Organ donation laws should be unified and modernised

I have written this proposal in 2023 to the Parliamentary Health committee and feel committed to share it again, with a few modifications. Speaking from a 'lived experience', I would welcome changes to legislation which would allow greater opportunities of organ donation for a patient dying from circulatory death due to the withdrawal of life support.

My story

My son Angus died aged just 26, early in 2023. He suffered a tragic accident whilst on holiday in Korea, falling off a 4th floor roof after celebrating the Lunar New Year. He had two cardiac arrests on the way to hospital in Seoul and the following day, after detecting further bleeding on the brain, had a decompressive craniectomy. This saved his life, but he remained unconscious with many broken bones throughout his body. He then had a tracheostomy fitted, and after a further 21 days, we flew him home to the Alfred Hospital, Melbourne but despite reducing the sedatives he never regained consciousness and could only breathe for a short amount of time without life support. His brain injuries were severe, permanent and deteriorating. Faced with the reality that he would never live other than in a vegetative state, we made the decision to withdraw his life support.

Angus was a registered organ donor. His heart, liver and 2 kidneys were assessed as suitable for donation and 4 recipients were identified. The forms were signed, the recipients chosen and lined up and everything was in place ready to proceed. This took an extra day than originally first proposed, somewhat stressful, but I was aware of the enormous effort that goes into lining up donors.

We were advised that Angus needed to die within 30 minutes of his tracheostomy being removed to donate his heart and liver and within 90 minutes to donate his kidneys. Any longer and those organs would suffer warm ischemia due to oxygen deprivation, and would be no longer viable for donation. Unfortunately, Angus breathed independently for a few hours, dying 5 hours after his tracheostomy was removed. This meant he could not donate any organs.

I am aware now of new perfusion technology (NRP[1]) which has recently reported to increase the use of donated organs after circulatory death (taken up in Europe) but will require changes in the definition of death before permitted in Australia (I would recommend changes to allow this practice). However, this would not have been useful in Angus's case due to his prolonged agonal time.

My proposal

I want to change the law to avoid this happening in the future. Angus died following doctors performing passive euthanasia (removal of life support) – this is legal. I would like it to be legal for doctors to perform active euthanasia in an operating theatre, where organs are removed under general anaesthetic, as an alternative to, or simultaneous with, withdrawal of life support. This would also require changes to the dead donor rule but I believe, in limited circumstances, it would be ethical to do so.

Organ donation under anaesthesia would involve the patient being given a general anaesthetic, taken into surgery and all viable organs removed for donation (or, if permitted, NRP can occur at the same time). This means death would occur either due to the removal of organs or removal of life support, or both. However it must be made clear that the cause of death is the injury or damage that initially occured.

The circumstances where I believe this should apply are as follows:

(1) A decision has been made that continuing life-sustaining treatment is futile and no longer in the patient's best interests. As a result, the decision has been made to withdraw life support from a patient. This requires no change of law and would continue as it currently is.
(2) Once that decision has been made, the separate organ donation team can begin discussions with the patient's relatives about the prospect of organ donation. Again, this requires no change of law and would continue as it currently is.

(3) If the patient has consented to organ donation under anaesthesia as an alternative to withdrawal of life support and the family of the patient consent to it, then this can take place.
(I propose introducing this as an opt-in scheme, as an add-on to the existing organ donation scheme). This proposal **would not** replace existing practice, but would be an additional option available to those who wish to utilise it. Anyone who felt uncomfortable with the idea of having their organs removed under anaesthetic but still wished to donate their organs after death, could do so under existing schemes.

I believe that limiting organ donation under anaesthesia strictly to these circumstances would not result in any "slippery slope" arguments or risk of exploitation. It would **only** apply to patients whose death is imminent and inevitable. It would **only** apply to patients who had consented to this (albeit at an earlier time) and their families also consented. This is not a novel idea, and I quote from the article Truong and Robinson 2003[2]

'We believe, however, that the ethical foundations of organ recovery need not rest on the problematic determination of death. We instead propose that the ethics of organ donation be based on the ethical principles of nonmaleficence and respect for persons rather than on brain death and the dead-donor rule. These provide a straightforward, ethically transparent, and potentially practical method for guiding the practices surrounding organ donation.'

Thus, this change in law (and the wording of the definition of death) would support key ethical principles fundamental to the organ donation process:

Autonomy - the patient's wish to donate their organs would be respected. They would not be denied their wish because the agonal process following withdrawal of life support took too long.

Dignity - the patient would die under general anaesthetic, treated with dignity by the operating team. They would not suffer distress, pain or discomfort common during the agonal phase, which can only be described as undignified (and distressing for the family by the bedside).

Non-malificence - this is cited as a reason for the dead donor rule. However, operating under general anaesthetic would cause no pain or suffering to the patient. The fact that the procedure would cause the death of the patient should not be viewed as causing them harm, because their imminent death is inevitable following the withdrawal of life support. Arguably, withdrawal of life support causes more harm and distress to the patient as the agonal period can be painful.

Other ethical principles which are worth considering are directly connected with these. If the patient suffers a slow, distressed death, this inevitably causes distress and suffering to the family who have to watch this happen. This is worsened by the unknown length of the agonal phase. Once life support is withdrawn, families do not know if the patient will die within minutes or hours. That uncertainty adds another layer to the distress.

The rights of the potential recipients must also be considered. Those waiting for organ donations are in desperate need. Their quality of life is often diminished whilst waiting for an organ and many die whilst on organ waiting lists. This was the case with Angus, he could have donated 4 organs. He could have saved and/or significantly improved the quality of life of 4 people and their loved ones. These people have suffered and will continue to suffer because Angus did not die quickly enough for them. Whether he had died within 5 minutes or 5 hours, nothing would have changed for us in that we still lost Angus. His death was inevitable. But for these 4 potential recipients, the fact Angus died slowly means they lost the chance to live. We believe this is wrong. Angus wished to donate his organs to these 4 people. His death would have been less senseless had he been able to do so. There is an additional layer of grief for my family because Angus could not do so. His organs were cremated with him when they could have lived on through someone else.

I would welcome an opportunity to share my 'lived experience' and believe a change of law on these grounds would be ethically sound, safe from exploitation and would significantly increase the number of organs viable for donation.

[1] Villanova et al (2025) Normothermic Regional Perfusion in Controlled Donation After the Circulatory Determination of Death: Understanding Where the Benefit Lies (2025) Transplantation ■ Volume 109(3) pp 428-239)

[2] Truog and Robinson (2003) **Role of brain death and the dead-donor rule in the ethics of organ transplantation** Crit Care Med 2003 Vol. 31, No. 9 *pp 2391-2396)