## Donating organs after death: ethical issues

Ethical issues in organ donation Discussion paper No. 1

National Health and Medical Research Council

NHMRC

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#### 1. Introduction

Since organ and tissue transplantation is now an established part of Australian medical practice, Australians need to think about whether they wish to make their organs and tissues available for transplantation after their death. Many people may not be sure about organ and tissue donation. The decision to donate is an ethical decision, one which involves thinking about the ethical issues from two different perspectives: (1) whether or not to donate one's own organs and/or tissues after death and (2) whether or not to donate the organs and/or tissues of a relative who has just died.<sup>1</sup>

The goal of this paper is to provide a balanced discussion which will help people to think through the ethical issues well in advance of a decision having to be made. It does not cover all details of how organ and tissue donation may be carried out in particular cases, for the procedures vary not only between the different organs and tissues, but also (to some extent) between hospitals. Rather it tries to provide a sketch of the main ethical issues involved in donation and transplantation in order to help those who are interested in these issues to reflect on them.

Australia is a multicultural community. It is important that all members of our varied community feel assured that their views on organ and tissue donation and transplantation are respected. It is important that the practices of organ and tissue donation and transplantation take into account the cultural, ethical, spiritual and religious views of all those concerned. This need to respect different viewpoints gives added importance to ensuring that each person makes a wise decision on donation.

The paper begins by considering why it is important to think about organ and tissue donation. It then sets out in brief what actually happens when organs and tissues are donated after death. The main reasons why some people decide to donate organs and tissues, and why some decide not to, are discussed. Then, because making a decision after the death of a relative is a very different thing from making a decision in advance for oneself, some of the issues special to making a decision on the death of someone else are discussed. Finally, and by way of summary, a list of questions to think about is set out.

<sup>&</sup>lt;sup>1</sup>This discussion thus concerns 'cadaveric' organ donation and is the first in a set of four discussion papers prepared by a Working Party of the Australian Health Ethics Committee (AHEC) on the subject of the ethics of organ donation and transplantation. The second paper in this set is entitled *Ethical issues in donation of organs or tissues by living donors*; the third is entitled *Ethical issues raised by allocation of transplant resources*; and the fourth is entitled *Certifying death: the brain function criterion.* 



# 2. Why think about the ethics of donating organs after death?

The decision whether or not to donate organs and/or tissues for transplantation is an ethical (or 'moral') decision. That is to say, it is a decision which expresses a view about how it is best to live, about which choices are ethically-sound ones (generous, fair-minded, courageous, etc.) and which ones are ethically-unsound (mean, unjust, unfair, cowardly, etc). The discussion here aims to ensure that, whatever decision the person makes, whether to donate or not to donate, that decision will be a well-informed one, one that is freely chosen, and one that is compatible with the ethical beliefs of the individual concerned.

In making a decision, individual people will have to do the thinking for themselves. There is no one 'right' answer to the question of whether or not to donate. Nor can anyone else tell you what decision you should make in your circumstances. Only you can judge what will be a sound decision in your particular circumstances. On the other hand, there is much that can be said that will help to ensure that the decision you make is a wise decision. Some of the 'background' ethical issues might be summed up in the following way:

- Organ and tissue donation involves making a decision about how someone's body is to be treated after death. There are many different views about this, but what they have in common is the idea that the dead body must be treated with respect. This treatment of the dead body has great significance, not only for spiritual and religious reasons but also for cultural and non-religious reasons.
- Organ and tissue donation may be seen as one of the last acts of the person who
  donates. It is a decision about how that person wanted to live his or her life
  and be remembered in death.
- Organ and tissue donation is also an ethical decision because it is intended to benefit others, the recipients of organs or tissues by transplantation.<sup>2</sup>
- Organ and tissue donation is a decision which will affect those who are left behind after someone has died. Since the issue of organ donation often arises after a sudden and traumatic death, the feelings of the bereaved family are very important.

<sup>&</sup>lt;sup>2</sup> Here we are primarily considering organs used for transplantation, but organs and tissues can also be donated for medical research and for teaching purposes.

