Submission number: 019
Email received from: Wendy and Dale Nichols
Date received: 10 August 2008

Research Director
Review of Organ and Tissue Donation Procedures Select Committee
Parliament of Queensland
Corner George & Alice Streets
BRISBANE QLD 4000

Dear Ms Cawcutt

We submit our response to the Issues Paper for your consideration. Our submission is based on our experiences as a DONOR family.

We have responded to most of the issues as they were raised for comment. Beforehand however, we felt it may be useful to "set the scene" of our donation 12 years ago, to provide some insight into our thinking on certain matters. We acknowledge that our experiences may be quite different to those of other donor families and that a decade ago, we knew very little about organ donations.

In December 1995 our son was 18 years old and "brain dead" as the result of a car accident. The ambulance officers and hospital staff had done what they could to help him. Obviously we were shocked and sickened by the unexpected tragedy. It was impossible to accept the inevitable. Our son did not look dead. He looked fit and healthy; "like a Greek God" said one nurse, so when we were approached about organ donation, as his mother, I could not envisage my son's body being 'cut up' and parts removed! His older sister felt the same way.

The fact that my son had "ticked the box" on his licence a month earlier, meant nothing to me; we had not talked about the topic. Our son could not have known how any of us would be feeling at that time. Whilst his father and his older brother had no objections to the organ donation, they would not agree to it while our daughter and I were so opposed.

The transplant co-ordinator was patient with us. She explained not only the donor operation but also the required autopsy. When my daughter and I realised that not all of our son's organs had to be donated, we were able to reach a compromise. She could not bear the thought of someone else with her brother's eyes and I could not bear for him to lose his heart. We agreed to the other organs being donated.

Our son/brother was dead. We are the ones who had to go on living and in particular, to live with the donation decision.

The transplant co-ordinator was true to her word in everything she said would happen both in the short term and the long term and we are very grateful to her for her honesty, commitment and professionalism. SHE made all the difference.

Now, more than a decade later, I wish I had allowed my son's heart to be donated but at that time and for years later, my decision helped me to survive.

Issues for Comment

3.5
What requirements for consent to organ and tissue donation should apply? If possible, please outline your reasons.

The written consent of donor and written consent of senior next-of-kin should be required.

However the donor's "written consent" should be more than just a "tick in a box".

The donor's express permission could be qualified by statements re:

- the name/s of next-of-kin with whom s/he has discussed the decision
- the sources of information used to make an "informed" decision (perhaps a list of sources could be provided)
- the organs and/or tissues to be donated (again, a list of all possible organs and tissues could be provided so a person could exclude something if they do not want to donate that part for whatever reason).

The written consent of senior next-of-kin should include a statement to say that they understand the express wishes and views (not just a tick in a box) of the donor and that s/he agrees/disagrees to the donation. If the next-of-kin disagrees, perhaps s/he should be asked for a reason why – to help with future education/awareness programs.

Should the role of next of kin or family be different if a person has given written consent to organ and tissue donation?

As above.

If the next-of-kin understands the wishes and reasons of the donor then it is more likely that the relative will agree to the donation.

If the relative does not agree, then that next-of-kin's decision should be final. It is the "living" who has to live with the decision.

What is the best way to use a donor register in connection with consent when donation is being considered?

Not sure what this question means.

Do you support introduction of an opt-out or presumed consent system?

No.
What reasons do you have for supporting or not supporting an opt-out or presumed consent system?

- People should make an "informed" choice and not leave the donation to chance.
- It is more difficult for next-of-kin or family to make a decision if they have not discussed the issue with the donor.
- Organ donation is a gift of life; not an imposition.

- There are enough willing donors but not the resources to convert the potential into actual donations.
- Who is assumed to be a donor – everyone – including babies, children?? Raises questions as to who can opt out and how.

What role should a deceased person's family or next of kin have in consent to organ and tissue donation?

Family should be encouraged to be party to the discussion and decision-making of the individual wishing to be a donor.
The final decision should rest with the next-of-kin and family.
"Family" can include so many people apart from biological parents and siblings so the system needs one person to agree/disagree to the donation. One can only trust that the most senior next-of-kin takes into account the wishes of the donor and the family.

3.6

If a presumed consent system was to be introduced, what mechanisms should be introduced for people to opt-out?
How could simple and reliable access to an opt-out mechanism be ensured?

