

## **Inquiry into the Transplantation and Anatomy Bill 1998**

***A submission to the Legal Constitutional and Administrative Review Committee by the Victorian Institute of Forensic Medicine, (VIFM) incorporating the Donor Tissue Bank of Victoria (DTBV).***

### **1. Introduction**

Clearly the motivation of this Bill is to save lives by increasing the number of organs available for donation. This is a motivation shared by the VIFM and DTBV. However, as acknowledged in the second reading speech, the proposed amendment is an isolated measure in the context of a situation that requires a more comprehensive response. We consider that, on its own, this amendment has the potential to create more difficulties for those administering organ transplant programs in Queensland, and could even have the opposite of the desired effect.

### **2. The importance of consulting next-of-kin**

The proposed amendment seeks to empower "designated officers" in hospitals to override the wishes of next-of-kin in cases where they are in conflict with those expressed in life by the deceased – specifically in the context of the deceased having indicated on his/her drivers licence a willingness to donate body parts after death. This amendment is in keeping with the general intention of Part 3 of the *Transplantation and Anatomy Act 1979, (Qld)* to maximise the amount of tissue available for transplantation and other medical or scientific purposes and to respect the previously expressed wishes of the deceased as to use of his/her body after death. Under the legislation the decision-making role of next-of-kin in this context is clearly intended to be secondary to ensuring that the wishes of the deceased are respected.

These provisions (and equivalent ones passed in each Australian State and Territory) were based on the recommendations of the Australian Law Reform Commission in its 1977 report on *Human Tissue Transplants*. The report's recommendations reflected strong support for the advancement of transplant procedures and medical research and their potential benefits for the community. And in relation to supply of human tissue, (aside from in very limited circumstances), the Report supported the principle of consensual giving.

Since the ALRC Report was written and the consequent legislation passed, there has been limited promotion and education about the benefits of tissue donation after death. There have also been significant legal and practical developments in the notion of what constitutes informed and valid consent in the context of medical procedures – developments that have made medical practitioners wary about acting where there is any hint of an objection to a procedure. In addition, the rise of the consumer movement over the last 20 years, has empowered the community to question medical paternalism and

legitimised an expectation of consultation on issues affecting individual rights, such as, in the present context, rights over the disposal of remains of a deceased family member. So, despite the intention of the legislation to facilitate the collection of donor tissue, and prioritise the deceased's wishes, human factors such as the reality of next-of-kin objecting have intervened to make administration of the legislation somewhat problematic.

The proposed amendment would strengthen the authority of those charged with collecting tissue for donation. However, clearly legislation is a blunt instrument in this context. It does not deal with the underlying 'human factors' which problematise the administration of the current provisions. As noted in the second reading speech, a decision from next-of-kin not to permit removal of tissue for donation, despite the deceased having indicated otherwise, can be attributed to the state of emotional distress of relatives at the time of a sudden death, or it may be that the proposed actions are in conflict with deeply held spiritual or other beliefs. In these circumstances we believe that it is too simplistic to say that "the acquisition of organs is good, and necessary and saves lives". We consider that the approach mandated by the amendment lacks the flexibility required to ensure that "saving lives" through organ donation does not come at the expense of increasing the trauma suffered by family of the deceased and inhibiting the grieving process necessary to recover from the loss of a beloved family member – matters which are of immediate concern to those "at the coalface" of human tissue donation.

In our experience at the DTBV, one of the key factors in successfully obtaining human tissue for donation is ensuring that family members of the deceased are treated with respect and that consultation about tissue donation is conducted with sensitivity and compassion. We believe this approach to have a sound ethical base and to be consistent with standards that have been evolving over a number of years in the human tissue donation field, and which are now generally applied across Australia and in other jurisdictions where ethically based donation programs are administered (whether or not there is legislation requiring such consultation).

The proposed amendment may be an attempt to clarify or reinforce the current legal position with regard to decisions about tissue donation in certain circumstances, but we would suggest that its lack of harmony with what has become acceptable practice amongst tissue donation organisations, will make its strict application fraught with difficulties. This includes the potential for negative media attention involving aggrieved next-of-kin. Even media coverage of the story from the opposite angle – that a hospital did not fulfil the wishes of the deceased – is unlikely to have a positive effect on the rate of tissue donation.

### **3. A more comprehensive approach – promoting tissue donation and a national organ donor registry**

The rate of organ donation is much more likely to be positively affected by a well-informed and strategically implemented education program for the community - promoting family discussion about the issues so that an understanding can be reached in life about the reasons for an individual's wishes about what happens after their death, instead of families being forced to confront the issues at a time of great stress. Teaching and discussion of relevant issues should be integrated into all levels of the education system and into training of all medical/health practitioners. More information about, and awareness of the choices available regarding tissue donation after death would better prepare families for dealing with difficult, often emotionally charged decisions, in the event of a sudden death. We believe adoption of such an approach would result in fewer objections of the type the proposed amendment is seeking to circumvent.

We also agree with the point made in the second reading speech that "in the long term Queensland needs an organ database". We understand from the Transplantation Promotion Council and the Australians Donate organisation that there are plans to enhance the operation of organ donor registries in other Australian jurisdictions, to create a nationally effective database. We support such a project as an appropriate approach that has the potential to take account of the many complex issues that arise in the context of human tissue donation. These include a number of practical considerations:

- The driver's licence with the authorisation may not be with the body at the time of death. 24 hour access to a national organ donor registry via authorised internet connection will ensure that the relevant information is available in time to make the necessary arrangements for tissue removal and storage.
- State and Territory Transport Ministers have given approval for nationally uniform driver licensing provisions and are currently in the process of implementing them. This cooperation amongst the jurisdictions provides a good foundation for a nationally effective database of organ donation information linked to driver licensing administration, including electronic transfer of information from licensing authorities to an organ donor registry.
- Administration of the database can include regular checks with potential donors to ensure their consent is up-to-date.
- More exact consents can be maintained – it may be that a person wishes to donate certain body parts and not others.

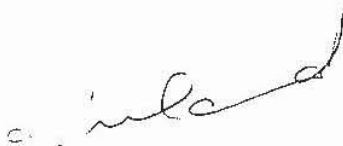
### **4. Conclusion**

In conclusion, the VIFM and DTBV suggest that the Legal, Constitutional and Administrative Review Committee should strongly consider not endorsing the Bill to the Assembly, for the reasons outlined above. Instead, we suggest that the Committee recommend that, if the Assembly is concerned about increasing the number of organs available for transplantation in Queensland (and Australia), it should provide active support for the establishment of a

nationally effective organ donor registry, and increased community education about the positive aspects of organ donation.



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