Why should you think about it now? People often put off thinking about organ donation, perhaps because they do not want to think about death. But there are good reasons for considering it carefully. For one thing, if you do die unexpectedly and your relatives are faced with the question of donation on your behalf, it will be easier for them if they know what your wishes were.<sup>3</sup> For another thing, you may also like to know that, if the situation arises, your wishes regarding donation will be known and carried out. In this respect, family discussion about the wishes of family members regarding donation is important. In addition, donor cards and drivers' licences are useful records of the wishes of individuals.

One reason why some people may be reluctant to donate organs is that they do not know very much about what happens. In the next section the procedures of the donation side of transplantation are set out.

<sup>3</sup> Though the law in Australia allows an individual to express his or her wishes regarding organ donation before their death, in practice families are consulted. In addition, if someone dies and his or her wishes regarding donation are not known and there are no known relatives to be contacted, the law allows hospital authorities to consent to the 'donation' of that person's organs for transplantation.

Donating organs after death: ethical issues

#### 3. What actually happens

#### (a) The procedures involved

The procedures for organ and tissue donation vary slightly among hospitals around Australia. This section is intended as a guide only, to give you some idea of how things are done here in Australia. It is also intended to help you to think about what you have a right to expect, to clarify how you think things should be done in this area of medical practice.<sup>4</sup>

If someone who could be a potential organ donor dies in hospital, then the family is likely to be approached about organ donation. The views of the family are sought in order to find out whether the deceased had expressed any wishes on the matter. This usually happens after death has been determined.

When deciding about donation, you or your family may also be deciding which organs and tissues may be donated and whether they are to be used for transplantation and/or research. You may want to discuss this with a doctor. If you decide to donate, you may allow only some organs to be donated and not others. More commonly donated organs include kidneys, heart, lungs, liver and pancreas. The most commonly transplanted tissues are corneas, but bones, skin, and heart valves may also be donated.

If it is agreed that donation may take place, then various blood tests must be carried out on the donor's body. These tests are done for the benefit of recipients and they are only carried out after death has been determined and when it has been decided that donation will go ahead. The donor/donor's family is not charged for these tests.

The family of the donor will also be asked to consent to an autopsy on the donor's body. Though the purpose of an autopsy is generally to determine the cause of death, in this circumstance it is to detect other disorders which may have an impact on the health of the recipient. It should be noted that in some States, if an autopsy is conducted, it is legally permitted that the organs or tissues removed for the purpose of the autopsy may be used for medical or scientific purposes.

In some cases, for example if the death was the result of an accident, it is required

<sup>&</sup>lt;sup>4</sup> You may be interested in obtaining a copy of the NHMRC report *Recommendations for the donation of cadaveric organs and tissues*, which provides guidance for the conduct of the professionals involved in organ donation and transplantation, available for sale through the Australian Government Publishing Service (AGPS) on phone: 132 446 (freecall). You may also be interested in obtaining a copy of the relevant Human Tissue Act adopted in your State or Territory.

by law that the coroner be consulted for consent to donation. There will always be an autopsy in cases involving the coroner.

Some organs and tissues can be retrieved after the heart has stopped beating. For the retrieval of other organs, however, it is necessary for the donor to remain on a ventilator. The machine is kept going until the operation in which the organs are retrieved because it is necessary that oxygen supply to the organs is maintained for successful transplant. Often this involves some delay: a transplant team may have to come from outside the hospital, or the hospital may wait for a relative to arrive.

In this time left before organ donation, the family should be able to stay with the body of their deceased family-member, although the logistics of donation sometimes demand that the time available is limited. When the person's body is taken to the operating theatre, the ventilator will still be going, and medical personnel will be in attendance.

The operation is equivalent to a major operation with the distinction that, at the end, the organs are removed. The operation is as deliberate and exacting as any normal operation, and the organs are removed with great care. The operation usually takes some time, depending on which organs are removed. Following organ removal, and depending on the cause of the injury, the body is generally restored to a normal appearance. After the operation for organ donation, the family may wish to spend time with their relative's body. It is well recognised that this time spent with the body of the deceased person is an important part of the grieving process.

