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National Health and Medical Research Council

MAKING A DECISION ABOUT ORGAN AND TISSUE DONATION AFTER DEATH



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Endorsed 15th March 2007

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This booklet is derived from *Organ and Tissue Donation after Death, for Transplantation: Guidelines for Ethical Practice for Health Professionals*, which was developed by the National Health and Medical Research Council in 2006.

The booklet aims to help people think through some ethical issues and make informed decisions about organ and tissue donation after death.

The booklet may also assist families thinking about organ and tissue donation following the death of a family member.

If this is the case, health professionals caring for the patient can provide more detailed information specific to the particular situation.

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I ORGAN AND TISSUE DONATION — BACKGROUND

People have different feelings about donating organs and tissues after death for transplantation. Your wishes are more likely to be carried out if you have discussed them with your family and registered your consent or objection on the Australian Organ Donor Register.

Many people live longer or enjoy better quality of life as a result of an organ or tissue transplant. Organs that can be transplanted include the kidney, liver, heart, lung and pancreas. Transplanted tissues include skin, bone marrow, heart valves and corneas of the eyes. Transplant operations have been taking place in Australia for many years and have good success rates.

As medical advances continue, the demand for transplants keeps growing. There are not as many organs and tissues available for transplantation as there are people who need them. Many people die while waiting for a suitably matched organ to become available.

Some organs and tissues (eg bone marrow and kidneys) can be given by living donors — a separate booklet on living donation has been developed by the NHMRC. However, in Australia, most transplanted organs and tissues come from people who have died.

WHO CAN DONATE AND WHAT CAN THEY DONATE?

Anyone over the age of 16 can choose to donate organs and tissues, after death, for transplantation. Age and medical history are always considered but you shouldn't assume that you are too old or not healthy enough to donate.

If you decide to register as a donor, you can choose which organs and tissues you will donate. However you may not be able to donate all the organs and tissues that you specify. This depends on how you die and whether you die in hospital.

- Few people die in a way that allows them to donate **organs** — in fact, only about 1% of people who die in hospital each year may become organ donors. This is because organs for transplantation need to be removed soon after death. This can usually only happen when a person has died in hospital following a severe brain injury (eg from a stroke or car accident) or when a person is unable to survive severe injuries or other illnesses.

WHO NEEDS ORGAN TRANSPLANTS?

Most people who need an organ transplant have a serious illness or an organ that is no longer working properly.

The transplant may stop the person dying (eg a heart transplant for heart failure) or improve quality of life (eg a person with a kidney transplant no longer needing dialysis).

WHO NEEDS TISSUE TRANSPLANTS?

Patients requiring heart valves may have been born with a heart problem or have a disease that affects the valves, such as rheumatic fever. People who suffer from corneal blindness can be helped by corneal transplants. Burns and accident victims need skin grafts. The donation of bone can greatly assist people who have suffered serious accidents or have bone cancer.

AUSTRALIAN ORGAN DONOR REGISTER:

Call — 1800 777 203

TTY — 1800 552 152
(Hearing or speech
impaired)

TIS — 131 450 (Translating
and interpreting service)

Web — [www.medicare
australia.gov.au](http://www.medicare
australia.gov.au)

Email — [aodr@medicare
australia.gov.au](mailto:aodr@medicare
australia.gov.au)

Mail — AODR, Reply Paid
711 Hobart Tas 7001

Or visit your local
Medicare office

ORGAN AND TISSUE DONATION — IT IS UP TO YOU.

Whatever decision you
make, it should be well-
informed, freely chosen and
fit in with your beliefs.

We hope that this booklet
helps you with your
decision.

- More people die in a way that means that **tissues** can be donated. This is because most tissues don't have to be taken from the body straight after death. These tissues can be donated whether or not the person dies in hospital. If they are medically suitable, they can be stored in tissue and eye banks for future use.

HOW DO I REGISTER AS A DONOR?

Until recently, States and Territories had different ways of recording people's intentions about organ and tissue donation (eg driver's licenses, donor cards).

The Australian Organ Donor Register is the national register of organ and tissue donors. When people over the age of 18 years sign onto the register, their consent or objection to donation is recorded on a database. People aged 16 or 17 years can register an intention or objection to donate and consent is then discussed with the family at the time of death.

Authorised health care professionals can check the Register 24 hours a day, seven days a week, from anywhere in Australia. This system aims to make sure that, wherever possible, people's wishes about donation are carried out.

