Submission number: 037
Email received from: Cynthia Burnett
Date received: 15 August 2008

Research Director
Review of Organ and Tissue Donation Procedures Select Committee
Parliament of Queensland
Cnr George and Alice Streets
Brisbane 4000

Dear Select Committee Members

Thank you for the opportunity to express my views as a citizen on this important issue. I would like make a few short comments on the Issues Paper, July 2008.

Introductory comments
I am a 61 year old single female who is both a regular blood donor and a registrant, many years ago, on the organ donor register. My views on these issues are not constrained by any particular cultural or religious beliefs. However, I appreciate the need for the cultural and religious perspectives of others to be taken into consideration by governments when deliberating such matters.

I think it is a pity that blood and organ/tissue donation is seen as an altruistic gesture by the few for the benefit of the many; why can't it be altruistic on the part of the many for the many? I don't see how adopting a presumed consent model would really change this aspect.

For me, a simple analogy is that if we want the right to access a range of civil services (eg. transport, roads, rubbish collection etc), then we should contribute to the costs and we do, via rates and taxes. In regards to the right to access health services, then it seems to me not unreasonable to expect people to pay to access these –through having health insurance and by being prepared to donate blood, organs and tissues not just out of altruism but also because one day we may wish to have the right to access these ourselves.

I believe that one long term disadvantage of the public health system is that it has engendered a mentality that whatever a patient needs can be and will be provided by the system at no or little cost to the patient. This is an unsustainable position.

Adopting a presumed consent system, with limited, legitimate exceptions may make some feel that this is "big brother" making registration to the system mandatory. This kind of approach, for peoples' own benefit, has been seen in other areas of life and people have come to accept it. For example, rules about using seat belts and not smoking in public places weren't popular to start with but have become accepted by reasonable people as necessary.

Having read the issues paper, the position that most closely reflects my own views is that of the Austrian position (p16) : a hard presumed consent system, no consultation with relatives and for those choosing to opt out for whatever reason, allocation of the lowest priority in the event that they should later wish to have a transplant of some kind.

Ethically, I do not accept that because we love people, that we in any way "own" or "have stewardship" over their bodies, except in the case of minors or mentally incapacitated people. Therefore, I do not believe relatives should be making decisions and that is why the Austrian position is attractive. The issues paper does not indicate whether this position has, in fact, increased the numbers opting in to the system. However, administratively and ethically, I see it as the most clear cut position. There will need to be some exceptions, however (see below).

It may be that a presumed consent system is the first necessary step to introducing other complementary measures that make the whole package more readily accepted and more easily administered (Eg. Greece).

Issues for comment listed in the Paper.
P18,

- **What requirements for consent to organ and tissue donation should apply and give reasons.** If the system remains much as it is, that people must actively sign onto the register, then consent should include that the person signing on to the register be of sound mind, capable of understanding what will happen if any of their body parts are taken and also being aware of what consequences opting out could have for them personally in the future (ie. being a low priority recipient). This might mean that anyone wishing to sign on should have a certificate of sound mindedness from their doctor and a letter indicating that the person has been fully informed. If, on the other hand, a system of presumed consent is introduced, then the issue of public education and awareness becomes critical for that consent to be fully informed consent. Then the question should become, what requirements for opting out should apply? In this situation, I think there is a case for relatives, in conjunction with specialist medical counsellors, to make the decision to opt out on behalf of people who are of unsound mind, (for any number of reasons). People who have specific religious or cultural beliefs that lead them to opt out should nevertheless be very aware of any implications this may have for their own future health care.
- Where a person has given written consent, this should not be overridden by family members, unless it can be proven that the person had changed their mind but had not done whatever necessary to opt out prior to sudden or unexpected death, eg. proof from non-family witnesses to conversations about a change of heart or expression of change of heart to the person's doctor or similar.
- I fully support the introduction of a presumed consent system. This system has the potential to save much agonising decision making and much grief over not being able to have a transplant.
- I do not believe family should be involved where written consent or even presumed consent applies unless in the case of exceptions similar to those mentioned above.

