELL: We looked at this a couple of years ago and said that, being conservative. there were probably another 16 transplants per year from a lung point of view that we could do. A number of these were based around logistics, so if we could park the organ while the operation was done and then sort of swing it in afterwards, it would be okay. The theory, increasing practice overseas, is to attempt to resuscitate marginal organs, but it is the opportunity cost: if you can get one out of four, that is a lot of money to spend for not much, but if you can get two or three out of four it becomes justified.

Annabelle CLEELAND: We heard from Spain earlier in the inquiry around their profile of donors—age and demographics, really. Do you think that in Australia we should be reviewing some of that, trying to get those that have fallen out of the donor profile before considered?

Gregory SNELL: We have looked extensively at that in our patient group, and we push the envelope as much as anybody in the world. We have already expanded the age criteria, the highest-age acceptance, and we are the only ones who get lungs really sizeably from any other state. We give almost none to Queensland or New South Wales, and they regularly give to us—so we have worked hard on that side. From a lung point of view, I do not think there is much opportunity for that. I think that machines would help the heart group to use more marginal hearts.

Annabelle CLEELAND: Yes. Right. In your experience do you think that hospital-based staff are having that conversation with all potential donors? Are there any missed opportunities when it comes to the staff and a potential donor in the hospital at the moment?

Gregory SNELL: In the big hospitals I do not think there is. But as we heard before, I think particularly around DCD there is the opportunity to look in smaller centres and with older patients and voluntary assisted dying, where if people knew the possibility of organ donation, they might suddenly prick their ears up and say, 'Actually, that is what I want to do. Can you help facilitate that?' Yes.

Annabelle CLEELAND: I appreciate your time put into several reports in this space. But is there anything else you wanted to get off your chest that could contribute to this inquiry that you think could combat some of the barriers that exist in donor registration but also the health services?

Gregory SNELL: At the various inquiries we have talked quite a bit about the logistics and retrieval aspects, and as I hinted at before, it seems a bit strange that we have nurse coordinators ringing to negotiate with pilots about aircraft that fly to Townsville or Perth or Darwin for that matter. There was interest from Toll Holdings and the other trucking guy, Fox, about looking at the transport logistics for organs and things, with comments from them sort of saying, 'If we can get crayfish into Japan in eight hours from out of the water,'— in whatever it is, 16 hours—'then how is it that you can't ship organs around, and why can't you use the Amadeus system of air cargo transport?' And so I think there are efficiencies. We move blood, we move organs; I would wonder whether someone could be improving the transport arrangements and logistics for us.

Annabelle CLEELAND: Wow, that is a great comment in this inquiry, actually. Have you ever been aware of an organ that has not been able to be utilised because of the transportation challenges?

Gregory SNELL: Yes.

Annabelle CLEELAND: How often would that occur?

Gregory SNELL: Logistics make up quite a part. I think it is 18% of organs not used from memory; I could look that up. It is just wrong place or no surgeon available in South Australia to retrieve for us or getting to and from Tasmania, so there are issues around logistics.

Annabelle CLEELAND: If you could supply any data or background to that comment, it would be really powerful. Thank you for your time.

The CHAIR: Just before we wrap up, I am very conscious of the time but I do want to quickly just ask, given your role, if you could touch on how Victoria supports Tasmania with organ and tissue donations and transplants and retrievals.

Gregory SNELL: Until about five years ago there was no organ donation system in Tasmania. There is now a state director and at least a couple of coordinators and they very much take their lead of what we seemed to accept from them. It is a challenge in terms of DCDs because again there is this logistics thing. 'How sure are you that they are going to have a cardiac arrest, because it's expensive to put on a plane and have a team wasted for half a day or so going to Tasmania.' They try and do as much as possible, but they struggle a little bit based on what to them seem to be the quirks of our system of retrieval.

It is like the other interstate groups: we have to have a team that is available to go and retrieve the organs and get them back. Getting recipients from Tasmania is actually perhaps more difficult—getting air transport sometimes in the middle of the night. They have only got one or two air ambulances that can actually take people on oxygen and bring them across. There are very few flights at the end of the day to bring people across, so we struggle to get Tasmanian recipients.

Getting blood across, logistics again, we have to crossmatch and stuff so we often are needing blood separately from the teams and things, and there is no-one with any other skills there to help facilitate that. We put more organs into South Australians than we get organs; we put more organs into Tasmanians than we get organs from.

The CHAIR: Okay. It sounds like there is a fairly significant role for Victoria to play in supporting some of those smaller states with organ transplants?

Gregory SNELL: There is. And at different times we have been approached, particularly by the South Australian—there have been government questions and donation questions and unit questions about whether they could have a preferred provider because they would like it to be us, at least in thoracic organs. That does not sit well with the state sharing arrangement, but that would actually work best if we were the sole provider. We could provide them with the rest of the backup services.

The CHAIR: Cindy.

Cindy McLEISH: I have just got a quick question. With somebody who is a donor, they do not always specify what organs they are happy to donate. Do we always maximise the use of a donor or do we go in and take the heart and that is it—or do the heart and lungs and leave the rest?

Gregory SNELL: We try and take—'take' is the wrong word—we try and utilise what we possibly can but the heart—lung team, if we are flying long distance, the kidneys would be someone else's responsibility, for example. At times the heart is looked at and the lungs are left behind, again if they are not matched or whatever. You try and help another unit. You might try and retrieve for them and have them packaged and sent to Queensland or vice versa. There is an attempt to do that, yes.

Cindy McLEISH: Okay. Thank you.

The CHAIR: Professor Snell, thank you very much for appearing before the Committee today and for your contribution to this incredibly important inquiry. The Committee very much appreciates the time that you have taken to prepare both your written evidence that you provided and your evidence that you provided to us today.

You will be provided with a proof version of today's transcript to check, along with the question taken on notice. Verified transcripts and responses to the question taken on notice will be published on the Committee's website.

The Committee will now take a 40-minute break, and I declare this hearing adjourned.

Witness withdrew.