Organ donation does not affect funeral arrangements.

#### Tissue banks

Though organs must be transplanted promptly, some tissues can survive much longer and may therefore be kept in tissue banks. Tissues which may be banked include corneas, bones, heart valves and skin. The relatives of the deceased person will be approached by a co-ordinator either from the Red Cross or from one of the tissue banks for consent to the removal of specific tissues.

#### (b) What is 'brain death'?

The law in Australia, as well as elsewhere, recognises that there are two ways in which death may be determined: firstly, when the heart has stopped beating and breathing has stopped permanently; and secondly, by the permanent loss of brain function. These are two ways of finding out the answer to the same question: is

the person dead? The second way of determining death is commonly called the 'brain death' criterion.<sup>5</sup>

The death of a human being consists in the irreversible loss of the integrated and co-ordinated life of the person as a single living organism. Developments in twentieth century medicine have meant that, in some cases, a person's breathing and heartbeat may be kept going artificially by a machine, even though the person is actually dead. In these cases, it is not possible to determine death by the cessation of heart beat and breathing. Instead, doctors have developed the criterion of loss of brain function.

The functioning of the brain is central to what it is to be a living human being. It is the function of the brain to coordinate the way all the various organs of the body work together in the life of an individual. If the brain permanently stops functioning, this is the end of a person's life, the end of the integrated life of a human being, even though it may be possible with machines to keep some organs such as the heart and kidneys going.

A series of tests must be done to ensure not only that there is no possibility of recovery but also that the brain has permanently and completely stopped functioning. Once the brain has ceased to function, the person is dead. If organs such as heart, liver and kidneys are to be donated for use in transplantation, the person will normally be declared dead using the 'brain death' criterion and his or her body maintained on a ventilator, because it is necessary that oxygen supply to the organs is maintained if the transplant is to be successful. Though the person on a respirator may look as though he or she is still alive, it is the ventilator that is artificially maintaining the breathing and heart-beat.

In practical terms, certifying death using the 'brain death' criterion requires strict clinical tests. Two experienced doctors must determine, independently of each other, that there is permanent loss of all brain function. Neither doctor may have any interest in any organ transplantation that may follow.

In determining death in this manner, it must be known for certain what caused the brain injury and the injury must be severe enough to explain the loss of brain function. Often this requires special investigations such as CT scans (computed tomography scans, in which X rays and a computer produce pictures of cross-sections of the brain) and the four vessel angiogram (an X-ray test where dyes are put into 4 different arteries of the brain). Also, there are certain drugs, and certain metabolic conditions (conditions of the body's physical and chemical processes) which might cause temporary or reversible loss of brain function. These possibilities

<sup>&</sup>lt;sup>5</sup> What follows is a short account of 'brain death'. If you are particularly interested in this issue, you may wish to read the discussion paper *Certifying death: the brain function criterion* developed by the Australian Health Ethics Committee and available from AGPS on phone: 132 447 (freecall).

must be ruled out. This having been done, there must be a period of observation during which routine neurological examination (examination of the brain and nervous system) does not find evidence that the brain is working.

The features of brain death include deep coma and the complete absence of all reflexes of the brain stem (the brain stem is the stalklike portion of the brain which connects the brain with the spinal cord; the reflexes of the brain stem include breathing, coughing, gagging and responses of the pupils of the eyes). An important test is that when the ventilator is disconnected for several minutes, there is no evidence of spontaneous breathing (during this test a continuous supply of oxygen is delivered to the person's lungs). Disconnecting the ventilator causes levels of carbon dioxide (CO<sub>2</sub>) and acid to rise and, if the brain were capable of functioning, this would make spontaneous breathing occur. In the case of trauma, brain stem death leads to a fall in blood pressure and circulatory arrest.

If there is any possibility that drugs or metabolic disorders may have caused the brain not to function, or if the necessary tests cannot be performed, then death cannot be determined. Sometimes death is confirmed by showing that there is a complete lack of blood flow to the brain. This often occurs with 'brain death' since the brain swells inside the skull, and eventually the pressure becomes too high for blood to flow. This can be shown by radioisotope studies (tests which use radiation emitted by radioactive substances put into the body) or by angiography.

