



QUEENSLAND HEALTH

Submission No 18

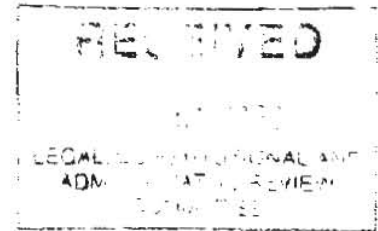
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8th June 1998 *JA*

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

Dear Mr Fenlon

Please find enclosed a submission requested by your department inviting comment on the Transplantation and Anatomy Act Amendment Bill 1998.

The following submission has been prepared by the three Donor Coordinators for Queensland based at the Princess Alexandra Hospital.

Yours Sincerely

Tina Cooper

Greg Armstrong

Caroline Windle



**SUBMISSION TO THE LEGAL, CONSTITUTIONAL AND ADMINISTRATIVE
COMMITTEE**

INQUIRY INTO THE TRANSPLANTATION AND ANATOMY ACT
AMENDMENT BILL 1998

Background:

This submission is presented by the three Donor Co-ordinators, employed by the Princess Alexandra Hospital to co-ordinate the retrieval of organs and tissues for transplantation in the State of Queensland.

The responsibilities of the Donor Co-ordinators include ensuring that the legal and medical criteria associated with organ and tissue donation are met, according to the Queensland Transplantation and Anatomy Act 1979. With the respect to the legal criteria, the Donor Co-ordinator is responsible for ensuring that the wishes of the deceased regarding donation are respected and carried out, according to the criteria currently represented in the Transplantation and Anatomy Act 1979. The determination of the deceased's wishes is ascertained by discussion with the immediate family.

The medical criteria associated with the donation process requires the Donor Co-ordinator to offer expert advice on the management of a potential donor and to exclude potential donors on the basis of medical unsuitability, based on transmissible disease or documented exclusion criteria.

Outside of the legal and medical criteria, it is also the responsibility of the Donor Co-ordinator to provide support and follow-up for the donor family and the hospital staff involved with the donation process (Intensive Care Units and Operating Theatres).

Professional education, public awareness programs and liaison with the media are also indicated in the position of Donor Co-ordinator.

The current experience of the three Donor Co-ordinators in this area is 12 years, 8 years and 7 years respectively. Contact with the donation process and donor families over the past ten years would exceed 500 families. It is with this first hand experience that the following submission will address the issues outlined in the Private Member's Bill.

PRESENT SITUATION:

In order to make recommendations, it is necessary to highlight the present situation in relation to the consent process of ascertaining the deceased's wishes.

1. A written consent (Driver's Licence or Donor Card) can be reversed at any time by a verbal statement.
2. Because of the above, the next of kin are consulted to determine the deceased's last wishes.
3. The legal document that the senior available next-of-kin sign states that the deceased 'had not expressed an objection for the removal of tissue for transplantation.'
4. There is no obligation to proceed to donation.
5. Where the deceased wished to be a donor and the next of kin object, the donation is not carried out because of possible outcomes. (experience proves this is very rare)
6. Those directly involved in donation, eg. Donor Co-ordinators, have no access to the driver's licence data.

As Donor Co-ordinators, we are encouraged to see that Members and their constituents take such a keen interest in the Queensland donation and transplantation results, but feel strongly that the proposed Bill will have no effect and the current situation will remain unchanged and could possibly have negative effects on current donor rates.

POSSIBLE RAMIFICATIONS IF THE BILL WERE TO BE IMPOSED:

- If the Driver's Licence were to be the sole legal avenue of indication of consent, it would be necessary to have immediate access to the data. Currently, Section 14A of the Transport Act prohibits access to this information as breach of privacy and confidentiality.
- The Drivers Licence will only cover those who drive. Family discussion must still be the direction taken for people who don't hold a licence or minors.

