

Standing Committee on Public Administration resolved to establish an inquiry into organ and tissue donation in Western Australia.



Legislative Council

Administration Committee: New inquiry into organ and tissue donation

The Standing Committee on Public Administration today announced the commencement of an inquiry into organ and tissue donation. The Committee's inquiry will consider issues and opportunities to improve organ and tissue donation rates in Western Australia.

Response to the Key Issues considered by the Committee:

Author: DonateLife WA / NMHS

This submission includes experience from DonateLife WA clinical staff who are directly involved with end-of-life care and conversations with the organ donor family.

1. The effectiveness of the current model for organ and tissue donation in Western Australia

In 2008 the Council of Australian Governments (COAG) endorsed the Australian Government's National Reform Program to implement a best practice approach to optimise donation opportunities and improve access to transplants for all Australians. The Organ and Tissue Authority (OTA) was established in 2009 to deliver the Commonwealth's National Reform Program. The OTA State and Territory Funding Agreement provides funding to states and territories to maintain an organ and tissue donation service delivery model (DonateLife Network). The DonateLife Network Clinical Practice Improvement Program (CPIP) identifies key elements that are key to achieving best-practice organ and tissue donation in the intensive care and emergency department environment. These include:

- 100% routine referral to DonateLife of all planned end of life in the Intensive Care unit (ICU) or Emergency Department (ED)
- 100% Checking of the Australian Organ Donor Register (AODR)
- 100% of the donation conversation with families have a donation nurse specialist involved.

There has been significant growth in donation and transplantation outcomes since the national program commenced in 2009. Increased consent rates are reported when families are supported in donation conversations by donation specialist staff with knowledge about donation and transplantation processes providing detailed information about the possibility and process of donation.

Approximately 2% of deaths in hospital occur in a way that organ donation is medically possible. The importance of a national approach with trained experienced staff within the hospital system is recognised. Evidence suggests that the care families receive and the quality of the communication with staff, including when discussing donation, influences their satisfaction with the process as well as consent rates for donation. *The Best Practice Guideline for Offering Organ and Tissue Donation in Australia* outlines an evidence-based approach for referral of potential organ and tissue donors and discussing donation with their families.

The current model includes roles that are critical to achieving increased donor identification, Family Donation Conversation (FDC) and consent for donation. The donation specialist nurse (or donor coordinator in WA) have specialist knowledge related to donation and transplantation and can provide detailed accurate information about the possibility and process of donation. They have access to real-time information about donation suitability for transplantation. They undergo specific, regular, and focused training in communicating with families about donation and are regularly involved with donation conversations.

The personal experience of staff directly involved with end-of-life care and conversations with the organ donor family support what is effective and issues that impact on organ and tissue donation rates in Western Australia.

Personal Experience A –organ donor with family consent

I was the primary donor coordinator for a middle-aged man who suffered a traumatic brain injury after being hit by a motor vehicle while riding his bicycle. He progressed to brain death and his wife consented to organ donation on his behalf. The family donor conversation with his wife was significant in that she was clear that organ donation wasn't for her and that her preference was to withdraw medical support and allow her husband's heart to stop.

Consent for organ donation was only obtained because the patient was registered on the Australian Organ Donor Register (AODR), and the family was made aware of his wishes through a registration check, which became part of the family donor conversation. The wife consented to organ donation to "honour the wishes and memory of her husband."

From personal experience there are many more examples where donation did not progress because the family were unaware of the intention of the potential donor as they were not registered, and it had not been discussed. While registration doesn't guarantee consent it helps alleviate difficult discussions and decisions when families are often exhausted, traumatised, and grieving. It also helps bring the life and wishes of the deceased into the conversation and donation as a means of honouring their life and wishes.

In subsequent conversations with the wife since donation, her decision to donate has been extremely helpful in her own personal bereavement and healing process. She has verbalised that she is comforted by knowing that her husband has been able to help others.

