T R A N S C R I P T

LEGISLATIVE ASSEMBLY LEGAL AND SOCIAL ISSUES COMMITTEE

Inquiry into increasing the number of registered organ and tissue donors

Melbourne—Monday 19 June 2023

MEMBERS

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

WITNESSES

Ms Georgina Callaghan, Donation Specialist Nursing Coordinator,

Ms Laura Fleckner, Donation Specialist Nursing Coordinator, and

Ms Anna McNamara, Donation Specialist Nursing Coordinator, Alfred Health; and

Dr Joshua Ihle, Senior Intensivist and Clinical Lead of Organ Donation, Alfred Health, and Medical Consultant for DonateLife Victoria.

The CHAIR: Good morning, everyone. I declare the public hearing of the Legislative Assembly Legal and Social Issues Committee's Inquiry into Increasing the Number of Registered Organ and Tissue Donors open. Thank you to our witnesses who are appearing before us today. I welcome from Alfred Health Dr Joshua Ihle, Senior Intensivist and Clinical Lead of Organ Donation, and Medical Consultant for DonateLife Victoria; Georgina Callaghan, Donation Specialist Nursing Coordinator; Laura Fleckner, Donation Specialist Nursing Coordinator; and Anna McNamara, Donation Specialist Nursing Coordinator. Thank you for appearing before the Committee today.

All evidence given today is being recorded by the Hansard team 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.

Witnesses will be provided with a proof version of the transcript to check. Verified transcripts and other documents provided to the Committee during the hearing will be published on the Committee's website.

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

Joshua IHLE: I want to thank the Committee for the opportunity to speak on this really important issue. For the members of the public who have not read our submission, it can be summarised as follows: the *Human Tissue Act* authorises organ donation occurring when a person has consented to the donation of tissue after their death. At law, where registration has occurred, there is no need to involve the person's family. However, the current practice in Victoria is to ask family members whether they consent to organ donation. The practice makes family members responsible for assenting to or declining organ donation, and they must navigate this decision in what is otherwise the worst day of their life. But unlike many of the other aspects of health care, we as clinicians have no capacity to shoulder the burden of decision-making with family members.

Registration is incredibly important because it helps frame the family's discussion about what is best for the patient and their family. Registration assists us to bring the patient's end-of-life wishes into the conversation around organ donation. That said, we allow family members to decline to assent to organ donation even when a person has registered. We have had adult patients who register and who have given explicit instructions about their wishes in advance care directives only to be overruled by other family members. There are many decision points along the way that will influence a family's willingness to assent to organ donation. The Committee should focus on all of these, not simply the act of registration, as a means of facilitating organ donation. Ultimately, we want to make these discussions commonplace, so every Victorian family can have them and therefore approach end-of-life decision-making from a place of certainty and security rather than ignorance and apprehension.

We also believe that it is appropriate to align both the law and the practical processes associated with organ donation so that they are consistent with the general principles that apply to medical decision-making generally. For example, the *Medical Treatment Planning and Decisions Act* sets out a series of principles aimed to ensure people have bodily autonomy. Consistency with those principles would mean that where a patient has been explicit and detailed about their wishes and followed the relevant procedure, family members should not be able to override their wishes. Donors should be able to appoint any person they choose to make decisions about organ donation rather than simply relying on family members. And if no such person is appointed, then to be eligible to make decisions about organ donation, family members must be in a close and continuing relationship with the person whose organs are being considered for donation, something that is currently not required.

The following additional points by my team may assist to put this submission into context.

Laura FLECKNER: Thank you, Josh. Thank you, Committee, for your time this morning. First, we accept that the whole of society is on a journey in this area. In Alfred Health in 2023 our practice is to discuss organ donation with every family involved in end-of-life decision-making, even when the patient is not registered and even when we know that the patient will not be suitable to donate. When a patient is not suitable to donate, we let the family know that we routinely refer all patients approaching end of life to donate life and to explore the potential of helping others through organ donation and that unfortunately donation is not a possibility for their loved one. We acknowledge the wishes of the patient, if they are registered to be an organ donor, and we thank the family for their loved one's generosity in thinking of others through registering to be an organ donor. This

practice has three benefits: it raises the concept with the family to inform their future decision-making; it means that we can be clear that we raise organ donation without exception; and it ensures that, in every case, the communication loop is closed so that we can honour the patient's wishes.

But our practice is not the practice everywhere in the state, and it has only occurred at Alfred Health within recent years. We have embedded this practice as Alfred Health is not only the second-largest donation centre in the state but also the statewide service for heart and lung transplantation and a renal transplant centre. Other Victorian health services do not have the same exposure to the life-saving benefits of donation that we have, which means that they have not faced the need to maximise opportunities for donation. As a result clinicians at these health services may discuss organ donation almost apologetically. But if health professionals are not yet comfortable maximising the opportunities to discuss organ donation, we must acknowledge that there is work to do for every person involved at every stage from registration to donation.

Anna McNAMARA: Second, registration discussions are not made from an informed position. We have had patients who explicitly registered on the donor register that they did not want to be a donor, not because they were against donation, but because they were for it and felt that their organs would be unfit for donation due to smoking. We have had many conversations with people outside of work who tell us that we would not want their organs because they are too old, unfit or they drink too much. But when we speak to these people or patients or families and explain that at least some of their organs might be perfect, they change their mind. But if people have little understanding of whether they would be suitable donors, they have no understanding of what donation involves. If we want people to discuss end-of-life decision-making and organ donation, it would be vital for them to understand what this involves.

