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Submission N07

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Mr G Fenlon MLA
Chair
Legal, Constitutional and Administrative Review Committee
Parliament House
George Street, Brisbane QLD 4000

31 May 1999

Dear Mr Fenlon

Inquiry into the Transplantation and Anatomy Act Amendment Bill 1998

We thank you for your letter of 5 May inviting our written submissions which are being provided by means of this joint letter. Our involvement in tissue and organ donation has been extensive and in the case of Ms Daly in several capacities.

Dr Charles Naylor - Deputy Director of the John Tonge Centre for Forensic Sciences (or equivalent) since 1987 with extensive involvement in facilitating therapeutic tissue donation and operating the Ethics Committee established in 1995. I am a medical practitioner specialising in anatomical and forensic pathology. Having been educated at Cambridge and London Universities, I trained as a pathologist in Cambridge (1977-1983) and subsequently worked at the University of Zimbabwe (1983 - 85) and St Thomas's and Guy's Medical and Dental Schools. (1986-87).

Ms Michelle Daly - Senior Counsellor John Tonge Centre for Forensic Sciences, a Social Worker, responsible for the co-ordination of support services to families bereaved by a death reported to a Coroner. I have worked in this position since its establishment in mid 1994. From 1988 - 1994 was a Senior Social Worker at the Princess Alexandra Hospital, where I established the social work service to the Intensive Care Unit at that hospital.

The proposed amendment is based on the assumptions that the shortage of organs and tissues for donation is principally related to the need to consult with families and that these difficulties could be overcome by giving the "Yes" on the driver's licence legal force. These assumptions are false and the reasons for the shortage are far more complex:

- Some families of potential donors are simply not approached, either because the patient is not recognised as a potential donor, or because medical/nursing staff are reluctant to make the approach.
- Families in which there had been prior discussion during the deceased's lifetime regarding organ /tissue donation are unlikely to go against the wishes of the deceased.
- Families who are approached in a sensitive manner by someone skilled are more likely to grant consent. Approximately 60 to 80 % of families approached consent to donation, with skilled and sensitive professionals achieving rates at the higher end of the range.

- The drivers licence is not always a reliable indicator of a person's wishes. For example, some people will tick "no" on their licence, even though they are not opposed to donation, because of their fear they will not receive maximum treatment in hospital if they have indicated they are a donor. Alternatively, they may have changed their mind since renewing their licence. Consultation with the family can clarify these points.
- Giving a "Yes" legal force would not eliminate the need to consult with the family. For example, the Therapeutic Goods Administration requires information on lifestyle risk factors in the deceased such as intravenous drug abuse which are used to exclude some potential donors. There is also the possible need to check for withdrawal of consent.

Given that the types of deaths that result in organ/tissue donation are usually tragic and unexpected, it is imperative that tissue and organ donation programs somehow accommodate the sensitivities of the deceased's family and avoid causing unnecessary additional distress. Many families who have consented to organ/tissue donation consider this decision provided them with something positive to come out of an otherwise tragic situation. This is because they are consulted, and provided with the opportunity to consider donation, rather than it proceeding against their wishes. The danger of the proposed Bill is that needs of the family may be disregarded once consultation is no longer a legal necessity. This may then lead to complaints and adverse publicity, which may reduce the availability of organs and tissues. It is therefore essential that there be resources directed to:

- Providing training to staff to ensure medically suitable donors are identified as such.
- Providing staff with training to improve their skills in approaching families to seek consent. Programs such as ADAPT are tailored to meet the needs of medical, nursing, social work and pastoral care staff by providing understanding of bereavement reactions, skills training in interviewing families, and an understanding of the process of organ donation to clarify any misconceptions that staff may hold.
- Public awareness programs, as evidence again suggests that where people make a decision during their lifetime and communicate this to their family, their family are likely to uphold their wishes at the time of their death.
- Support programs for donor families, which acknowledge the gift they have given.

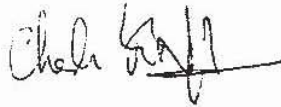
In addition to the major concerns articulated above, there are a number of other practical, ethical and legal problems in terms of implementation of the proposed amendment:

- a) Ticking a form when renewing a licence does not constitute informed consent. New arrangements would be needed to ensure that potential donors understood what donation entailed and its implications and hence establish that the consent was informed and therefore valid.
- b) Blanket consent, ostensibly given for organ and tissue donation in general, is arguably not informed unless the organs and tissues for donation to which the donor is consenting are specified in the consent. In other words, there should be an option to include/exclude particular organs or tissues to make the consent valid. This is all the more important as the range of organs and tissues are constantly being expanded due to advances in medical techniques
- c) The mechanism for recording the consent (e.g. in a database) would need to include safeguards to ensure its correctness (e.g. scanning of consent forms directly onto the database).
- d) The record would need to include options besides YES or NO, such as "Undecided". The danger is that a system which did not include "Undecided" or similar options might be ambiguous or default to NO (as it seems the present database may do)
- e) A mechanism would be needed to check at the time of death, whether the consent had been revoked as appears to be required under Sections 22(6) and 23 (3) of the existing Act. (A legal opinion regarding the need to check for revocation might be required).

- f) A mechanism would be needed to allow efficient and prompt access to the relevant fields of the driver's licence database for the medical personnel seeking donation. This may need other legislative amendments and changes in the database, etc.
- g) The database would need to distinguish between old style (and hence invalid) consents and new informed consent, so that this distinction would be clear to the user.

In conclusion, the proposed Amendment Bill is strongly opposed, both because the arguments underpinning it are flawed and because its application is unworkable. The laudable objective of Mr Turner MLA to improve the availability of organs and tissues for transplants would be more readily achieved by a range of initiatives as indicated above.

Yours sincerely



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