Experience as a donor coordinator has highlighted:

1. Registration on the AODR as an important means of identifying patient's intentions/ wishes and as a tool in conversations with families to help support organ and tissue donation.
2. As registration is voluntary (and requires the community to actively register) many potential donors aren't registered, and donation is declined as families are unaware of the deceased's wishes and they are not prepared to make an already difficult decision on their behalf.
3. Families are being asked to make decisions when they are often exhausted, traumatised, and grieving. Increasing donor registration rates can aid in helping families make difficult decisions at a challenging time. Registration can often assist in relieving the burden of often traumatised and exhausted families from having to consider the wishes of their loved one.

I believe that policies and interventions which increase organ donor registration, the visibility of DonatLife and cultural change resulting in the acceptance of organ donation conversations in end-of-life care could help improve donation rates. Not limited to, but ideas to assist this include:

1. Increased funding for public programmes promoting organ donation and encouraging the community to have conversations around donation (public promotion, volunteer programmes to increase visibility and resources, promoting the visibility of recipients and the change it can make to lives). These programmes can be used to help change the culture around organ donation so that it is a natural and expected part of end-of-life care conversations.
2. DonatLife is currently invisible being in a suburban precinct in Mt Hawthorn. Being in a more public location and affiliated with a specialist area with greater public profile and access would aid in promoting organ and tissue donation and registration by being more accessible to the public.
3. Organ/Tissue donor registration through such processes as drivers licence registration (or opt out provisions). This will help simplify the registration process and encourage the community to consider organ donation prior to life changing events.

Personal Experience B – potential donor where family declined.

A man was admitted to Intensive Care after a fall that resulted in a traumatic brain injury. The intensive care senior registrar had a conversation with the family about the possibility of their loved one becoming an organ donor by donor after neurological determination of death (DNDD). Neurological death is determined by an irreversible loss of neurological function of the brain. It is diagnosed according to criteria and testing defined by the Australian and New Zealand Intensive Care Society (ANZICS), documented in the ANZICS Statement on Death and Organ Donation .

The doctor explained that their loved one would not survive from his injuries and the family were devastated. During this conversation the doctor decided to inform the family that the patient had registered his intent to be an organ donor. The family expressed surprise as they did not know he

was registered on the Australian Organ Donor Register (AODR). The doctor explained he may have done it through the driver's licence, or he could have gone online, and this caused the family to laugh as they said, "he had never been online in his life".

The doctor gave them a couple of hours to consider what they wished to do, and in the meantime called DonateLife WA. I am a donor coordinator and attended the hospital to be with the doctor for the next meeting with the family. When I arrived, the doctor said that I could not be part of the conversation as the family had not been advised that I would be coming. I waited outside and after 15 minutes, the doctor returned and advised me that the family said, "they were overwhelmed with events and unable to consider donation despite knowing he is registered on the Australian Organ Donor Register". They declined to meet with DonateLife staff, despite the doctor explaining that it would be helpful to meet with me, that I was an experienced ICU nurse, gentle and supportive who would not force them to donate. They declined.

I feel this was a lost opportunity and one that I fear could cause regret among the family. The Core Family Donation Conversation training provides me with specialist training to help support families in this situation including:

- Discussing the AODR - When someone has registered their wish to be an organ donor on the AODR, that information should be shared with the family early in the conversation. I had a copy of the registration form that I wanted to give to the family. I feel this would have empowered them to be able to support his wishes. Families tell us that it makes the decision easier for them, and we know that the consent rate is significantly higher when families know their loved one's wishes. Our role is to help families support their loved one's wishes.
- Time frame concern and overwhelmed with grief and fatigue- I could have supported them to understand the requirements for investigations and step them through the process. In the meantime, I would have encouraged them to go home and have a break, or we could arrange a room for them to rest in and organise a drink and something to eat. They were so overwhelmed with fatigue and being at the bedside for nearly 24 hours.

The doctor had also attended the core Family Donation Conversation training but has not implemented the best practice guidelines, which recommends a collaborative approach when meeting with the family. The advantages of this training model include:

- Donor coordinators can build a rapport with the family before donation is raised and provide a collaborative approach for donation. They have extensive experience and training to support families in grief and the donation conversation.
- The donation specialist workforce was created to provide patients and families the resources and time to identify, inform and manage donation rather than relying on Intensive Care specialists medical staff being able to manage additional workload.

- The donor coordinators can complete medical/social history information and donor consent which reduces delays for the family, ICU and operating theatres and transplant services.

