JEENSLAND



The Prince Charles Hospital & District Health Service

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INQUIRY INTO THE TRANSPLANTATION AND ANATOMY AMENDMENT BILL 1998

Submission to the Legal, Constitutional and Administrative Review Committee

The effect of the Amendment would be to view the indication by the deceased person on their driver's licence of their wish to be a donor in the event of their death as a signed document and to proceed to retrieve and transplant tissue without any other consent or consultation process.

While we support the aim of increasing the number of organ and tissue donors for vital life sustaining transplantation work, we do not agree with this proposed amendment for the following reasons:

1. The indication of wishes regarding donation made by persons on obtaining a driver's licence is not **informed** consent. Queensland Transport, the body responsible for issuing licences, does not provide the information about donation on which **informed** consent can be made. Staff in Queensland Transport have not received training to enable them to explain donation processes and they are aware that the current answer given is an <u>indication</u> of wishes only.

2. Included in the current process of obtaining informed consent is the opportunity for donor families to distinguish between circumstances (brain death or circulatory death) in which they are giving consent. Thus next of kin may not wish to consent when their relative has suffered brain death and is on mechanical ventilation (a potential multi-organ donor) but may consent when circulation has ceased (a potential tissue only donor). Equally there is currently the opportunity for the donor (via a donor card) or the family to choose which particular organs or tissues they wish to donate. The process of gaining informed consent distinguishes all organs and tissues, obtaining consent for donation of each one. Experience of this Health District in obtaining consent for donation of tissues during many years is that almost all next of kin consider very carefully the type and use of different tissues before wishing donation to occur.

3. Indications on the driver's licence may not reflect accurate, **current** wishes of the deceased, since licences are valid for several years in Queensland. **Consultation with the family has in our experience revealed changes in attitude, especially by younger persons.** If there is total reliance on licence records and "the person relying on subsection (2) has no reason to believe the indication is incorrect or the consent has been withdrawn" (Clause 3 of the Amendment), then drivers need constant access to a register in Queensland Transport to record changes of mind. Such a mechanism is not in place.

4. Lack of consultation with the family will deny the rights and needs of families to receive "compassionate, ethical and sensitive treatment" as per NHMRC "*Recommendations for the donation of cadaveric organs and tissues for transplantation*". 1996. Lack of knowledge of what procedures are undertaken in relation to their loved one is a denial of their rights. It is increasingly recognised worldwide that families need to know what tissues are retained either for diagnostic or therapeutic and medical/scientific purposes. In countries such as France which have presumed consent to donation and a non-consent register, families are still consulted. (Ref: Address by Professor Didier Houssein, DG Establissement Francais des Greffes, *Improvements in Donation in France: lessons from a crisis*, at the Inaugural National Forum On Organ and Tissue Donation, Canberra, April 1999).

5. In our experience there are few occasions when the next of kin will seek to override the deceased's wishes. On these rare occasions, there have been strong cultural, emotional or practical reasons which the deceased may not have anticipated. It is our belief from personal experience in these situations that, had the deceased been able to foresee the distress and difficulty of the family, their concern for these loved ones would have taken precedence over their wish to donate. (Examples could be given if required by the Review Committee at a later date).

6. In many cases, consultation with the family is vital in order to establish absence of medical and social risk factors which may preclude donation because of potential harm to transplant recipients.

7. NHMRC Guidelines recognise that "In practice, the rate of donation depends less on ...legal arrangements than on public awareness and education". Legislation to facilitate retrieval of organs and tissues without respect for the dignity of the prospective donor family will not improve the community's willingness to donate.

8. Without new mechanisms for health professionals to access Queensland Transport licence registers on a routine basis, any change in the legal status of donor indications will be of no consequence.

We should be happy to provide further clarification of any of the above points if required. Thank you for the opportunity to comment on the proposed Amendment.

Kery Hie

Mary Haire Director Social Work Services 7th June 1999