We acknowledge that the most likely recommendation from this Committee is an education campaign. Such a campaign is undoubtedly important, but it will need to have at least two separate aims and audiences. The first aim is to encourage all people, but particularly young people, to register as organ donors and/or discuss the many ways in which a person might be suitable as a donor, placing emphasis on the facts. To be a suitable donor, you would likely be in an ICU, on a ventilator and often in sudden and unexpected circumstances. The second aim is to encourage all people, particularly older people, to assent to donation and/or discuss the many benefits and occasional burdens that donation involves.

Georgina CALLAGHAN: Third, we know that these decisions linger long in people's lives. We get calls from families once their loved ones have passed many months later stating that they found their loved one's organ donor card. We often will sometimes get calls from aged care facilities as well asking if one of their residents has the potential to help others through organ donation. We also work with a donor family support coordinator, who follows up with all families who have considered organ donation for their loved one. From these conversations we are aware that some families have come to regret their decision to say no to donation, but no-one, however, reports regret at having said yes.

Given this ongoing effect, we believe that there is value in a registration process that supports donors' views, perhaps a little more strongly than is currently the case. We allow people to decide what happens to their assets after their death, but we do not allow people the same authority in relation to their own bodies. We might be a little bit biased but given the fact that one is about money and the other is literally a matter of life and death, we believe that we might have our priorities a little bit mixed up here.

Those are our main points. There is one last matter that might be useful for context. It is that where a family assents to donation, we have no idea who ends up receiving the organ. Our time as donation specialists is only ever the start of a story, and we do not get to see how that story ends. We never get to see how it turns out, whose life is saved and what they get to do with their second chance at life. We think that might be a challenge that this Committee faces. The decisions that you make will start a process that hopes to sway people's minds at different times in their lives, but though you will not know how the story ends, you will have changed it, and we are grateful for that support. Thanks.

The CHAIR: Thank you. Can I take this opportunity to thank you, as donor specialist service coordinators, for all the work that you do and the role that you play in organ and tissue donation and quite frankly saving Victorian lives. Thank you very much. Thank you for taking us through your practice and the role that you play at Alfred Health, and in particular thank you for explaining to us how you speak to families, family members and potential organ donors.

You mentioned that your practice is to have that conversation with all families and potential organ donors who are approaching the end of life and how that is unique to the Alfred. Can you speak to how this program came about, what made the Alfred decide to start the program and also the success of your practice—for example, have you noticed any increase in organ and tissue donation?

Laura FLECKNER: Yes. I might take that if that is okay. Our practice is assisted by DonateLife, so we are employed by Alfred Health but of course we are obviously overseen by DonateLife. We receive our communications training and Josh received his communications training from DonateLife, and it is then our role to embed that practice within the hospital. I think Alfred Health is quite unique, as I sort of alluded to in my little speech, in that we have so many transplant recipients, particularly heart and lung, in the ICU where we work. I think that has enabled us to get the practice consistent and be able to build on it across the ICU nicely.

Joshua IHLE: I might add to that as well. There is a huge amount of work that has been done at OTA and through DonateLife. We have developed a best-practice model, and there is a recommendation to all clinical staff about how the donation conversation should be had. That is about making sure that everyone is given the opportunity—that every time someone is approaching death the registry is checked and that when you are having a conversation with family members that that is done by a trained requester, and usually that trained requester should be someone that is separate to the treating clinical team. So there are all these recommendations that have really been guided by data that shows what the best outcomes are in terms of getting consent for donation that will ultimately lead to transplantation. One of the things that we have done at Alfred Health is that we have tried to normalise that as much as possible. We talk about these statistics on a weekly basis and see whether we are meeting our targets. Did we refer every patient? Did we check the registry? Have we had what is called a collaborative request with one of the donor coordinators? This is spoken about fairly routinely now. I think what that has done is it has normalised these practices. That is one of the Committee's challenges here; it is about normalising the donation conversation outside of the hospital.

The CHAIR: You have pre-empted my next question, which is: it sounds like you have done a remarkable job in normalising that conversation within the hospital, but do you have any views or suggestions as to how we can normalise that conversation outside of the clinical setting?

Joshua IHLE: There are lots of ideas. I mean, it is clearly a multipronged attack that it needs. How do we change the way in which our society perceives the culture around organ donation? That is the question here. We have spoken about the model of care for when the patient comes into hospital, but what we have to do is change the way in which society perceives organ donation and normalise the conversation at as many different touchpoints as possible so that society's expectation around organ donation changes. We could talk about different ideas of how that can be done. I know DonateLife spoke a lot about normalising it through non-confrontational registration processes, such as your licence. But precipitating conversation amongst the public in a non-confrontational manner, in as many opportunities as possible, is probably what needs to be done.

The CHAIR: Thank you. I will hand over to my colleagues for some questions. Annabelle?

Annabelle CLEELAND: Thank you. Thank you so much for your time. It is an emotional topic, as I am sure you are all aware. I just want to understand—you shared a graph this morning by DonateLife. It said there were 1400 potential organ donors and there were about 1300 requests. Is there ever a time when there is an eligible donor and that conversation does not occur with the next of kin or family? This is probably less at the Alfred, because I know you run really well-respected conversations and communication, but probably more at regional hospitals. Are there any sorts of training or resource barriers to having that conversation with eligible donors?