P19

- **Mechanisms for opting out.** Use of the infrastructure of the existing register, if viable, where people must supply a signed document, outlining reasons, with proof, for exemption and stating that they understand the consequences of opting out for their own future health care. Once a person has opted out, they could be supplied with a card or document by the authority that they carry at all times. A copy could also be held by their GP. I can't see how any opting out system other than a centralised one in each State or Territory could would effectively. To ask GPs and/or other health care workers to take on a role in this would be messy. If not the existing register, then some such body specially set up under the relevant legislation in each state, if the legislation is not nationalised, for this pupose.

- Where a presumed consent system is in place and the deceased had not opted out, there is no role for the family. I say this because it is about respect for the wishes of the person they loved.
- **Exclusion of particular categories of people.** Other than mentally unsound people or minors and people of particular cultural and religious beliefs, the only other kind of category I can think of c
- ould be people who have a history of certain types of (chronic) illnesses that may render any or all of their organs/tissue unsuitable for donation or people who have been on long term medication that may have an adverse effect upon the quality of organs/tissue.
- **Children opting out.** If parents choose to opt their children out, then this should be done within a given time frame of the birth of the child, say the first twelve months. The child then remains opted out until the child is, say, at least sixteen. If the adolescent wishes to remain opted out, then fine but there should be a way for them to opt in if they wish after that.
- **Support for clinical staff under a presumed consent system.** I think all hospitals should have on hand a trained counsellor at least. There may be a need for other administrative or technical support as well.

P20

- **Safeguards and limitations to presumed consent.** All migrants coming to this country would need to be made aware of this system as soon as possible, if not before they migrate. This is a group that could easily slip through the cracks of any system and hospital staff may need to be prepared and equipped to deal with a situation such as an unexpected death, the family knows nothing about the system and they want to opt the deceased out. Limitations that I can see would apply to those exempt as discussed above.

P21

- **Should presumed consent cover all types of uses for organs and tissue?** I think allowing people to pick and choose would create an administrative nightmare and be open to error. However, if it could be administered relatively straightforwardly, then, yes, people should be able to be specific. This would probably only affect a small percentage of the population, I am guessing.

P22

- **Is the current system okay?** Yes, in terms of how easy it is to register; probably No, in terms of the numbers of people who do register. Additional multiple measures would need to be put into place to encourage much greater participation. Measures that are proving successful elsewhere in the world should be examined carefully to assess their potential in the Australian context. One way could be to again use the argument that if a person in a non-donor, then they do not receive priority listing if ever in need in the future. This may sound a bit like a “big stick” approach but ethically, it seems fair and reasonable.

P27

- **Actions to improve donation rates in Qld?** Here, I would just like to say that whatever measures are considered worthy of introducing to increase donation participation, authorities would need to keep in mind that a balance between the costs and numbers of people likely to benefit should be weighed up. Many areas of health care that affect many, many more patients than those needing transplants continue to remain inadequately funded.
- **Incentives to potential donors.** Absolutely no incentives, financial or otherwise, should be offered to any potential donor or their family members, in cases where family may be making the decision to donate or not. Once incentives are introduced, the system is open to abuse, and abused it will be. The system should remain altruistic, no matter how many people participate.
- **Better public awareness.** Public education and dispelling of common myths will be critical to any attempt to increase participation rates. Some ideas that come to mind:
    1. Highly visible brochures in all doctors' clinic that are actively promoted by staff. Drs should be required to ensure that they discuss/draw attention to organ donation with all their current and new patients.
    2. Informed discussion in secondary school curriculum eg. Physical Education and Health.
    3. Aged care facilities could be required to ascertain if the issue has been discussed with the patient, ensure the patient in fully informed and assist the patient to register in the current system, if they wish to be registered.
    4. Offices to do with immigration could deal with this as well in the form of brochures printed in various languages.
    5. Advice on good marketing strategies could be sought and large, eye-catching posters produced to ride on the backs of buses, billboards and in hospitals etc.

Sincerely

Cynthia Burnett