Submission to

Review of Organ and Tissue Donation Procedures Select Committee

Submission made by the Queensland Bioethics Centre, July, 2008

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Preamble

The Queensland Bioethics Centre is an agency of the Catholic Archdiocese of Brisbane and acts as a resource for the wider community. Through its Director, the Centre offers consultation, research, counselling, instruction and provision of information on contemporary questions associated with bioethical issues.

The director is the spokesperson for the Catholic Archdiocese of Brisbane on bioethical issues.

This submission is made by Ray Campbell, Director, Queensland Bioethics Centre and on behalf of the Catholic Archdiocese of Brisbane.

The Catholic Church and organ donation

The Catholic Church supports organ donation. Several Popes have explicitly affirmed the goodness of organ donation. Pope John Paul II mentions organ donation in this Encyclical Letter, *Evangelium Vitae* (The Gospel of Life) where he says that " the donation of organs, performed in an ethically acceptable manner, with the view to offering a chance of health and even of life itself to the sick who sometimes have no other hope" is a praiseworthy gesture (n. 86, 1995).

John Paul II considered the issue more fully in 1991 in a discourse to an international congress on organ transplants. Some of his observations are pertinent to this inquiry. He noted "this form of treatment is inseparable from a *human act of donation*. In effect, transplantation presupposes a prior, **explicit, free and conscious decision** on the part of the donor or of someone who legitimately represents the donor, generally the closest relatives." (Found in *Dolentium Hominum*, 21 (1992) n.3 12-13)

The decision to donate one's organ(s), even if it is to occur after death, is seen as "an act of great love, the love which gives life to others". For this reason "a transplant, and even a simple blood transfusion, is not like other operations. It must not be separated from the donor's act of self-giving, from the love that gives life." "Love, communion, solidarity, and absolute respect for the dignity of the human person constitute the only legitimate context of organ transplantation." (ibid.)

The Catholic Church and the "presumed consent" option.

As far as I know there is no authoritative teaching of the Catholic Church on the explicit issue of the "presumed consent" option regarding organ donation. But a response would have to be line with the general principles outlined by Pope John Paul II as given above. This is a matter where ethicists within the Catholic tradition might arrive at different conclusions.

Given the general principles outlined I would argue that the preferred position of the Church would be a "opt-in" system rather than an opt-out system.

As Pope John Paul II indicated the act of donation requires "an explicit, free and conscious decision". An opt-in system is more likely to ensure that this is the case rather than an "opt-out" system where it would appear that the State is making the decision for the donor (while leaving the potential donor free to opt out).

I personally would argue that Queensland should not introduce an opt-out system for organ donation. My reasons are given below.

Reasons against an opt-out system.

1) As already stated organ *donation* should be an explicit choice by the individual (or his/her representatives) motivated by care and concern for the well being of others. As an act of donation, organ donation should not be coerced nor should it be considered in some way obligatory. It is always a gift. Although an "opt-out" system does not necessarily prevent the choice from still being an act of love, it does tend to militate against it and introduces a different ethos into organ donation. Introducing an "opt-out" system might actually lead to less support for organ donation from those who support it as an act of explicit donation.

2) The introduction of an "opt-out" system could lead to a decrease in the number of organ donations. An "opt-out" system has an element of coerciveness about it. Australians are notorious for responding somewhat negatively to coercion. Although we do have a supposedly poor rate of people self-nominating as organ donors, the introduction of an "opt out" system might lead to a large number explicitly opting out. Relatives are most unlikely to over-ride an explicit "opt-out" wish of a deceased person. Furthermore, relatives themselves are likely to experience the process as more coercive under an "opt-out" system and once again could react negatively if relatives are still going to be given a say. An opt-out system could threaten the general "good will" there is towards organ donation.

3) Generally speaking in health care in Australia informed consent has to meet fairly stringent criteria. We have what we might call a high standard of informed consent. An "opt-out" system would seem to allow for a very low standard of informed consent and in that sense goes against the prevailing ethos in health care. The acceptance of such a low standard of informed consent in this area could have repercussions in other areas of medicine. It is very dubious when silence is taken for consent.

4) An opt-out system can lead to injustices against those who for cultural or other reasons would not want to be organ donors. The mere existence of the possibility of opting out does not guarantee that all those in the community will be equally well educated and aware of what needs to be done to opt-out. It is reported that in

Poland where they have an opt-out system "only a small fraction of Polish society is aware of the opt-out system and the general register for their opt-out decisions."[1] There arises a good chance that organs might be taken against someone's will simply because they did not know how to avail themselves of an opt out option. As the ethicist Gilbert Meilander expressed it: "… a consent that must be presumed is one that only the articulate and the powerful are likely to avoid giving."[2]

5) There is no evidence that "opt-out" itself actually increases organ availability. A change to the system in Queensland would seem to run a great risk with very little evidence that there will be a positive return. Neither the National Organ Donation Taskforce nor the National Health and Medical Research Council have supported the opting out system.