- If "broad" access were gained, relevant staff would act on the information stated on the licence. Because a Driver's licence is valid for 5 years, no provision is made for the holder to change their mind in writing.
- Subsequently, if a licence indicated "no", **no** approach would be made to the family. If no discussion is made with the family, there is no way of knowing whether or not the deceased had previously changed his/her mind and more recently had decided "yes".
- If the licence indicated "yes", it would be presumed that the deceased had not changed their mind to "no". If the family were not consulted, and organs were retrieved, the family could possibly claim that the deceased had previously rescinded the decision identified on the licence. This could potentially lead to devastating negative publicity and impact on the program as a whole.
- No allowance has been for data entry error. It is well documented in New South Wales that computer data entry on 16% of licences was incorrect. There have been several cases cited in Queensland which have been brought to our attention that the incorrect entry was made on the licence, despite indicating "yes" on the prescribed form.

It would be naive to think that enforcing a practice where a recorded document indicating a wish to donate and **excluding** the family at an emotional and devastating time for them would be "good practice".

Experience with donor families over the years has primed us with the important information that family discussion has produced a positive outcome for all. Organ donation is often the only positive outcome for families who have suffered a sudden and tragic loss. The decision making process and the ability to carry out the last wishes of the deceased have proved to be very important in their grieving process.

RECOMMENDATIONS:

1. The Bill **not** be adopted in Queensland
2. Access to the drivers licence data should be provided and restricted to Queenslanders Donate, Queensland Health.
3. The current wording on the licence application form be changed and also include:

In the event of my death, I wish to donate my organs/tissues for the purposes of transplantation into the body of a living person, if possible:

YES NO UNDECIDED

4. *I have told my family of my wishes* **YES NO**
4. Development of mechanisms to encourage the referral of all potential donors (as prescribed in the recently formed Queenslanders Donate) to evaluate medical suitability for donation, determine deceased's intention re donation, and ensure suitably trained personnel are involved in the discussion of donation with the next of kin
5. Development and implementation of ongoing public education and promotion campaigns regarding donation.
6. Development and distribution of information material for new and renewing licence holders.

The above recommendations will:

- Assist in the development of a national donor register
- Meet the public's perception that those responsible for donation (e.g. donor co-ordinators and requesting staff of Queenslanders Donate) have access to the drivers licence data.

- Ensure the wishes of the deceased are known
- Reduce the stress for those involved in discussing donation
- Provide valuable data for quality assurance measures
- Ensure trained personnel are involved in the presentation of the donation option
- Develop a better informed public

As donor co-ordinators, we support the principles as set out by the NHMRC:

NHMRC (National Health and Medical Research Council)

Recommendations for the donation of cadaveric organs and tissues for transplantation

Endorsed June 1996

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Donation of cadaveric organs and tissues is possible only because of the death of an individual, usually in a sudden and unexpected manner. Affected families are exposed to extraordinary stress at such a time. Much information must be passed on to the family members and be understood in a short period of time. Prior discussion and a decision by the deceased about donation of organs and tissues is of major assistance. While family discussion and knowledge is increasing, in many cases it has not taken place.

The arrangements for donation of organs and tissues must be handled with great care and sensitivity. Everyone involved must realise the difficulties of decision making for families who do not know the wishes of the deceased. Even if the wishes are known, it is a difficult time for the family. Good practice often goes beyond whatever would satisfy the basic requirements of relevant legislation. In this way, a satisfactory outcome can be achieved in a difficult ethical environment.

The Fundamental Principles embodied in this document are these:

- The fundamental principle upon which these Recommendations are based is respect for human dignity. This includes the dignity of the prospective donor, the dignity of the prospective donor's family, and the dignity of the prospective recipient. The professional's ethical and legal duty of care is derived from this principle.
- Provision of care to the patient takes precedence over the interests of organ and tissue donation.
- The decision of a person about whether or not to donate organs and tissues must be respected.
- The goal of organ and tissue donation is to benefit a recipient and the duty of all those involved is to protect the recipient, as far as reasonably possible, from harm.
- Recognition of the needs of health professionals involved in organ and tissue donation is also an application of the fundamental principle of respect for human dignity.