Georgina CALLAGHAN: I think sometimes it is just the pure logistics of some of our regional centres. They may very well refer to DonateLife for consideration of organ donation, but given the distance of some of the hospitals within the state, it might not be possible for a donation specialist to be present to support that intensive care unit or emergency department to raise organ donation. It might be another clinician, who may or may not have done the same communication training as us, but very rarely, I would think, would we not have the conversation altogether. But I suppose one of the barriers is having the right people in the room to be able to support families and provide them with information to consider organ donation in regard to their loved ones' end-of-life care.

Joshua IHLE: I wonder if you want to talk to the auditing process for all deaths.

Georgina CALLAGHAN: For all hospitals that have DonateLife coordinators or donation specialists, all referrals do get audited, and all deaths will be reviewed to ensure that we are not missing any potential suitable donors for either solid organ or even eye and tissue. We then will review the process. Did we check the register? Did we have conversations? The timings of those conversations—were they appropriate? There is this continual review of process to ensure that we are maximising and looking for all opportunities, where possible, across the state.

Annabelle CLEELAND: I would be interested to know the results of maybe, if there was discrepancy between the deaths reviewed and the referrals, if there was an opportunity to potentially invest in more regional coordinators in this space, is that possible?

Georgina CALLAGHAN: I cannot speak to the regional centres, as we are based at the Alfred, even though we do service the state when we are on call. So I am not sure as to what their audit data is, but from an Alfred perspective, like Josh had alluded to, we do review it weekly with all of the intensive care consultants as well to be able to generate that discussion and look for that real-time feedback.

Annabelle CLEELAND: Okay. I am quite interested to understand the logistics of operating a hospital like the Alfred and then having retrieval teams. How do you manage that theatre program? And I asked this earlier as well, have you had to decline an organ because the logistics of managing the theatre has clashed, between staffing and availability and scheduled surgeries?

Anna McNAMARA: The logistics is a really tricky question. As soon as we come out of consenting a family our usual practice particularly at the Alfred would be to go straight to theatre and give them an early notification to say that, 'We're working up a donor and we're looking at potentially theatre tomorrow or the next day'. They use the emergency theatre booking. There is always an emergency theatre at the Alfred and that is what they would allocate the donor to, and from then if it was a heart and lung donation, they would also need to involve their transplant teams so they can bring in their recipients as well. So in terms of the logistics of declining donation, I would say we do not have any missed organs because they just somehow make it work. Staff work overtime as well to get things across the line. Do you guys want to speak to that?

Laura FLECKNER: It is very rare.

Anna McNAMARA: It is very rare.

Laura FLECKNER: If in the instance, say, we have gone to the Alfred and said, 'Look, we've got this donor coming' and they are unable to accommodate it and the family cannot wait another day, which is more than understandable from an emotional perspective, we would proceed to offer, as per our rotations, to the home team or the most urgent listings first. If they cannot work with the logistics of needing it to happen today, then we would also see if intrastate teams could come and do the retrieval if that would assist or ease any theatre logistical issues as well. Generally, we can get the space in the theatre; it is more getting the retrieval surgeons to the theatre to do the retrievals, if that makes sense.

Anna McNAMARA: So if there is a donor in Mildura and they are donating their heart and lungs, the Alfred team will go to that centre to do the retrieval and then they have to come back to the Alfred and do the transplant as well, so there are those logistics of that team being off the floor for that amount of time and then having to use a theatre to perform the recipient transplant surgery as well.

Annabelle CLEELAND: So when that retrieval team go to Mildura, as an example, what impact does that have for scheduled surgeries that day? Are they paused, delayed, compounded?

Laura FLECKNER: We are not theatre coordinators, but generally there are cancellations or pauses and re-juggling of lists to accommodate the donation, yes.

Joshua IHLE: The reality is I think if there is a donor in the Alfred, that they will then occupy an emergency theatre because this is an emergency operation, and it has to be squeezed into the scheduling because it is not otherwise scheduled. And that theatre will be occupied for the procurement of the organs and then if those organs are going to be transplanted in the Alfred—and the Alfred being the only heart and lung

transplant centre and also being a kidney transplant centre—they may require another three theatres on top of that in the emergency situations. So this is also in an institution that is one of the trauma centres, so if you get a bad head injury coming in that also needs an emergency theatre. So often it comes at a cost of business as usual, and the knock-on effect I think is delays in often elective surgery of two to five days. Whether that be because of facilities because there is no emergency theatre that is available for it and we have got to squeeze it in, or whether it becomes a personnel resource issue because you are getting the same people to be doing the procurements and the transplant, it is very challenging.

Annabelle CLEELAND: If I can ask another question—from that challenge in the pressure and management and overtime and hours, what is the average career of a donor coordinator? Do you know how long you can –

Anna McNAMARA: I would love to do it forever, because I love the job. We generally come from an ED, ICU or theatre nursing background, so we are used to these very stressful situations and dealing with family. We have still got donor coordinators who have been around for 10, 15 years. I cannot –

Laura FLECKNER: I think it just depends.

Anna McNAMARA: Yes, it just depends. It is not –

Annabelle CLEELAND: So I guess what I am asking is: is there a concern around burnout because of that pressure and juggling these pretty high-pressure circumstances and emotional –

Anna McNAMARA: Now that the roster is in a better position in terms of staffing, we do not have as much burnout. But, I mean, we are human, and it is a really hard job. So there is definitely potential for that, but the more staff that we have definitely takes that burden off.