TALK TO YOUR FAMILY

People's opinions about organ and tissue donation and transplantation are influenced by their cultural, ethical, spiritual and religious views. This makes it especially important for all Australians to make their own decision about donation.

Discussion with your family and friends is a central part of this. If you die in circumstances where organ and tissue donation are possible, your family will be contacted and asked how you felt about donation. Although it is the senior next of kin who actually agrees to organs and tissues being removed, other family members or close friends may be involved in discussions about your wishes.

All Australians are encouraged to:

- think about organ and tissue donation;
- talk about it with family and friends;
- make a decision; and
- record that decision on the Australian Organ Donor Register.

2 WOULD MY DONATION BE MANAGED WITH CARE?

It can be hard to decide about organ and tissue donation if you don't know what would happen and how your family would be cared for during the process. This chapter explains the systems in place to make sure that all those involved in organ and tissue donation are cared for and supported.

ETHICAL PRINCIPLES

Organ and tissue donation in Australia is based on the following ethical principles.

- Organs and tissues are only removed once the person is dead.
- Donation is intended to benefit others. No reward or even acknowledgement by those who benefit is expected.
- A person's wishes about donation are respected.
- Families are given time to consider and discuss their views. If a close family member objects, donation will not go ahead.
- Families are supported and cared for throughout the donation process. Counselling may be provided at the time of donation or later if the family wishes.
- The person donating is always treated with respect and dignity.
- Organs and tissues are allocated fairly, following specific processes for each type of organ or tissue as well as criteria for matching the donation to the recipient.

Health professionals work within a code of ethics and follow professional guidelines. This means that there are standards directing what they do and how they do it.

Health professionals assisting patients who may be suitable donors and their families have relevant experience and training. Whatever the situation — whether in a small country hospital or a large city hospital — the family will be supplied with all the information that they need. They will also have access to counselling and other types of support.

WHAT ARE ETHICS?

Ethics are about your personal beliefs, and about the way we think and behave as a community.

Ethics are about the rules of behaviour and human duty, morals and values — that is, understanding right and wrong, justice and injustice, good and bad, and doing the right thing.

Every State and Territory has a law about certifying death.

It is only after death has been certified that organs and tissues can be removed.

Would my donation be handled with care?

At each hospital there is also a ‘designated officer’ — someone who makes sure that organ and tissue donation is managed properly. The designated officer makes sure that:

- accepted medical criteria have been used to confirm death;
- the Australian Organ Donor Register has been consulted to find out whether a person has agreed or objected to donation;
- the necessary consent has been given by the person’s next of kin;
- the process is carried out following standards for hospital practice and the law; and
- the family has been cared for and supported.

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“When Nathan told me he had registered as an organ donor, I didn’t think I would be involved if it ever happened. Then he had the accident. The hospital called me in and the doctor explained that Nathan was not going to survive. He was really thoughtful and gave us time to understand the situation. There was no pressure about organ donation — it was what Nathan wanted so I agreed.”

3 WHEN IS DONATION POSSIBLE?

Organ donation is only possible when the person who wishes to donate dies in hospital and under certain circumstances.

Tissue donation may be possible in different situations.

DOES THE WAY A PERSON DIES AFFECT DONATION?

Organ donation

There are two sets of circumstances that may lead to a person being suitable for organ donation after death:

- when the person's brain is so severely damaged that all brain function is irreversibly lost (also called *brain death*) but breathing is still being maintained by a ventilator, or
- when it is clear that a person in hospital will soon die because of his or her injuries or illness.

Tissue donation

Most tissues do not require a constant blood supply to be suitable for transplantation and can be stored for some time before being transplanted. While more people die in a manner suitable for tissue donation, not all tissue is suitable for transplantation so supply of tissues is also limited.

DONATION AFTER LOSS OF ALL BRAIN FUNCTION

Head injuries, stroke, infections or a long period of time without oxygen (eg from drowning) may damage the brain so severely that it stops functioning. The person will need the support of a ventilator and other medical treatments while assessments take place.

Over a period of time, the doctors caring for the patient carefully observe the development of the injury or disease. If the doctors then believe that all brain function has been completely and permanently lost, a series of clinical tests is carried out. The tests check for any sign of reflex activity (such as breathing, coughing or gagging). The tests are carried out twice, each time by an experienced doctor.

"After the stroke they had Kevin hooked up to all sorts of machines. Somehow he still looked the same though, and I was sure he would pull through. I didn't really believe them when they said his brain had stopped working.

The doctor asked me if I would like to be there when they did more tests. It was hard to watch because he didn't respond to anything, he didn't even blink. It helped me to be sure that it really was the machines and not his brain that kept him breathing."

