

Submission

on

Organ and Tissue Donation Procedures

to the

**Review of Organ and Tissue Donation Procedures
Select Committee**

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14 August 2008

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1. Introduction

On 29 April 2008 the Queensland Legislative Assembly resolved to establish the Review of Organ and Tissue Donation Procedures Select Committee from 12 May 2008. The Select Committee is required to table its report in the Parliament by 28 October 2008.

The Select Committee is required to investigate and report on the following issues:

1(a) Given the relatively low organ and tissue donation rates in Queensland, should a system of presumed consent or 'opt-out' for organ and tissue donation be introduced in Queensland?

1(b) If so,

- *should presumed consent for removal of organs and tissue:*
 - (i) be absolute, or should further recourse be required to the wishes of relatives and/or legal guardians in this decision?*
 - (ii) apply to all persons, specifically considering the age, decision making capacity, cultural and religious beliefs of the person? If not, what exemptions and safeguards should apply?*
 - (iii) allow these organs and tissue to be used for other purposes such as research?*
- *what mechanisms should be put in place to enable persons to explicitly register their objection to their organs and tissue being removed?*
- *what would be the implications, including financial implications, of introducing a system of presumed consent for organ and tissue donation on the operation of all existing legislative, administrative and governance frameworks, including in other jurisdictions?*
- *what, if any, other matters should be considered in the regulation of this issue?*

2. In addition to the issue of presumed consent for removal of organs and tissue, are there any additional options that should also be considered to increase public awareness of and improve the organ and tissue donation rate in Queensland?

2. Organ donation or organ procurement?

The term “organ donation” aptly expresses what has been the basic principle underlying this practice. A “donation” is a gift freely given by one person to another. To donate an organ is an extraordinary expression of human solidarity.

For a gift to be given freely it requires a deliberative act on the part of the donor. For such an act to be truly free it requires, firstly, an absence of any coercion and, secondly, adequate information so that the gift is based on a proper understanding of what is involved in making it.

The proposal that “consent” to organ donation be presumed, would if adopted, fundamentally alter the nature of this act from being one of donation – a gift freely given – to procurement.

No one is proposing a system of “presumed consent” for, say, donations to a fund to feed starving children in Africa. It is well understood that while giving to this or other charitable causes is praiseworthy, people ought to remain free to give or not to give.

If this is clear regarding gifts of money it ought to be even clearer in regard to gifts of parts of the human body.

Human beings are bodily beings. A bodily organ or tissue is part of our being, part of who we are. To give renewable tissue, such as blood or bone marrow, or a paired organ such as a kidney or lung, while we are alive is to give something of ourselves. Thankfully no one is yet proposing presumed consent for this kind of organ or tissue donation.

When we die our bodies do not become the property of the state.

Our wishes – expressed before death - or the wishes of our next of kin, our families, ought to determine what happens to our bodies. Are we buried or cremated? Is our body donated to a university medical school for use in teaching anatomy? Are some of our organs removed for transplant to another person?

The proposal for a shift to “presumed consent” or “opt-out” for organ removal after death for transplant is a proposal that the state exercise a proprietary right over our bodies, while allowing an “opt-out” as a kind of concession.

This proposal is wrong in itself as the state has no such proprietary right over our bodies.

2.1 A right to receive an organ transplant?

Most arguments for an opt-out system begin with an observation that organ donation rates are not meeting the demand for organ transplants. This is unfortunate but it is not a sufficient argument for introducing an opt-out system. An opt-out system assumes that potential organ recipients somehow have a “right” to receive an organ. However, there is no such right. None of us can possibly have a right to receive a part of another person’s body. Organ transplants rely on the generosity of organ donors – persons who freely choose to make a gift of their organs after death. Potential organ recipients and those concerned for them are entitled to appeal openly to the public for the gift of organ donation but they are not entitled to the procurement of organs without the freely chosen consent of a donor.

2.2 Popular support for presumed consent

Some public opinion surveys return higher percentages of support for a move to presumed consent for organ removal than the percentage of the public who have actually recorded their willingness to be an organ donor. The obvious response to such surveys is to suggest that those supporting a move to presumed consent should themselves record their willingness to be an organ donor. There is no justification for imposing an “opt-out” system of the whole population even if there is majority support for such a system.

2.3 All those who don’t want to be an organ donor would opt-out

Proponents of an “opt-out” system naively assert that all those who did not want to have organs removed for transplant would take the necessary steps to “opt-out”. This claim is usually linked to a proposal for a publicity campaign about the new system. However, it is clear that despite repeated publicity campaigns promoting organ donation those who actually take the steps to register as organ donors remain fewer than those who, when asked in a survey, express a willingness to be an organ

donor. There is no reason then to assume that all those who had a reservation about being an organ donor would actually take the steps to register their decision to “opt-out”. No publicity campaign will reach all people. In particular, those who are more socially disadvantaged are less likely to be exposed to any such campaign and less likely to have the skills necessary to take the steps needed to opt-out. There is a real danger that an “opt-out” system will put the socially disadvantaged at more risk of being used for organ procurement without them ever having given it any consideration let alone freely consented to make such a gift.

3. Family veto

In the event that a system of “presumed consent” is adopted it would be essential to include a right for the family to veto organ removal for transplant. The death of a loved one is always a profound event for family members. Deaths which are likely to result in a deceased person being considered a potential source of organs for transplant are more likely to be unexpected deaths such as from road accidents, diving accidents, aneurism etc. Families coping with the sudden death of a loved one should not be faced with the removal of organs for transplant from the body of their loved one against their wishes. This could only complicate and prolong their grief.

Such actions are likely to bring organ removal for transplant into disrepute and to increase public reluctance to be involved.

4. Minors and persons with intellectual disabilities

No person lacking a capacity to understand what is involved in organ donation and to choose it freely should be considered eligible for organ removal under an opt-out system. Minors (all persons under 18) should be excluded as should all persons with an intellectual disability of such a nature that they lacked this capacity.

Any proposal to the contrary would make it clear that what is being proposed is not at all a model of “presumed consent” but a straightforward claim of the state to have a right to procure human organs as it is patently nonsensical to talk of “presumed consent” in this context from persons lacking the capacity to take the steps to “opt-out”.

5. Use for research

Proposal for shifting to “presumed consent” for organ removal for transplant depend for their appeal on the immediate and urgent life threatening condition of a potential organ recipient. There are no grounds for broadening such proposals to cover the procurement of organs and tissue for research. While such research may of course eventually contribute to improvement in human well-being this is not sufficient justification for a presumption of consent.

6. Conclusion

The proposal for shifting to an “opt-out” system for organ and tissue removal for transplant should not be supported as it is contrary to the notion of organ donation as a freely chosen act of human solidarity and can only be based on a claim by the state to ownership of the bodies of its citizens.

If, notwithstanding this fundamental objection such a system is adopted, it should include a right for the family to veto organ removal; it should not apply to minors or persons lacking the ability to understand and consent to organ donation; and it should not apply to organ removal for research.