Annabelle CLEELAND: And what impact did the pandemic have on donor surgeries?

Joshua IHLE: It had a huge impact, I think. Ultimately, there were not enough people coming into hospital who were sick and would otherwise be considered appropriate donors. We had challenges in being able to establish a rapport with family members, and that therefore influenced the way in which we could have a conversation around end of life and donation. I think families were exhausted about the logistical challenges by simply coming into hospital to see their loved one die, and so the idea of continuing another conversation around organ donation—you know, you have heard previously that the consent rates just dropped off drastically and we have not been able to get them back. It is a bit unclear as to why we have not been able to regain those consent rates, but it has had a huge impact.

Annabelle CLEELAND: Do you have any indication of why we have not been able to bounce back with the family consent rates?

Joshua IHLE: I think the bureaucracy about coming to visit families, for want of a better term, was very challenging. I think it put the clinical staff in a really awkward position because decisions were made without the sympathy or the empathy around, you know, the people who have to tell family members that they are not allowed to come in despite that their loved one might be dying. So that was challenging, and I think that there is still a bit of residual effect from that. We used to have no specific visiting hours; we would support families to come in whenever they liked. Although the rules are relaxing somewhat, they are still more rigid than what they were pre pandemic. So I think trying to develop a rapport with the family so that the family can trust the healthcare sector, for want of a better term, has been really important.

Annabelle CLEELAND: And just finally—sorry, thank you for your patience—the number of people that are waiting for an organ is currently nationally at 1900. So how many could you estimate would die because they have become too unhealthy to receive an organ or have actually died while waiting for an organ on the list? Could you have any indication?

Joshua IHLE: I do not think we can answer that. It is probably a question that is specific to individual transplant teams. They will know what the mortality rate on their waiting list is for each of the organs. We are kind of on the donation side of things. And, yes, we will take care of the patients. I will take care of the patients

in ICU once they are transplanted, but I am not intimately involved in that sector. There is the slight delineation between the donation and the transplantation sectors.

The CHAIR: Thanks, Annabelle. Christine.

Chris COUZENS: Thank you so much for your contribution today. We really appreciate it and your submission. And thank you for the work that you do, it is incredible. Can you tell me how often transplants occur at the hospital?

Laura FLECKNER: I think we would not have the statistics exactly because we are on the wrong side of the fence, but it is a near daily basis of some description, whether that be renal transplants, which we do not see back in the ICU—but I do not know, how many have we seen through ICU? It has slowed a little bit in the last month.

Joshua IHLE: It is slow, but at its peak, between 100 to 120 lung transplants per year and about 25, 30 heart transplants. We are not a very busy renal transplant centre, and generally speaking, when kidneys are transplanted, they do not require ICU care in the post-operative period, so we do not see them.

Chris COUZENS: What information could be recorded on the register that would help you with your conversations with families, do you think?

Laura FLECKNER: I think it was Ella that said some sort of disclosure that you have had a conversation with your family member, and I think that is the key point.

Chris COUZENS: Just in terms of that education piece and awareness piece, I suppose, and when you are talking to families, particularly Aboriginal families and CALD community families, is there a particular training program that you do to engage those families? Can you just talk me through what happens there?

Georgina CALLAGHAN: Yes. So we do not have a specific training program as such in regard to First Nations people, but from our perspective at the Alfred we are very proactive in engaging with our Aboriginal liaison officers to be able to help support us to then be able to help support the patient and the families. Like any family, it is, I think, about having a good sense of cultural humility and really understanding what is important for that patient and family within their end-of-life care and making sure that we can help facilitate whatever is important to them and their beliefs.

Chris COUZENS: Thank you. Thanks.

The CHAIR: Thanks, Christine. Chris.

Chris CREWTHER: Thank you. Firstly, thank you for your submission and for being here today and giving evidence. My first question is: do you think the policy that registrations can be overridden by family should be abolished altogether, and if so, should there be any exceptions to that?

Joshua IHLE: A great, prickly question. Look, the fact of the matter is that there are inconsistencies within our society. You know, why is it that the *Human Tissue Act* speaks to one process and, practically, we speak to a very different process? As Georgie made very clear, it seems silly that we would not allow that for materialistic things, yet we do allow that for things like organs. It would appear a pretty bold move and would require a huge education component to be able to change that, but that process might speak to how we start to culturally change how we perceive organ donation in this country. Why is it that in other countries it is more socially acceptable to support organ donation? Places like Spain and Portugal have a much easier time in trying to achieve a higher number of organ donors and therefore transplants. So maybe there is opportunity for the government to step in and say, 'Look, we need to align the laws with practice here, and the motive is to change how we culturally perceive organ donation. Are we as a society going to be supporting this, or are we not?' That is the question. I think in principle we do, but in practice maybe we do not.

Chris CREWTHER: And going to my second part of that question, if this was to be implemented as policy, that family members cannot override a donor's wishes, should there be any exemptions or exceptions that you could think of, if that were to be the case?