The official time of death if the 'brain death' criterion is used is the time at which the final tests are done.

If they are given careful explanations, most families eventually accept the reality of death using the 'brain death' criterion. Part of the reassurance is the certainty that blood circulation, and all other bodily functions, would rapidly stop after the ventilator is switched off, and that this is bound to happen even if full medical treatment is continued.

If you find yourself in the situation where a relative has been determined in this way to be dead, and you feel confused or uncertain about the determination of death, you may find it helpful to discuss your uncertainty. You may wish to talk to the doctor in charge, or you may find a nurse or some other person easier to talk to. You may wish for more time to absorb the fact that death has occurred, or you may wish to consult a religious leader, your own local doctor or other person important to you. In some countries such as France an angiogram of the brain is taken which shows that all blood flow to the brain has stopped, and this is shown to relatives. Some people find such clear and enduring 'evidence' of death very helpful.

When someone dies, it frequently happens that their family and friends are present at the bedside when the last breath is drawn and the heart stops beating forever. However, if organ donation is to occur, the ventilator will not be turned off until

the body is in the operating theatre, so the family and friends will not be present at that time. Some people are prepared to forgo this opportunity so that they can help someone else; to others, it will seem too much to be asked to do in these circumstances. After the operation, the family and friends should be able to spend some time in the presence of the body of their relative.

Remember that there are Australia-wide guidelines which set a high standard of conduct for all clinical staff involved in organ donation.<sup>6</sup>

#### (c) What happens to the organs and tissues?

Sometimes organs and tissues cannot be used for medical reasons. But if they are suitable, the organs and/or tissues donated will go to the recipient(s) to whom they have been allocated.<sup>7</sup> If the organs cannot be used for donation, they may be used for research provided that consent has been given for this purpose. All such research has to be approved by an Institutional Ethics Committee (IEC).

After donation, it is possible for the donor's family to get some general information about how the recipients are doing. The medical profession is required to protect the anonymity of the donor and the recipients, but as much detail as possible will be given, as long as this could not lead to individuals being identified.

Generally speaking, organs are transplanted into Australian recipients. However there are several exceptions to this rule:

- Since New Zealand does not have a liver transplant program, Australians and New Zealanders requiring liver transplants are placed on the one waiting-list and livers (from Australian and New Zealand donors) are allocated on a 'bestmatch' basis regardless of whether the recipient is an Australian or a New Zealander.
- In the event that there is no suitable Australian or New Zealand patient awaiting liver transplant, the organ may be offered to overseas patients, very often children, who have come to an Australian hospital to wait for organs. (Donated organs and tissues are provided free of charge. However, in these cases patients are charged full cost recovery for the procedure by the transplanting hospital. Though this practice in no way involves the sale of organs, it does mean that the patients from overseas who receive organs from the Australian community must be able to meet the costs associated with transplantation. These costs are sometimes met by the patient's government or by humanitarian agencies.)

<sup>7</sup> If you are interested in issues related to the allocation of donated organs and tissues, you may wish to read the AHEC discussion paper entitled *Ethical issues raised by allocation of transplant resources*, available from AGPS on phone: 132 447 (tee).call

<sup>&</sup>lt;sup>6</sup> NHMRC Recommendations for the donation of cadaveric organs and tissues for transplantation (1996).

- Australians and New Zealanders requiring heart-lung transplants are also
  placed on a waiting-list and these organs are allocated on a 'best-match' basis
  regardless of whether the recipient is an Australian or a New Zealander.
- If there are no potential recipients, either Australian or from overseas, then
  organs are not removed.

#### (d) How will the family feel afterwards?

Something you may like to take into account is how you think your particular family members may feel at this time.

After the death of a family member it is natural to feel grief. For some people organ donation is a positive aspect of death and helps them in coming to terms with the death of their loved relative. For others, organ donation is too difficult at the time. If the decision to donate organs has been made by the deceased and he or she has discussed this previously, then this can make a difficult situation much easier.