Personal Experience C – importance of early referral

I was referred a potential donor female patient from ICU. She was registered on the AODR as an “Intent” for all organs and tissues. The patient was admitted into hospital three days before the referral to DonatLife WA occurred. I was contacted to talk to the family on the third day after hospital admission. The donor had suffered an intracranial haemorrhage that did not progress to brain death; therefore, I provided information to the donor family about Donation after Circulatory Determination of Death (DCDD) donation pathway.

Donation after Circulatory Death is possible in certain circumstances where the patient has no hope of recovery, continuing life sustaining treatment is not considered in the patients’ best interests, and the patient is unlikely to progress to neurological death. Where the patient’s family accept this and agree to withdrawing life sustaining treatment and to commencing end of life care, organ donation maybe considered.

The family were open to hearing the information about organ and tissue donation and became very upset and angry when they were informed of the donation timeframes that would be necessary to complete organ donation. The family felt very frustrated as they had had several conversations with the ICU team during their loved one’s admission and the topic of donation had not been raised despite the inevitable outcome that their loved one was going to die. The family felt they could not support organ donation via the DCDD pathway as they did not wish her palliation to be extended. The family also advised me that they would have supported organ donation if they had been approached sooner. The ICU team delayed referring the patient sooner as they felt she may progress to brain death although this did not occur. The outcome was the family supported eye donation and she became an eye donor.

This example highlights the importance of referring early and not delaying organ donor referrals with the intention of waiting for the patient to progress to brain death. This involves ICU teams inviting donor coordinators into end-of-life care meetings early. In this case if donation had been raised earlier the family would have been supportive and consented to organ donation. Respectfully, I am not diminishing eye donation, but this loved one could have potentially donated kidneys and four people would have benefited from donation instead of two people.

Changing ICU work cultures is important and as a donor coordinator I want to be included in the end-of-life conversations early. This will enable families to receive information that is accurate and delivered in a sensitive way, so an informed decision on donation is made. Using the collaborative Family Donor Conversation model ensures that all end-of-life conversations include trained FDC specialists, which is proven to increase donor consent rates.

Personal experience D – importance of hospital-based staff

An elderly patient was confirmed brain dead at 3:00 p.m., request for a family donor conversation at 3:08 p.m. and a meeting organised at 3:13 p.m. which meant it was impossible for a donor coordinator to get to the hospital in time. The Intensivist opened the donation conversation by stating he was not a donor, and he doesn't recommend registering on the AODR because he did not want to put the pressure on his own family to make that 'difficult decision' if it was him. He wanted his family to make a decision that is comfortable for them at the end of his life. He also went on to say, *'do not let anyone coerce you into changing your mind if your answer is no to donation'*. This was directed at DonateLife as we explore declined consents.

One of the patient's daughters turned and said she would like to follow suit with the consultant in not registering on AODR because what he said felt right for her. As the donor specialist nurse, I sat in the meeting for 45 minutes and had no opportunity to speak. However, when the intensivist shared some wrong information, I did interrupt to say I will provide information about organ donation.

At the end of the 45-minute meeting, I insisted to get 5 minutes with the family to answer organ donation questions and correct the wrong information that was delivered. I did use the five minutes and followed the web coaching training, which is advanced training provided for donation specialists that I had undertaken a few months ago. This family declined donation based on what was said by the consultant, the fact that patient was not registered, and they were not sure what he would have wanted.

The next day, after family had said their final goodbyes, I just happened to walk past the family room, they were quite upset. I could not walk past without checking if they were ok or needed anything. I sat with them for about an hour just listening to some of their beautiful memories of him. We did not talk about organ donation until one of his daughters said, *'we are so lucky his funeral is organised, not like the organ donation question that was asked'*, something that they had never thought about. She also went on to say this should have been discussed earlier when he was well. She then asked me for a link to AODR. We have flyers in the family room with the registration QR code, which I showed to her, and she registered immediately. The sibling that said she would not register, said to her sister to share the link with her also. They both said they would register and share on their social media about the importance of having the conversation before people are in this situation.

In the little time that I got to spend with the family, it might have influenced in the change in the family's behaviour from *'I don't want to register'* to *'yes this is important, and we will register'*.