Joshua IHLE: I think the exception would be if there was more recent information that maybe was in contrast to their registered wishes. We have certainly had situations where people have registered on the AODR either in support of organ donation or not, only to find out that there has been more recent information that has come to light in discussions with loved ones. I think that is really, really important, because ultimately what we want to do is not just increase donation rates, we want to give people the opportunity to make an informed decision, and if we have been able to give them that opportunity to be informed and they still decide no, then we feel that that is our job done well.

Chris CREWTHER: This is a two-part question—it will not be too much of an attack-dog question. Do you think that registration going beyond a yes or no decision may reduce registration rates?

Laura FLECKNER: I do not think so, because I think more information is better. It is a more informed decision, and therefore they will know more about what to expect. Hopefully they will then have that conversation with their families too, so they will know what to expect when we have the conversations.

Joshua IHLE: At a bare minimum, if I can, have the option of yes or no, and then if you do want options beyond that, then it is not mandated—but at a bare minimum, yes or no.

Chris CREWTHER: If there was to be a more complex set of questioning with registration, do you think that there perhaps should be a two-step process, whereby there is a simple registration, so someone is locked into the system to start with, followed by a follow-up registration system, where then they can get more complex information, like the binding form of registration of donor wishes that you talk about in your submission?

Joshua IHLE: Yes. I think there is opportunity there, and that might speak to the situations where it might be a bit more mandated. We have spoken about consent or intent, and with people who register their wishes it is probably not an informed decision. But there is an opportunity for people that want to make an informed decision to be able to ask more questions and then that be a bit more legally binding.

Chris CREWTHER: In a more complex registration or complex follow-up following the simple registration, do you think there should be an ability to nominate multiple next of kin or multiple family members, who are then notified that the person has registered as an organ donor? Do you think that should be part of that more complex registration or follow-up, to ensure that family members do know about a donor's wishes?

Laura FLECKNER: I had not really thought of that one.

Anna McNAMARA: So long as it was the right next of kin—like, it was not their neighbour or a friend when they did have proper family members, because then we would again come across those hurdles. I think there would be no harm in that. It is just triggering more conversations with different people. We do find that when we discuss donation with families, some of the reasons that they say no are because they do not want to wait the time—the one to two days. I think there does need to be information for donors and families that it is a process and that there are ante-mortem interventions that we need to do to ensure safety and so that we can find recipients. I think we do lose consent due to some of the unknowns, because it is not an informed decision for people.

Chris CREWTHER: Thank you. My final question, Chair, is: you talked about issues with the wording of the *Human Tissue Act* and there being a few examples that you have mentioned with issues that lead to a situation where a person cannot then donate their organs or where there are problems with the ante-mortem investigations—if I have got the word right. What would actually be your recommended changes to the wording of the *Human Tissue Act*? Have you got any thoughts on that?

Joshua IHLE: There are a few challenges with the *Human Tissue Act*, but one of them is the amendment that came through in 2019 that spoke to getting consent and authorisation for ante-mortem interventions when you are working up a potential donor who is going to die from circulatory death—so they are supported in the intensive care unit on life support. The *Medical Treatment Planning and Decisions Act* is silent on who can provide consent for medical treatment when the medical treatment is not going to be beneficial for that individual. This amendment was made to implement a process to get consent for these ante-mortem interventions. Whilst we appreciated that the primary objective was to kind of protect clinicians in providing

ante-mortem interventions, our personal experience is it has done nothing but be another barrier, and we have lost potential donors as a consequence of that. The reason for that is that the wording is very specific, and it asks that you get consent from the medical treatment decision-maker and that then you get two clinicians to come and examine the patient and then to document that they believe that the patient is going to die as a result of the withdrawal of life-sustaining therapy. That, as a result, has caused a huge amount of concern, because they believe that the patient is not going to die as a result of withdrawal of treatment and they do not want to be implicated in the death of that person; the person is going to die as result of their injury or illness. As such, clinicians have been unwilling to document the legislative requirements, and therefore the patient has not been able to go on to be an organ donor. We raised this I think with the government and wrote a letter and made recommendations to just simply change it to 'will die following withdrawal'. That would be a simple change.

Chris CREWTHER: Is it possible that you can share those communications with the Committee?

Joshua IHLE: Most definitely, yes. The second issue with the *Human Tissue Act* is that this is an Act that was written at the beginning of the 1980s, and medicine has progressed quite a lot. There are a number of technologies that are available and being used internationally to support organs or to support the donation process and assess the health of organs and therefore increase the number of organs that ultimately can be used. These technologies cannot be used in the state of Victoria at the moment because of simple things around the definition of 'death'. For example, it talks about the definition of death being 'irreversible cessation of the circulation'. There are technologies that we use where we artificially restart the circulation. It is used to save people's lives in cardiac arrest, and it is now being used internationally to assess the health of organs and hopefully be able to ultimately donate those organs. We simply cannot explore those technologies because the definition of 'death' would preclude that.

Chris CREWTHER: You talk about the 2019 changes and their being problematic, yes?

Joshua IHLE: Yes.

Chris CREWTHER: Were concerns raised about these changes and the problems they might cause at the time in 2019 or before then?

Joshua IHLE: Do you mean prior to being passed through Parliament?

Chris CREWTHER: Yes.

Joshua IHLE: My understanding—and I was not intimately involved—was that the first iteration was just fundamentally wrong, and therefore there was a huge focus on rewording so many components of that, which may or may not have taken away the attention from the exact wording that is required by the clinicians and the impact that that might have as to whether or not they got to sign that off. That is my own personal view. I think there was a lot of work done to make that amendment clinically correct, but that came at a cost of maybe some little nuanced detail.