Some people do feel that organ donation was the only good thing that came out of a tragic situation, and they feel glad that their relative's organs have helped others. Others feel strange to think that their relative's body is no longer 'whole' and that parts of their relative are still functioning inside others. Some people feel disturbed when thinking about the recipients of their loved one's organs; others find some comfort in this. Some people who decide against donation, or who were not asked or did not consider it, later wish organs had been donated. Others continue to feel certain that not donating organs was the right thing for them to do.

The medical profession recognises the extreme sensitivity of the donation process and the trauma and grief that beset donor families at the time of brain death. For this reason, training programs are available to staff members. Assistance to families in the weeks and months afterwards by grief counsellors is also available.

# 4. Reasons why some people decide, and others decide not, to donate organs after death

The main reason why people may consider donating organs is because of the very great benefit that this can bring to others. For example, you may think of it in terms of a legacy that you leave behind you for the good of needy strangers.

Organ transplantation may be a lifesaving treatment for patients with liver or heart disease, and it may be the only hope of treatment there is. For kidney patients, having a transplant can mean being able to cease dialysis (the process in which a machine performs the kidney's role of cleansing the blood), and this can bring a great improvement in health and lifestyle. For instance, it may enable a kidney patient to return to the workforce, or to work longer hours, and it can even mean that a woman can now have a baby. The transplantation of a cornea can give someone back his or her sight.

There is a shortage of organs for transplantation in Australia. As at July 1996, there were about 1450 people on waiting lists for kidneys; 93 waiting for a heart; 62 waiting for a heart-lung or lung only transplant and 46 waiting for a liver, plus others waiting for other organs or tissues (such as corneas) to become available. On average, a patient can expect to wait 1 - 3 years for a donated kidney for transplant and 3 - 12 months for a donated heart. Many patients die whilst waiting for organs.

There can be a shortage of particular organs for people from certain ethnic backgrounds, since tissue matching can be difficult. Tissue matching is the process by which likely compatibility between an organ and its potential recipient can be predicted on the basis of typing tissues from each individual. This match is a matter of a person's genetic make-up, so the chances are that a donor is more likely to match a recipient if they are from a similar racial or ethnic background. Tissue matching is particularly important in kidney transplantation.

Transplantation is generally a very successful procedure. The success rates of transplantations vary, but in all cases these have increased considerably since transplantation first began. It can be difficult in medical science to predict which procedures will become more successful and eventually routine. However, kidney transplantation is now considered to be accepted medical treatment and this is

likely to happen in other areas of transplantation. Many people feel that such advances in medicine are a great benefit and a source of much hope.

In summary, the main reason why people donate organs are because they think that after their death they would like to do something to help others who have great medical needs. Some also feel that members of their particular family may find it a comfort to know some good has come out of a sad situation.

On the other hand, some people find the whole idea of organ donation too invasive. Some think that it is wrong to take organs from a dead body. Some are troubled by the determination of death by the 'brain function' criterion. Some people simply do not wish to consider donation at a time when they are grieving the death of a loved relative. And some people decide not to donate organs because they are not confident that donation would be in accordance with their dead relative's wishes

Some people think that transplantation is a very costly procedure from which relatively few people benefit. In fact, the costs involved vary a great deal depending on the type of transplantation. Some transplants such as heart and liver are specialised and relatively costly. However, giving a patient a kidney transplant is less costly than maintaining a patient on hospital-based kidney dialysis (in addition to having the non-financial benefits such as improvements to health and lifestyle, discussed above).

If you believe that your family may gain some comfort from donation, this may be a reason to consider it for yourself. On the other hand, if you feel that your family may be upset about donation, you may decide against it. This shows the importance of discussing donation with your family. You need also to bear in mind that the people who donate organs are mostly those who have died suddenly and unexpectedly and they are often quite young. For the families of these patients, death may be especially traumatic.

When deciding about donation for yourself before death, you may begin by thinking of how you would feel if you were in the position of needing a lifesaving organ or tissue transplantation. In making your decision, you also may feel, for instance, that you no longer need your body, and would like to feel that you had done something to help others. Or you may feel that it is important that your body remains intact for burial or cremation.

