Review of Human Tissue Laws

List of Questions Answered

1 What is your personal experience of how Human Tissue is obtained or used in Australia.

My personal experience revolves around the donation of his organs after determination that he was brain dead following a failed back operation [redacted] in 1993. My wife and I offered to donate his organs for transplantation. There was now discussion as to what organs or tissue were to be retrieved. We were only glad that his donation would prevent other families from the great pain and lose we were suffering. We accompanied Ben as he was wheeled by hospital gurney to the operating theatre and were asked to return to the Hospitals quiet room approximately 5 hours later.

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

- At the time of donation, it was explained to us by the Donation Coordinator that two independent doctors had to validate Ben's status through a variety of tests. In Ben's case they applied EEG, a brain dye test and a series of reflex tests.
- As the parents of Ben, we had to sign authorisation to allow for the donation of his organs and tissue (eyes) to proceed.
- We understood that within Australia organ donation operated within an "Opt-In System". For us, maintaining the "Opt-in System" is very important. Our donor loved-one is part of our family alive or deceased and such authorisation MUST remain with the family that has to live with the decision for the rest of our lives. To have that right taken away from Aussie families does not pass the "Pub Test". If the government is concerned about the low donation rate, then greater education of the Australian public must be undertaken to the extent that we openly accept organ/tissue donation is a standard and acceptable practice within the medical system. I believe this is the core reason why Spain continues to lead in this area.
- The Act is meant to enable/encourage maximum availability of human tissue to benefit the community while supporting both Donor Families who have authorised human tissue to be removed from their "Loved One" and the Recipients that are receiving the Human Tissue. It must be remembered that while Doctors/Nurses facilitate human tissue to be retrieved and transplanted, it is the Donor that enables this to occur in the first place. Therefore, more emphasis needs to be placed on involving and supporting Donor Families that have been through the system. Remember that constructive criticism can only build a stronger outcome.

3 What are good aims or objectives for the laws pertaining to obtaining Human Tissue.

- To increase trust in the organ/tissue donation process within the Australian community by being far more informed than they currently are.

- Far too much emphasis is solely placed in the National Organ Donation Registry or the placement of YES to donation on ones Driver's licence. This sole knowledge does little to help or comfort the family when making the decision to donate the organs/tissue of ones loved one. Knowledge of the donations process is critical and understanding what it entails while at the bedside hopping for a miracle can often be the wrong time to be approach this subject.
- Transparency is a must and made available at the time of making the decision of volunteering to become an organ/tissue donor. When deciding to register to become an organ donor information about the process needs to be far more transparent and easily available. It is also a must to make the family aware of one's intent to donate.
- One of the biggest obstacles is that there is not consistence across all States and Territories. A Donor Family can have differing experiences when their loved one's organs/tissue donations go across borders which can be very distressing.

4 What laws or principles should apply when removing human tissue.

- We were told that the process in retrieving Ben's organs/tissue would be undertaken as though he was undergoing an operation in Theatre with the utmost dignity. Western Australia's Health System has I believed past changes to their retrieval process where a medical technician can undertake the process and not necessarily in a theatre environment. This is not showing respect for the dead while they are intern saving the lives of the living. This approach undermines faith and public trust within the medical profession.

5 Priority reform areas

- It would make sense to me that the HTA be sectioned into specific areas that would only reflect subject matter pertaining to a particular topic e.g. Organ Donation or IVF etc

6 What other issues should be focused on in this enquiry.

- As a Donor Parent we had to sign authorisation to allow the retrieval of our son's organs & tissue. However, under the Human Tissue Act we no longer have the authority to talk about Ben in a personal way as it may allow others to identify who he/we are and where we live. Therefore, OTA/DonateLife screens all communication between Donor Families and Recipients regarding first/second names, contact phone numbers and any details that may provide the other party to make direct contact if they wished.
- As Recipients are alive to do what they will with their own personal information, their correspondence continues to be stripped of any personal information that applies to them.
- All correspondence between Donor Families and their Recipients is screened/scrutinised by DonateLife where they can block out, cut out or rewrite correspondence to remove comments they deem inappropriate. I believe the only other government agency that is allowed to do this is the Dept. of Corrective Services with communication between families and prisoners.

- The HTA established at a time when there was little or no input from Donor Families and Recipients on areas that directly impact on them. I am sure that well-meaning doctors, psychologist and bureaucrats believed that the confidentiality of both parties must be maintained to prevent bad press that may come from poor outcomes of such meetings. Adoption and IVF programs now provide the ability of parties to meet. I strongly believe that Donor Families and their Recipients are mature enough to be involved in this process. If one party reaches out to the other, then the decision of responding rests with the party receiving such information. Therefore, “Consenting Party’s” should have the right and ability to make contact. For those that seek contact, it provides closure and is an emotion benefit to both. Donor Families and Recipients have been seeking ways of circumventing this position for decades with limited success without experience and negative feedback that might have impacted on the donation rate. In fact, the opposite occurs when such meetings are publicised within the community. I have in fact met with my son’s [redacted] recipient and have a wonderful relationship for 16year until [redacted] passing as well as conducting a Contact Register that over several years in the late 1990s and early 2000s was successful in providing contact with six parties.

7 What inconsistencies persist within the Human Tissue Act that are causing problems within the HTA

- Rules/guidelines within the Act should apply equally to those the Act is meant to serve/support/protect as to those that have oversight of implementing the Act.
- Contact between consent Donor Families and their consent Recipients is a must that needs addressing. There was a conference held in Melbourne several years ago that delt with this issue that has a positive outcome. Unfortunately, it got buried because it went against the current HTA and nothing has come out of the conference. Now is the time for change.

8 Issues unlikely to focus on in this inquiry

- An issue that does occur with a degree of regularity is the impact that a limited waiting list has on Donor Families and Recipients. The Transplant Waiting list can vary between 1,500 to 1,800 and yet in kidney donation alone there are approximately 14,000 on dialysis. When a Donor Family agrees to full donation of their loved one’s organs, it is distressing and very disappointing to learn that not all ones’ organs could be utilised due to the limited transplant Waiting List. Likewise, it is distressing to Recipients to learn that such donations could not be used.