Chris CREWTHER: Thank you.

The CHAIR: Thanks, Chris. Gary.

Gary MAAS: Thanks, Ella, and thank you, all, for your appearance before this Committee today. I just want to say at the outset that I really appreciate your submission and I guess the emotional intelligence that went behind the words that you put in that submission. In my experience from clinical practices, it is not necessarily the way it is, but to see such strong emotional intelligence behind what is a very important and sensitive matter really stood out to me. I would firstly like to thank you for that. I am really going to focus in on 'words are important' in my next few questions, and I would like to start off by asking: you used the word 'assent' as opposed to the word 'consent'. Can you give me an answer to that?

Joshua IHLE: Yes. The *Human Tissue Act* speaks to exactly why.

Gary MAAS: Okay.

Joshua IHLE: The *Human Tissue Act* does not require that family consents. If someone has registered their wishes, then the patient has consented to organ donation. We are not formally seeking consent, because the *Human Tissue Act* does not require that of us. Rather, assent is what we are seeking.

Gary MAAS: All of the other submissions we received talk about consent, so okay, that is informative. Thank you. You spoke about the power of how a story ends, and you are really only seeing the beginning of that story. Do you have any views to share with the Committee of potentially, if there was the ability for the end story to be shared, what effect that might have on conversations with young people and so on? Do you have any views on that?

Georgina CALLAGHAN: I think for us within the donation sector a big part of when we work with families and we take them through the organ donation process is that all of the information we do seek about their loved one is confidential, so that way we are maintaining their confidentiality in regard to the health information, and that the process is kept that way. Recipients may want to reach out and find out who their donor family was or the donor family may want to know who their recipient family was, but we feel that we should be affording people the option of confidentiality within that.

Gary MAAS: Of course, and that makes a great amount of sense. But if there was the option for that—I think if people understand the power of the gift, that that might help those conversations.

Georgina CALLAGHAN: Whether or not all families would want that option—I mean, there are certainly families that do. So if both parties are willing and families are willing to share their stories, then I think that would be fine.

Anna McNAMARA: An example is we are holding our ICU education day for our fellow colleagues that work on the floor, and we are actually lucky enough to have a heart recipient that was at the Alfred. She is going to come back. She has volunteered to come and speak about her experience, and that just creates so much awareness within the team. We expect that our colleagues will go back and discuss with other colleagues that did not attend the day about this lady's experience. There are also some donor families that currently do speak to the public about their experience as well, and I have no doubt that that is encouraging to the community.

Joshua IHLE: The donation process I think has evolved drastically over the last decade or couple of decades, and we have been lucky enough I think at the Alfred hospital to be trying to push some of these best practice models. I think we have got a lot of cultural buy-in within the organisation, and I truly believe that one of the main reasons for that is that the people on the coalface, the clinical staff, see the impact of transplantation. That has allowed us to be able to evolve more rapidly from a cultural perspective than maybe some other hospitals that have not had the benefit of seeing transplantation occur.

Laura FLECKNER: I second that as well. Before coming into this role I worked in the Alfred ICU on the floor and then worked my way up to be an ANUM. So I looked after a lot of those heart-lung transplant recipients, and that has really helped inform my practice and motivate me to go on and work in the donation sector as well.

Gary MAAS: Okay. You spoke to conversations and a two-pronged approach, I guess, with people towards the end of their life and then getting younger people thinking about that as well. Your submission makes reference to a two-tier registration system. It is a very open-ended question. Would you care to speak to that?

Joshua IHLE: Beyond what has already been discussed, I think we need to increase registration rates. We need to create opportunities for that to occur in a simplistic manner, but we also need to then provide more information so that our society understands what the donation process is all about, and that is a bit more of an informed consent process. We do not feel that that should be mandated, because that is not something that everyone would otherwise want. But there are certain people that would like more information to be made available, and if they did have more of that information being made available, then as a society I do not think we should be allowed to overturn those carefully considered decisions that they have made.

Gary MAAS: Okay. Thank you. Does the Alfred compare itself? Is there kind of a benchmarking exercise that happens between hospitals, whether it be in other jurisdictions within Australia or even the rest of the world, in terms of donor registration and donor care?

Joshua IHLE: Not specifically to donor registration, but we certainly track those metrics around our best practice model and what is the outcome of that. And we can compare, you know, what are our donation outcomes and organs that are ultimately transplanted and how does that –

Gary MAAS: I said 'registration'. Let us go with model of care, sorry.

Joshua IHLE: So more so with the model of care, we can compare across jurisdictions and compare to different hospitals.

Gary MAAS: How does the Alfred's model compare with others across the metrics?

Joshua IHLE: Prior to the pandemic it was one of the best performing hospitals from those metrics, and I think that has resulted in us being, you know, until the last couple of years, the busiest organ donation hospital in the nation.

Gary MAAS: Anything else to add?

Laura FLECKNER: I do not think so. We have what we call the donor dashboard with DonateLife that does give us those metrics and helps us to see how we are performing with other hospitals within the state. So that does inform some of our practice as well.

Gary MAAS: Terrific. Thank you. No further questions from me.

The CHAIR: Thank you. Sorry, Christine, and then we will go to you, Chris.