If you belong to a religious faith, you may want to consider how organ donation and transplantation is understood from that religious point of view. Indeed you may wish to consult a religious advisor on the appropriateness of organ donation in your particular circumstances.

Much depends upon how you view the dead body and on your view of what a person is. For example, for some the dead body may simply be something that is

no longer needed by them, that may be valuable for others. For others, the body is too closely bound up with the person who has just died for it to be used in such a way. Some may feel differently about different parts of the body, for example, finding it more difficult to donate the eyes or the heart which seem, to them, to be more closely associated with the person than are other organs.



## 5. Making a decision when a relative has died

So far, this discussion has focussed on making a decision for oneself. Its purpose has been to help you to make an ethically-sound decision about whether to make your own organs available for transplantation after your death. We must now consider the ethical issues involved in making a decision when a relative has died. For though there are many ethical issues common to both, deciding on behalf of another raises some special issues.

Deciding about organ donation on behalf of a loved relative who has just died may be a very difficult decision to make. Often the relative's death will have been the result of a traumatic event such as a car accident or a head injury. This may make the death an especially sad one for family and friends. In other situations, tissues such as corneas and heart valves may be donated by people who have died in hospital wards.

Being faced with making a decision about organ donation after the death of a relative means that people are asked to make a serious decision at a difficult, stressful and emotional time. You may feel shocked, bewildered, angry, numb. But, for practical reasons, if organ donation is to occur, it must take place within a certain time period: so there will be only a limited time in which to make this decision. The difficult circumstances in which the decision has to be made make it all the more important that you are well-informed and that you feel confident that you have considered the matter as fully as you wish. Families are greatly assisted in their decision-making at a time of crisis if they have previously discussed organ and tissue donation and the wishes of individuals are known.

There are three scenarios that need to be considered:

(1) Your relative dies having made known his or her wish to donate organs after death: in this case, though Australian law says that a hospital has the authority to remove organs for transplantation, in practice in Australia the family is consulted in order to clarify what the person's wishes were in relation to organ donation and to see whether the family has any objections to the deceased's wishes being acted on. Though the law permits donation in circumstances in which the deceased has expressed his or her wish to donate, donation will not proceed in the face of objection from families.

If you know that your relative wished to donate his or her organs and/or tissues, this may provide you with a substantial reason for you to consent to the request for donation. However, quite often families have not discussed

- donation, because the subject has never come up or because thinking about death was just too difficult.
- (2) Your relative dies having made known to you his or her wish not to donate organs: in this case, when you have made this known to hospital staff, organ donation will not be discussed further.
- (3) Your relative dies and either had no views about organ donation (as in the case of a young child) or had not made his or her views known to you: in this case the hospital authorities will consult the family to find out whether anything is known about the deceased person's wishes and/or to find out whether the family will consent to donation on behalf of their deceased relative.

One thing that you may like to do in this situation is to make a judgement based on your knowledge of that person. What was his or her attitude to transplantation: had he or she ever shown any sign of being in favour or against it? Perhaps you recall something said in response to a television program, or a comment made about someone who needed a transplant, or a remark made about an actual case of donation. What were his or her beliefs and feelings about the body and about how it should be treated after death? Was he or she the kind of person who would want to help others? Would he or she have been likely to have discussed organ donation with someone outside the family? In that case, you may wish to contact someone else and try to find out your relative's attitude to donation that way.

In some cases, and especially in the case of young children, you may realize that you have no way of knowing what your deceased relative would have wanted. Or you may realize that he or she had no view on the matter at all. In these cases you will have to make a decision based on your own sense of what is the best thing to do in the circumstances

Whatever you and your family decide, it is important that you feel content with your decision and feel that you made it with enough information. This is something to watch out for especially in a medical setting, where people sometimes feel in awe of doctors and think of them as powerful and important people. As well, many people feel that they owe a debt of gratitude to the medical staff who have been treating their relative. However, in Australia, it is professional practice not to pressure people in any way.