Not sure about mechanisms as not in favour.

If presumed consent was introduced, should the family be asked if they object to organ donation if the deceased person has not opted out of donation?

Yes; for reasons explained above.

Should children and people with impaired decision making capacity be part of a presumed consent system?
Should particular categories of people be automatically excluded and not presumed to consent to donation?
When should children be able to opt-out of presumed consent?

Eligibility may be more of a legal matter; presumably if one can enter a legal contract, one could register (and opt-out)?
If it is considered inappropriate to register, for example, a child under 12, this doesn't prevent the family from having a discussion and individuals expressing their desire to donate or not donate.

What support would be required for clinical staff if a presumed consent system was introduced?

Not sure.

3.8

a) **What safeguards and limitations should apply to a presumed consent system?**
b) **Are there specific religious or cultural issues that should be addressed in consent to donation or organs and tissue?**

(a) Not sure

(b) Presumably the religious/cultural issues would be addressed by the donor and the family and senior next-of-kin when reaching a decision about donation. First staff to contact the family re donation would check on these issues before pursuing the donation request.

3.9

If an opt-out or presumed consent system is introduced, should it apply only to transplantation to another person, or also to other purposes such as research?
In an opt-out or presumed consent system, should it be possible to opt-out of donating for one purpose, but continue with presumed consent for another purpose?

The whole process should be about choice.

Be VERY careful talking about "research" and organ/tissue donation in the same breath! Don't confuse the public. Presently they are two distinct matters and should stay that way. There is more reluctance to be involved in "research" than in what is seen as the more direct and personal process of donation.

3.10

If an opt-out or presumed consent is not introduced, is the current system of consent appropriate?
Are there changes you consider should be made to the decision-making or consent system?

See first comments above.

4.10

a) **What action should be taken to improve organ and tissue donation in Queensland?**
b) **Are there particular hospital-based strategies that should be considered in Queensland to improve organ donation rates?**
c) **Should any incentives be offered to potential donors for organ and tissue donation?**
d) **What are your main reasons for supporting or opposing incentives? If you support incentives, what type of incentives do you consider may be appropriate?**
e) **What action should be taken to promote better public awareness of organ and tissue donation?**

a) More resources to facilitate the transplants are required – eg presently I don't think I could donate my cornea if I was in a Rockhampton hospital because there is no eye bank available. Resources are also required for a range of complementary strategies such as those mentioned below.

b) All hospital staff members have to be onside – perhaps more education for them, especially in terms of the long term savings if they are worried about prioritising the dollar?
More hospital transplant co-ordinators have to be trained and supported.

c) No incentives.

d) Donation is a gift; the process should not leave itself open to pecuniary influences; incentives may counter the belief that medicos will "do the right thing" by an injured/ill person.

e) Public awareness and information sessions should be conducted by experts and those who have experienced the process; not by television or other celebrities, even if their intent is honourable.

A unit of study re transplantation should be incorporated into the secondary school curriculum. Relevant staff should receive professional development conducted by experts.

Statistics can tell us whatever we want to hear; should be careful about their use especially in comparing Australia with other countries. For instance, a major difference between Australia and the European states is geography eg potential donors in Australia may be located hours away from medical treatment and "time" is critical. Not sure to what extent regional areas (other than eastern seaboard) can be resourced effectively because of distance.

The public should be praised for its effort; so many are willing to donate. It's the conversion rate that's the problem. We don't want people to die in accidents or to be given less effective treatment in order to increase organ donations.

The costs and benefits of organ/tissue donations could be spelled out more. For instance:

Transplant operations may cost considerable amounts but the successful operations then reduce the costs of ongoing medical care for that person and the release of hospital beds, as well as improved quality of life for the recipient AND their families (a family member/s may be on a carer's pension and confined to home to care for the individual).

eg It may cost say $70,000 for a kidney transplant. But if that person is taken off dialysis treatment, at a cost of $85,000 per year, then that's a huge savings.
Potential benefits of a donation should be highlighted. For instance, one donor has the potential to help over 60 people if you consider who can benefit from the donation of heart, lungs, liver, pancreas, kidneys, eyes, valves, skin and bone. What a legacy!

Yours sincerely

Wendy and Dale Nichols
10th August 2008