Chris COUZENS: Just one last question, Anna, you talked about the discussion you have with people about not being appropriate as a donor because of their lifestyle, perhaps. Where do you see the answer to that? Is that in the education campaign? I mean, obviously you and your colleagues discuss with people the right answers, but how do we get that out there in the broader community to encourage people to register? I suppose for me the way I look at is: if you are not suitable, you are not suitable and let the experts work that out at the time.

Anna McNAMARA: Yes, an education campaign would be the biggest one, because like you said, the barriers are people think that because they do have a few drinks, or they do smoke, or they do not go for a run or go to the gym that they are not suitable. So we just really need to break those taboos somehow. It is expected of us that we ask everyone in an ICU or ED that is dying about donation, so I would love to see it somehow flipped that families are expecting that conversation of us. But to answer your question, it is education, yes.

Chris COUZENS: Yes. Great. Thank you.

Joshua IHLE: One of the best education campaigns I have seen was done by the organ and tissue authority in America. It was an advertisement of a very crass gentleman who was a bit of a social misfit: he smoked, he drank, he abused people and then he died. Everyone was surprised that he was registered, and the campaign changed to say, 'No-one expected this, but actually he was a very giving gentleman. He gave his organs: his heart to this person, his lungs.' I would encourage you to just look that up.

A member: We will try and dig that one up if we can.

Joshua IHLE: It is a really powerful, powerful education campaign.

Chris COUZENS: Thank you.

The CHAIR: Chris.

Chris CREWTHER: Mine was just a quick follow-up to Gary's question and your comments before about DonateLife's dashboard. They talked before in their evidence about them only getting about $160,000 worth of funding and more funding would be useful. Do you find the dashboard is a useful tool, or could it be improved, particularly if DonateLife was to get more funding to help aid that improvement?

Laura FLECKNER: We find it a useful tool to see where we are performing and how we are benchmarking, particularly with the Royal Melbourne which would be our closest similar hospital in that as a trauma centre as well. It does ignite discussion between us and the Royal Melbourne, 'Hey, what are you guys

doing differently to get your consent rate up or referral rate up? What could we do?' As far as improvements, I do not know if I could suggest any improvements to the dashboard really.

Anna McNAMARA: I think we do not know where the reduced number of consents are coming from, like we have discussed. So I think we are probably not capturing the right data at the moment for that, so we do need more funding to be able to apply more tools to help us understand where that gap is and how we can improve.

Chris CREWTHER: Are there any ways that you can think of as well to improve the ways different hospitals, different health authorities and AODR and others are communicating to, I guess, better the rates of donations but ensure that people can get to where they need to go, whether it is Mildura or elsewhere, as quickly as possible to increase the rates of donations and donation success rates?

Laura FLECKNER: That is a complex question with a lot of different answers to it, I think. I do not think there is a silver bullet, unfortunately.

Annabelle CLEELAND: Speaking about resourcing—can I quickly jump in? In your view, is there currently an adequate number of donor coordinator specialists in Victoria?

Laura FLECKNER: I will jump in and say we would love to have more, particularly if, for instance, at the Alfred we could have a protected coordinator to do education solo. At the moment we need to juggle our education commitments with our casework commitments, and by casework, I mean active donation cases. We never can predict when someone is going to die and when someone is going to say yes to donation, so it makes it tricky to have ongoing, longstanding commitments and then jump in to facilitating a donation case. I think, yes, another role would be helpful.

Joshua IHLE: I might chime in and say, simply, yes. I have seen many of the donor coordinators change over the years. You asked a question around how long someone can stay in this role. Laura has alluded to two parts of the role: there is the casework, and then there is everything else—compliance with process, education throughout the organisation and trying to find opportunities to improve processes. The most rewarding—and I do not want to speak too much out of turn—but the most difficult part of their job is that they are having these really emotionally burdensome conversations with families, and you cannot do that for a whole career. You will burn out I think if you do that too frequently. And then they have to do the casework, sometimes through the night, right. So they are working a donor up through the night, and they are getting home to bed at 8 o'clock in the morning and then they are coming back again and picking up the case after they have had their 8 or 10 hours rest. Breaking that casework up with other equally important jobs that are maybe not so emotionally burdensome should be the goal. I do not think that they can achieve it nearly as much as they should be able to.

Annabelle CLEELAND: Would anyone else like to make a comment on that?

Laura FLECKNER: Thanks, Josh.

Annabelle CLEELAND: On that, there was a reduction of four people in regional Victoria. Do you feel like that has had any impact on organ donations out of regional Victoria?

Laura FLECKNER: I think it has, in that there was one particular centre that has seen some donor numbers through it, and unfortunately we did not have the nurse based there on site anymore. Those cases still went ahead. It just meant that we travelled out and serviced the case. I think the more coordinators we have embedded—I would love to see some in every health service. It makes such a difference. It just changes the culture, and it makes it easier to have the conversations and facilitate the whole process.

Georgina CALLAGHAN: I think just a big success of having embedded donation specialists within the hospitals is that they get to build relationships with their local communities and their local healthcare teams. But as Laura said, it does normalise the component of organ donation just as another part of end-of-life care, and that does take time and a presence there to help build that rapport and establish that kind of normality within an abnormal space of death and dying in hospital.