The decision that you have to make is not a purely rational or 'head' decision but also an emotional or 'heart' decision. You may need time to come to terms a little more with the emotional significance of events, maybe to accept that your relative really is dead. You may wish for time to imagine how you may feel afterwards, whatever decision you make; and how others in your family may feel. You may feel you need time alone, or time with just your family. You may need a private space in the hospital or you may need to go outside the hospital for a while in order to be able to think. For instance, you may wish to go and have a coffee somewhere,

or to consult relatives, friends, a religious or community leader, or to find a quiet place to pray or to meditate. If there are any questions that you have, you should feel free to ask them, or to have things explained to you, until you are satisfied that you understand.

What if you and your family cannot decide among yourselves? People have different ideas about how decisions in the family should be reached, and your family's cultural background may be an important factor here. It may be that someone is seen as the head of the family or as the prime decision-maker. Or, it may be that it is better that you try to make a joint decision. Or maybe in your family you turn to certain other people for advice in difficult situations: a grandparent, a beloved uncle, a priest or minister, an old school-teacher, the family doctor. You may also find a great deal of support and helpful advice from the nurses who have cared for the relative who has just died.

Sometimes people count as 'family' even when they are not blood relatives or legal or de facto spouses or adopted relatives. This may mean more time is needed to consult with another valued or trusted person, or the chance to phone someone living interstate or abroad. Sometimes, however, it is just not possible to get hold of other people in time. And sometimes it will not be possible for all members of a family to agree.

However the more that organ donation is understood and freely discussed among the family and all concerned, the greater the chances are that a decision can be made with which all those affected will be content. It is hoped that reading this paper (and reflecting on the issues it raises) may help you and your family to reach such a decision.



## 6. A summary of the questions you may like to ask yourself

In summary, this document has tried to guide you through some of the issues that you may need to consider when you are deciding whether or not organ donation is right for you, and whether or not you should donate your deceased relative's organs. Here are some key questions that you might like to consider in reflecting on these matters:

Do I think that donating organs and/or tissues for transplantation (or other purposes) is a worthwhile cause?

How would I feel if I needed a transplanted organ?

How does organ donation fit with my religious, spiritual and moral beliefs?

How would I feel if a friend or relative needed an organ?

What do my other family members think about organ donation?

Have I made my wishes about organ donation known to my family?

If I decide I want to donate organs, how will this affect my family?

Am I satisfied that I understand the concept of 'brain death' as a way of determining death?

Do I feel that I could trust the medical staff involved if I were ever in a situation to be a potential organ donor?

How do I think of my body after death?

Are there some organs I would like to donate, and not others?

Will my family try to carry out my wishes?

Will counselling be available for my family if they need it?

Am I satisfied that respect will be shown to my body?

Are there other people I would like to consult?



#### Appendix 1

#### **Transplantation Ethics Working Party**

#### Terms of Reference

The aim of the Australian Health Ethics Committee's (AHEC's) work in this area is to address in a broad fashion social issues not dealt with in the guidelines for donation of cadaveric organs and tissues currently being developed by the National Health Advisory Committee of the National Health and Medical Research Council (NHMRC)<sup>1</sup>.

The aim of the overall project is to produce information that:

- a) is both practical and informative;
- b) provides guidance to clinicians, policy makers and support services on ethical aspects of organ donation and transplantation; and
- c) provides a basis for informed community debate.

#### Membership

Dr Bernadette Tobin (Chairman) John Plunkett Centre for Ethics St Vincent's Hospital (NSW)

Dr Joan Asher General Practitioner (ACT)

Dr Paula Boddington
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Mr Sam Choucair (Convenor)
Federation of Ethnic Communities' Councils of Australia — Health Network (NSW)

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<sup>&</sup>lt;sup>1</sup>The NHMRC report *Recommendations for the donation of cadaveric organs and tissues* was finalised in June 1996 and is currently available for purchase through AGPS on phone: 132 447 (freecall).

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### The National Health and Medical Research Council

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The Council comprises nominees of Commonwealth, State and Territory health authorities, professional and scientific colleges and associations, unions, universities, business, consumer groups, welfare organisations, conservation groups and the Aboriginal and Torres Strait Islander Commission.

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