

Brisbane, Qld

Australia Law Reform Commission

3 July 2025

Dear Commissioner,

Submission to the Australia Law Reform Commission (the Commission) – Review of Human Tissue Laws

Retrieval of organs for donation and perfusion technologies

I am happy for this particular submission document to be available publicly as I have taken care not to use identifying information within it; however, I ask that my name and contact details not be associated with the submission document as it would lead to identification of my child and family.

I would like to make a submission to the Commission in relation to the retrieval of organs for donation and the availability of perfusion technologies from the perspective of an affected family and as a parent of a liver transplant recipient.

In early 2024, my child received their first liver transplant. It did not take long before problems started to arise: high fevers, pain, readmission after readmission to hospital, lots and lots of tests. Eventually, we were told that the first transplant was considered to have failed after just 15 weeks. They received a second transplant in mid-2024 which has proved successful, although there were also complications with the second operation which led to more pain and further surgery. Our child managed to go to high school for just 5 days in 6 months. Thankfully, by the end of 2024, they finally seemed on the road to recovery.

We were told that the reason the first transplant failed so rapidly was that the first donor liver had developed ischemic cholangiopathy, leading to recurrent cholangitis infections and necessitating the second transplant. This, we were told, was more likely to happen because the first donation had been a donation after circulatory death (DCD).

One of the surgeons made an offhand comment to us that there was a technology that was proven to reduce the incidence of ischemic cholangiopathy in DCD liver transplants and it is used elsewhere, but not legal in Queensland.

We later discovered that this was a reference to normothermic regional perfusion and it is presently not legal in Australia due to the definition of death used in legislation around the country, including section 45 of the *Transplantation and Anatomy Act 1979 (Qld)*.

The Commission has no doubt received submissions from medical bodies and practitioners on this topic. I would like to add the perspective of a transplant recipient's family: to learn that there is an established method which could potentially have saved our child the extra surgeries, pain, time in hospital, time away from friends, and time learning at school, but it wasn't used for them because it can't be done in Australia is heartbreaking, frustrating, and bewildering.

As parents, we spent literally months extra staying in hospital, taking unpaid leave from work, and generally putting our lives on hold to try and get through 2 transplants and their ensuing complications within a 5-month period.

The second donor liver could have potentially gone to another child and improved a second life; instead, it had to be used for our child again.

As our child is still a teenager, they also face the prospect of having to undergo a further transplant later in life, if and when their second donor liver starts to fail. Only now, that will be their third transplant, and they will face the greater risks associated with the increasing number of surgeries.

We had no idea about this issue before going into the transplant process. We assumed that Queensland and Australia would have used the most up-to-date surgical techniques and practices. We don't blame anyone and recognise that people made the best choices they could with the information available to them at the time, but the reality is that when surgeons selected the first DCD liver for our child, they were making a choice that increased the risk it would fail for our child and fail it did. To hear afterwards that things could have been different in a different country, and there are some outdated definitions that potentially led to this situation for our family, is honestly perplexing and deeply disappointing.

I would urge the Commission to consider how the current legal situation is impacting patients and their families. The fact that Queensland and Australia is somewhat behind in addressing this issue has had, and is having, real effects on people's lives.

The Commission's review is wide-reaching and there may no doubt be areas which require extensive and time-consuming review and consultation. The final Report is not due until August 2026, and legal change will likely take months - if not years - to follow that. Please, do not delay enacting this particular change because it is quite possible that more donations will fail in the meantime.

Sincerely,



Parent, Liver transplant recipient.