Anna McNAMARA: Our best practice is to always have one of us in the room for the conversations, and if that does not happen—so at the Alfred or Royal Melbourne it is always followed up directly with the people

involved if we have not been able to participate—I would say that those regional centres do suffer because we do not often participate in those conversations because we cannot get there quick enough. We often encourage the intensivist or the registrar over the phone to have those conversations. We often say they can have us on FaceTime to meet the family, but they are really hard barriers to get through. Regional centres do suffer in that respect. If the family consented, then we would drive or fly up to the centre and work the two or three days there to work the case up.

Annabelle CLEELAND: Is there a potential for a dual role, like to be an organ donor specialist coordinator if you are in a regional centre that does not have the workload necessarily for a full, dedicated person?

Georgina CALLAGHAN: Yes, there is.

Laura FLECKNER: I think part-time—and they generally work as an intensive-care nurse or an ED nurse in their other sort of FTE.

Annabelle CLEELAND: Yes, okay.

Joshua IHLE: And I think they currently have nurse donation specialists, as I think it was referred to by the previous submission, which is different to the donation specialist nurse coordinator. They have different levels of training and therefore experience.

Annabelle CLEELAND: Thanks, Ella.

The CHAIR: Thank you. I just have a few questions, which I hope we can move through quickly because we are at our time. You have spoken quite a bit today about some cultural change that is needed across society to normalise organ donations. I am wondering if you can tell us a bit more about what you hear from families as to why they do not consent.

Anna McNAMARA: Yes, I would say the time frame would be one of the things that I have noticed. Families—we often have these conversations when they are understanding that their loved one is going to die. They do not want to wait one or two days because it is too much; they do not want to put their loved one through that. Another thing is that they have not had the conversations and do not know what they have wanted. I am sure Georgie can speak to it, but coming from New Zealand, when it is on your donor card, often families say, if they do not know, 'Is it on their licence?', and if not, then they would just not want to have further conversations about it, because they have not previously.

Joshua IHLE: I think it all falls down to the burden of the donation process and what their understanding of that is. Often their understanding is negligible, and they think that once the decision is made, then it instantly occurs. And this is during a time when they are already grieving the death of their loved one, so that burden of waiting a longer period of time is just too great and they do not want to support the process.

The CHAIR: Thank you. My next question is in regard to the register and just getting an understanding of when the donation specialist nursing coordinators access the register. Is that before having that conversation about consent with the families?

Laura FLECKNER: Yes. So best practice is that we would receive a page through our state pager, get the patient's details and demographics and plug them straight into the register. We can do it online, generally, while we are on the phone receiving the initial referral.

The CHAIR: And do you find accessing the register ahead of having that conversation—is that a helpful tool?

Laura FLECKNER: It is, and it has revolutionised our practice. It used to be you had to ring Medicare to be able to run the registry check, whereas now we can log on to PRODA while we are on the phone to the referrer, so that has really streamlined everything.

Georgina CALLAGHAN: And knowing whether someone has registered their intention or consent to help others through organ donation, it definitely does steer the nature of the conversation, particularly in those cases where people are registered as an organ donor. It really then becomes a conversation framed around more about how we fulfill their loved one's wishes through organ donation. When we do not know those wishes, it does

make it a lot more difficult. But I suppose they have maybe no other prior knowledge and it is really about trying to provide quite a bit of information to families who are already in the throes of quite intense grief, and that burden of decision-making is quite a lot for them during that time in their life.

Laura FLECKNER: I think I have had quite a few families say to me, 'Oh, that makes me feel so much better that they have registered, because I know that is the right decision.' On the other hand as well, families will tell me, 'But he hasn't registered either way,' or 'There is no evidence that he would want to become a donor, so I feel I can't make the decision for him. So we'll have to say no to donation.'

The CHAIR: And just as a follow-up question to that, is there any more information that could be on the register that you would find useful in your practice?

Anna McNAMARA: I think, like you discussed, that you have had the conversation with your family. That would be helpful for us to know going into those conversations. What else?

Joshua IHLE: Do you mean for the person that is registering, or for the donor coordinators who are checking the registry?

The CHAIR: Information that is already on the registry, so that the donor coordinators can check and see if this data is already entered—anything that would help you in your conversations.

Laura FLECKNER: I think that is the key point, that they have discussed it with family members. Yes.

Joshua IHLE: I think if there was a piece of work that provided some resources around the registration process to inform them a little bit about what the organ donation process involves—you know, 'Under what circumstances will you be considered an organ donor? What is the organ donor process? How is that involved? What period of time?'—just painting that picture somewhat. Then it informs the person registering a little bit about the process, which then speaks to changing how they perceive the organ donation process culturally. And then if there is clarity on this end from the donor coordinators that they have viewed this information, then that is a pretty powerful tool to say, 'Actually, they were well aware that they were going to die unexpectedly. They were well aware that it was going to take one to two days and they were going to burden the rest of their loved ones during the grieving process. And despite that, they still wanted to be an organ donor.' I think that would inform a conversation much differently to what it does now.

The CHAIR: Thank you. Thank you to all of our witnesses for appearing before the Committee today and for your contribution to this incredibly important inquiry. I think we have seen a really interesting side of organ and tissue donation today, particularly from the evidence given by our donation specialist nursing coordinators. Thank you, again, for appearing. The Committee really appreciates the time and effort taken to prepare your evidence and your submission.

Responses to any questions taken on notice are requested within two weeks, and questions on notice will be provided to you along with the transcripts. Thank you, again, for coming along today.

Witnesses withdrew.