To build that kind of rapport with clinicians and families we need to be seen in the clinical space. By the time this patient passed away, the family had already seen me in the unit, I have opened doors for them, helped them make phone calls, liaised with the doctors, and worked as part of the team. By the time of the Family Donor Conversation (FDC), I was not a stranger to them I think it still made it easier for the family to share so much of his life with me rather than warm up to someone completely new at such an emotionally draining time.

2 weeks later we had another potential donor, there was no collaborative FDC as the consultant wanted someone to join just before he went in to meet the family. This family also declined donation. The donor coordinator was travelling from the DonateLife WA office located in Mount Hawthorn and had to turn back. Regardless of the decline, the donor coordinator offered to still come into hospital, but the Intensivist declined. If someone was on site, they would have been able to engage with the family earlier to some extent.

Donor Coordinators provide a 24-hour service to be available for family donor conversations. Donation Special Nurses are located within the hospitals and provide education and leadership to optimise organ and tissue donation within the hospital. The importance of having donor coordinators located in the hospital and donation specialist nurses trained in family donation conversations is highlighted in this example. Time and distance were a major factor that contributed to the decision not to donate.

Opportunities for Improvement of organ and donation rates in Western Australia

These personal experiences highlight some important challenges that impact organ and tissue donation rates in Western Australia. Changes need to be made to further implement the factors identified in the Clinical Practice Improvement Program (CPIP).

A change of culture within the ICU is important to ensure that early referrals for planned end of life care are made to DonateLife WA. Evidence demonstrates that a collaborative approach with a donation specialist has a higher success rate for organ donation. An opportunity to support this is for donor coordinators to be located within the hospital setting rather than in an office that is remote from the hospital. This is the model that is used within other jurisdictions and has more success. Staff consistently on site will embed relationships and bridge the cultural gap. A review of the current organisation governance and how these impacts on decision making and change is also suggested.

Registration on the AODR is another significant factor that influences the family's decision to agree to organ and tissue donation. Community expectations and the understanding of what registering on the AODR actually means is important so that families or senior available next of kin (SNOK) are informed when they are asked to support donation. Opportunities to facilitate registration via alternate channels have been discussed at a national level. The state and territory drivers licence system has been identified as a method that will increase registration based on South Australia registration numbers who are the only jurisdiction that have this in place. There have been previous discussions with the Commonwealth Department of Health as the policy agency which should be followed up by WA State government.

There are a number of challenges associated with obtaining consent. Families are asked to provide consent and to assist with completing medical and social questionnaires which can be overwhelming. The family donation conversation includes information about the donation process, the time required for donation suitability assessment, to confirm matches with potential recipients

and retrieval surgery. This information is provided when families are grieving, fatigued and often at a stage of wanting to leave the hospital, to having everything over. As the assessment process becomes more complex the time taken to realise organ donation is lengthened. A review into this process and how to reduce the time is required.

Legislation defines who in the family is recognised as the legal next of kin authorised to confirm the deceased's person's decision for donation or to make one in the absence of a known decision. This hierarchy does not reflect cultural decision making, who the family recognises as being the decision makers, nor the extended blended families and the parents of minors who have disagreeing views.

The Family Donor Conversation training provides increased knowledge, understanding and skills in having conversations about death and donation so ensure families are provided with enough information to make an informed donation decision. The donor coordinator role is central to the family donation conversation. They provide detailed and accurate information about donation and have the skills to sensitively introduce the topic of donation and openly explore what donation may mean for a family, thereby assisting them in making a fully informed decision. Participation in FDC workshops is open to clinicians involved in providing end of life care in ICU and emergency departments and is a way of increasing engagement with DonateLife WA staff, demonstrating the key elements of best practice.

From a positive perspective, families value donation specialist staff being available with time and expertise to explain what organ and tissue donation means, the processes and how long things take. Many have stated that having outcomes retrieval surgery and transplant provide closure to the donation conversation and consent process. Hearing and seeing people speak about their transplant and what a difference it has made to their life, affirms the consent for donation decision. They feel empowered to be able to advocate on behalf of their family member when confirming a donation decision. Many require minimal follow up and support from the service.

Improving the organ and tissue donation rates in WA is contingent on providing funding to support the established roles and future expansion within this sector.