6) As noted in the issues paper a new national organ and tissue donation reform package has been announced. This package seems to include some of the measures that have led to improved organ donation rates in other countries. It did not include an opt-out system. It would seem to be prudent to allow these reforms to take hold and to judge their effectiveness rather than adding another new element. Indeed a move to an opt-out system at this time might actually threaten the success of the new reforms.

The question of consent and the role of next of kin.

As mentioned earlier the decision to be an organ donor should be a decision made by the donor, or in the event of the person being dead, by the next of kin. When made by the next of kin it should be made from the perspective of "this is something the deceased would have been happy to do (or not do)."

The question arises as to whether the next of kin can more or less override the expressed wish of someone to be a donor. It is important to note that even in many countries where they have an "opt-out" system, the next of kin are still consulted. Under both the "opt-in" and the "opt-out" systems the health care professionals normally will not proceed against the wishes of the next of kin.

Different health care professionals probably have different reasons for adopting this position. I think the practice shows a good deal of wisdom and sensitivity to the complex issues involved for people at the time of someone's death. It could be argued that if the possible donor had known that the donation was going to cause great distress to someone they loved in the circumstances as they now exist, then that person would not have gone ahead with the donation. In the clinical situation the health care team cannot try and assess all the interpersonal relationships involved and the reasons why family members might be refusing the donation. (I believe it is actually a very rare occurrence.) The proper response is to educate donors to talk

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[1] Zbigniew Szawarski, "Poland: the cost of transplantations", Transplants, Council of Europe Publishing, 2003.

[2] Gilbert Meilander, "The Giving and Taking of Organs", *First Things*, March 2008 (No. 181), 14-15.

about their wishes with their family well in advance. A system that simply moves ahead without any regard for the relatives who are mourning the deceased will look more like a "routine salvaging" system, and runs the very real risk of losing support from the public.

I strongly recommend against adopting an opt-out system.

In the event of the adoption of an opt-out system.

If the government should decide to adopt an opt-out system they should ensure that it is a genuinely "presumed consent" system and not just a system of "routine salvaging".[3]

For a system to be a genuine "presumed consent" system with a genuine option for opting out there would have to be an extensive and ongoing education programme so that people were well informed of their rights under the system. Indeed the public education programme for a genuine presumed consent system would have to be more extensive than for an opt-in system and ongoing (to allow for new members of the community being educated).

The method of opting out should be relatively easy and give some guarantee that a person will be identified as having opted out.

As there is much more chance of an injustice being done in a opt-out system the safeguards would have to be stringent.

A genuine presumed consent system would exclude those who would not have been able to consent anyhow. For such people it would be mandatory that the consent be obtained from the next of kin.

It would seem reasonable that one should only be included under the category of presumed consent only once one had reached eighteen years of age. This does not mean that organs from those younger could not be used, but it would only be with the consent of the next of kin.

Even in a presumed consent system it would be wise to follow the practice of other countries and allow the next of kin to have the final say.

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[3] See R.M. Veatch and J.B. Pitt, "The Myth of presumed Consent: Ethical Problems in New Organ Procurement Strategies", in Arthur Caplan and Daniel Coelho (eds) *The Ethics of Organ Transplants*, Prometheus Books, N.Y., 1998, 173-182. Veatch and Pitt argue that some countries which are said to have "presumed consent" regimes actually have "routine salvaging" regimes i.e. there is no presumption of consent, the state simply claims the organs.

Use of organs for purposes other than transplantation.

Under a presumed consent system, consent should only be presumed for transplantation, not for other purposes. If consent is presumed for other purposes, once again there would need to be extensive public education. If consent is presumed for other purposes it should be possible to opt out for one purpose but still have consent presumed for another purpose. This is simply a way of respecting the autonomy of the individual within a presumed consent system.

Other Options

As mentioned before the Queensland Government should allow time for the new initiatives introduced by the Federal Government to take effect. It should seek to fund better education on organ donation and ensure that there is adequate funding for the process of organ retrieval. Recent problems in Queensland (e.g. the lack of availability of a team to retrieve organs) would seem to indicate that the problems might be more within the health system than with the number of available donors.

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