

Individual experience submission by Bruce McDowell (DFA Chair), July 2025

I have completed questions one and two. My viewpoints on the other questions are reflected in the Donor Families Australia's submission.

Question 1. What is your personal experience of how human tissue is obtained or used in Australia?

In WA to answer this question I would have to leave out [REDACTED]. By including [REDACTED] name, [REDACTED] will contravene WA law and could be open to prosecution and penalties or fines. I will ignore that threat and continue. I did receive a letter from [REDACTED] [REDACTED] telling me she agreed with my interpretation of the law, [REDACTED] [REDACTED] I can only assume the Tissue Act is something that politicians and the public sector can ignore.

I received a phone call around lunch telling me [REDACTED] had been in a car accident halfway between Geraldton and Perth and we need to pack things and get on the road to Perth. [REDACTED] was studying at university and was driving back after a weekend at home in Geraldton. [REDACTED]

100 ks down the road there was a police alcohol check stopping traffic. We pulled over and requested any information that they may have. After conferring with others over their two ways they came to us in an official manner stating [REDACTED] had passed away on the road and that [REDACTED] was being taken to Perth by an ambulance.

After another 300 ks drive to Perth we joined one of our sons [REDACTED]. Around midnight we received a call from Donate Life seeking consent from us for [REDACTED] to become a Tissue Donor. My wife had to go through their questionnaire asking if [REDACTED] was a drug user, prostitute and many other questions. As much as the questions were very confronting, we understood why they were asked.

We were not told anything about the operation that was needed. We did not even know in what hospital [REDACTED] was in. There was no offer to see [REDACTED] at this time. We have since asked about [REDACTED] condition at that time and we were told you wouldn't know [REDACTED] was in an accident. Why weren't we invited to see [REDACTED] before the surgery? To this day this treatment of us remains the most disappointing aspect of saying yes.

We agreed to Donation knowing what [REDACTED] wanted. It needs to be stressed that at this point if that decision making process was taken away from us, we would have been shattered. [REDACTED] [REDACTED] and no one else has the right to make that decision that includes the designated officer. Bypassing the Family should never be an option and needs to be excluded from the legislation. Because Bypassing the Family is discussed frequently my family has withdrawn from the Register. We have had the conversation with each other so that only they know our personal preference. We actively advise our friends and those that want to engage in this topic not to register but to have the conversation if they want to be assured of not being bypassed.

No information was given to us about what we can and can't say about [REDACTED] donation after retrieval. We were horrified to find out from our own inquiries some years later that we were contravening legislation by talking about our [REDACTED] donation story.

Post donation we received a letter from Donate Life to let us know what had become of [REDACTED] donations. The letter was addressed to my wife and myself. It opened by thanking us for consenting to [REDACTED] becoming a Tissue Donor. From then on in the letter nothing was correct.

My wife and I would not have it any other way. [REDACTED] wanted to be a Donor. We said yes despite Donate Life. But I am sure there would be others who may not think the same.

Trust and respect are both lacking in this area of medicine.

Q 2. What is your personal experience of how human tissue laws work in Australia?

What a shemozzle. Donor Families and Recipients are now governed by 2 forms of government, both Federal and State/Territory. And the irony is most Donor Families wouldn't know they are governed by any as they assume they own their loved one's information, unconditionally.

I find that the Organ and Tissue Authority (OTA) will say no you can't do that as it against the law, [REDACTED]

They use the law to suit themselves, where a position doesn't suit them, they will invoke the law when a position does suit them, [REDACTED]

There doesn't seem to be any law around what constitutes consent. Families will be given information as it suits the staff at the time. Staff will gauge the condition of the family and will then tailor their information even if that means leaving important information out. It is almost as long as you get a yes.

One thing that is consistent with legislative change, current and recent around Donor Families, the law makers rarely make an effort to ensure Donor Families are consulted. Of recent legislative changes Federally and in WA no effort has been made to engage with Donor Families. Pleasingly the ACT and SA governments did consult.

Tissue laws relating to Donor Families around Australia are ignored [REDACTED] and replaced with [REDACTED] paternalistic viewpoint.

There is much that needs to be improved around [REDACTED] Tissue Donation. I spoke to [REDACTED] Tissue Bank and asked [REDACTED] if deceased donations were important to [REDACTED] business model. [REDACTED] confirmed that it is very important. I asked him how many Tissue Donor Families he has on [REDACTED] board. [REDACTED] looked at me quite surprised. Given Tissue Donation is important why aren't Tissue Donors represented on your board? [REDACTED] said, "the issues discussed are too sensitive and Families shouldn't be exposed to what is said at meetings". Surely if the principles of trust and respect are followed how could Families be offended? It is time for Tissue Donation to become transparent.

The WA government has just recently passed legislation approving the non-use of a surgeon to perform Tissue retrievals. The Health Department's Medical Director's rationale was that surgeons were not always available, and we don't want to lose those Tissues. Not one Donor Family was consulted with this change and yet it now means the Donor will be operated on by someone who does not need any medical qualification at all. In WA the Family is not told that the operation is performed in the basement of the hospital (morgue) by non-qualified people. The OTA still telling Families that the operations are performed by surgeons and their team in a theatre.

We need laws that are clear to follow for all concerned and are based on respect and trust and not the paternalistic views of a few in Canberra. And in particular not based on what is best for those who are to be the receiver of the gift. The laws should be about the Donor and the Family and what is best for them. This principle has been made very clear in the new Ethical Guidelines.