

Submission number: 029
Email received from: Leo Brown
Date received: 15 August 2008

Submission to the Review of Organ and Tissue Donation Procedures Select Committee

Submitted by : Leo Brown

Introduction

I have followed with interest the developments, trials and tribulations of the Organ Donor Program and have been impressed with the continuing success of organ transplantation regardless of the issues of supply and demand. It is comforting to know that the procedures and techniques are improving thereby providing better opportunities for potential recipients, but it is disappointing to see that the supply rate is not keeping pace with the demand for transplantation.

In this submission, I have addressed some of the matters raised in the Terms of Reference for the Review of Organ and Tissue Donation.

Presumed consent or 'opt-out' system

At the outset, I must say that I totally disagree with a 'presumed consent' system. I believe that it could be viewed as ethically unacceptable as well as being a 'big brother' approach. It could send the message to the community that the ownership of their organs and tissues, as well as their decision making, is being taken away from them demonstrating the loss of that ownership. It could also send the message that the government knows better than the potential donor and that the donor is unable to make a decision on matters related to their own bodies.

Although the opportunity would be there for the person to register their choice of opting out of the program, the reality could be that a person may wish to opt out, but may not have taken that step prior to an untimely death. This would place additional stress on the grieving family to make a choice which may be more complicated than if there had not been a presumed consent system in operation. The family would struggle with the dilemma of agreeing with organ and tissue retrieval whilst knowing that the deceased may have intended to opt out of the program.

I caution against the introduction of a presumed consent or 'opt-out' system for organ and tissue donation. I believe that the introduction of such a system would cause a great deal of harm to the organ and tissue donation program as it would be seen as a 'quick fix' by government rather than embarking on a more balanced approach including broader community education and enhancement of the goodwill of general public.

I recommend that the presumed consent or 'opt-out' system for organ and tissue donation not be established.

Program Awareness

Whilst it is accepted that there is a wide awareness of the organ and tissue donation program, I understand that the depth of community knowledge of the program is probably rather shallow. I consider that this is a result of the perception, and perhaps hope, of a larger proportion of the community that they are unlikely to be in a position required to make a decision on organ and tissue donation or transplantation. I have noticed that the program has received an increased exposure in recent times and, with the involvement of some high profile people, is regularly mentioned in the media. A continuation, and enhancement, of this community awareness program will increase the knowledge of potential donors and will benefit the donor program itself.

I understand that there is a concentration of effort on promoting the donor program across all sectors of the community and particularly in the school-age and young adult members of the population. Whilst this provides people with a broader understanding of the program, I consider that it could well be enhanced by adding another element to the education program.

I'm not aware of any preparatory education for relatives of potential organ and tissue donors. Whilst the donor may have made the decision to offer organs and tissues for transplantation, it is the bereaved relatives who are faced with making the ultimate decision regarding the donation of those organs and tissues. It is necessary to educate members of the public of the need for them to register as donors, but it is equally important to ensure that the potential bereaved relatives are fully aware of their role in the early after-death stage of the organ and tissue donation and retrieval process. This is a time of personal trauma for the relatives and also a critical time in the decision making window of opportunity for the retrieval of donated organs and tissues. I believe that the organ and tissue donation rate could be increased if the families of potential donors were better prepared for the decision making process following the death of a family member.

A community educational program with this focus could alleviate the fears and concerns that some relatives may have about the perceived violation of the deceased person's body by the removal of organs and tissues. I understand that some members of the community perceive that the removal of organs and tissues from a deceased person, who has already suffered some trauma leading to death, is a further humiliation for the deceased. This matter should be included in any educational program on organ donation and would assist family members in being better prepared should they be faced with the situation.

I recommend that an educational program, aimed at preparing people for the decision making process following the death of a donor, be established.

Role of deceased person's family

The family of the deceased person are an integral part of the donation process. They are usually thrust into a situation of untimely death and will have some difficulty in dealing with that situation. As well as finding coping mechanisms for this situation, they will be approached by organ donation coordination staff to discuss the matter of organ and tissue retrieval. This can be overwhelming if they have not discussed it fully in a less stressful situation. They are being asked to make decisions whilst coping with the stressful situation and can feel a sense of inadequacy and guilt in making such decisions at that time. There is

usually a limited window of opportunity for relatives to make a decision on the concurrence or rejection of organ and tissue donation following death, and they can sometimes feel that, in retrospect, they may have made a different decision, if they had been better prepared for the situation.

I consider that they should be directly involved in the decision making process following death and that their decision should be regarded as the most important factor in the organ and tissue donation program at that time.

One way of having a deceased donor's family involved earlier in the process is to provide an opportunity for them to agree with the donation prior to death. This could be established by encouraging potential donors to have next of kin support their donation and sign the donor registration form as a supporter. This could be preceded, or followed, by more information on the role of the next of kin following the death of a donor.

I recommend that space be made available on the donor registration form to allow next of kin to record their support for the donor and request information on the after-death decision making process.

Incentives for donors

The organ and tissue donation program provides opportunities for people to provide life saving support to other people. This is the ultimate gift to our fellow human beings and should be done unconditionally. Whilst some contributions to offset the cost of funerals or other financial burdens, would assist some families, I consider that it should not be a regular element of the donation program. If financial incentives were implemented as part of the donation package, I believe it would degrade the integrity and goodwill of the program. It could also have a negative effect on the donation rate as some people would withdraw from the program, fearing being labelled as a cheapskate, donating organs and tissue to get a free funeral.

The donor program is an altruistic demonstration of goodwill amongst the population and it should be protected at all cost, irrespective of the number of donors.

I recommend that financial incentives for organ and tissue donation not be established.

Promotion of public awareness of organ and tissue donation

The donor program already has a good deal of recognition in the community, but the exposure needs to be maintained consistently. The regular avenues of newspapers, radio and television could be complemented by more use of displays and educational sessions at community events, shows, school fetes, open days, health promotion displays and theme weeks. Visits by donor coordinators and ambassadors as guest speakers at schools, universities, vocational and tertiary educational organisations as well as personal profile articles in newspapers, magazines and radio and television appearances would provide a broad educational program to all age groups within the community.

I visited the Brisbane Ekka and did not see any advertising material highlighting the benefits of the organ and tissue donor program and the need for donors.

I recommend that the advertising program for the organ and tissue donor program be extensively increased to ensure the widest dissemination of information to the broadest possible audience.

This submission has been prepared and provided for consideration by the Committee.

I am available for further interview on this matter if required. My contact details are:-

I trust that the information and recommendations provided herein are worthy of consideration and add value to your deliberations.

Yours sincerely,

Leo Brown
14 August 2008