Health professionals caring for the family will be able to answer questions about the way death is confirmed and about the process of organ and tissue donation.

A person whose brain has completely stopped functioning has died.

When the ventilator is switched off, circulation will stop soon after and then other bodily functions will begin to fail.

“It was a complete shock when they asked me whether Jack would have wanted to donate his organs and tissues. They said he hadn’t put his name on the register. He hadn’t even talked to me about it.

I had to tell them ‘no’. I just couldn’t be sure of what he would have wanted.”

For a person to be declared dead after loss of all brain function, both doctors who performed the tests must be in agreement that there was **no** response to **every** one of the tests and that the loss of function extends to the brain stem, which is involved in vital reflexes (eg breathing). If patients cannot have all of these clinical tests because of their injuries, special x-rays are done to check whether there is any blood flow to the brain.

Donation may only be considered after the person has been declared dead. Some people do not accept that a person dies when they lose all brain function.

DONATION AFTER LOSS OF CIRCULATION

Sometimes the severity of a person’s injuries means that he or she is unable to survive. When it is clear that a patient with permanent injuries will not recover or survive, the doctors may talk to the family about discontinuing treatment.

If the family is in agreement and treatment is discontinued, as the person dies, the heart stops beating and the blood stops circulating.

In these circumstances, it may be possible to donate some organs if they are removed soon after the heart stops beating. If the family agrees, the patient may be moved to an operating theatre before death and measures taken to prepare for donation after death. If the patient lives for longer than expected, organ donation will not take place and the patient will be cared for until their death.

It is possible to donate most tissues in both of these circumstances.

4 WHAT IS THE PROCESS OF DONATION?

Special care is taken to make sure that the process of organ and tissue donation meets strict safety, ethical and legal requirements.

When a patient dies in a way that makes them suitable to donate organs or tissues, the Australian Organ Donor Register is checked to see whether the person had registered consent or objection. To protect confidentiality, this can only be carried out by authorised staff members.

Whether the person has registered or not, families are involved in the process. Family members will be asked:

- whether there are circumstances that the person would have wanted taken into account; and
- whether the person may have had a change of mind since registering.

If there is no written or verbal objection to donation or the person had not registered, the family will be given information about the process and asked whether they agree to donation.

Donation will not go ahead without the family's agreement.

- If the family agrees, the next of kin will be asked to give consent, which will be recorded. As part of the consent process, he or she will also be asked which organs and tissues may be removed for transplantation.
- If the possibility of donation causes the family significant distress, no further discussion will take place.

Throughout this process, the family will be supported by experienced staff members who are trained to answer any questions the family may have.

Families play an important role in decision-making.

No-one is pressured into agreeing to donation for a relative who has just died

“When Jessie died, we followed her wishes and agreed that her kidneys and liver be removed. It was a hard call when her body had been through so much already but the people at the hospital were really kind. The donor coordinator stayed in touch with us through the whole process and made sure that we understood what was going on. We are still in touch with him and he recently sent on a letter from the recipient of one of Jessie’s kidneys.

I know we did the right thing and it makes me proud to know that we did what Jessie wanted us to do.”

The donor or donor's family are not charged for donation or any care given after death has been certified

The processes of donation and transplantation are completely separate.

Apart from ensuring that the organs arrive safely at their destination, no-one caring for the donor or family has any involvement in the transplantation that follows.

IF DONATION GOES AHEAD

If it is agreed that donation may take place, a number of things happen — some medical and some related to paperwork.

The designated officer in a hospital (or the medical supervisor in a tissue bank) makes sure that the whole process meets both legal and ethical requirements. Care is also taken to make sure that the family is looked after.

There are some things that happen for the benefit of transplant recipients.

- The family is asked questions about the donor's health and lifestyle. This is to reduce the risk of transmitting infection to the transplant recipient.
- Blood tests are performed.
- The donor continues to receive all the care necessary to preserve organ function.
- With family consent, an autopsy may be carried out to make sure the donor had no conditions (such as cancer) that could affect the health of the recipient.

The family may choose to remain at the hospital for the entire donation process or after they have given consent they may wish to go home. The process involved in organ donation can take quite a few hours to coordinate. The family is likely to be able to spend time at the bedside with the person who has died.

How are the organs and tissues removed?

The operation to remove organs and tissues is performed by experienced professionals, with the care and precision of any other operation. The person's body is treated with the same respect and dignity given to a living person, the wound is closed and the body is made to look as normal as possible.

After the operation

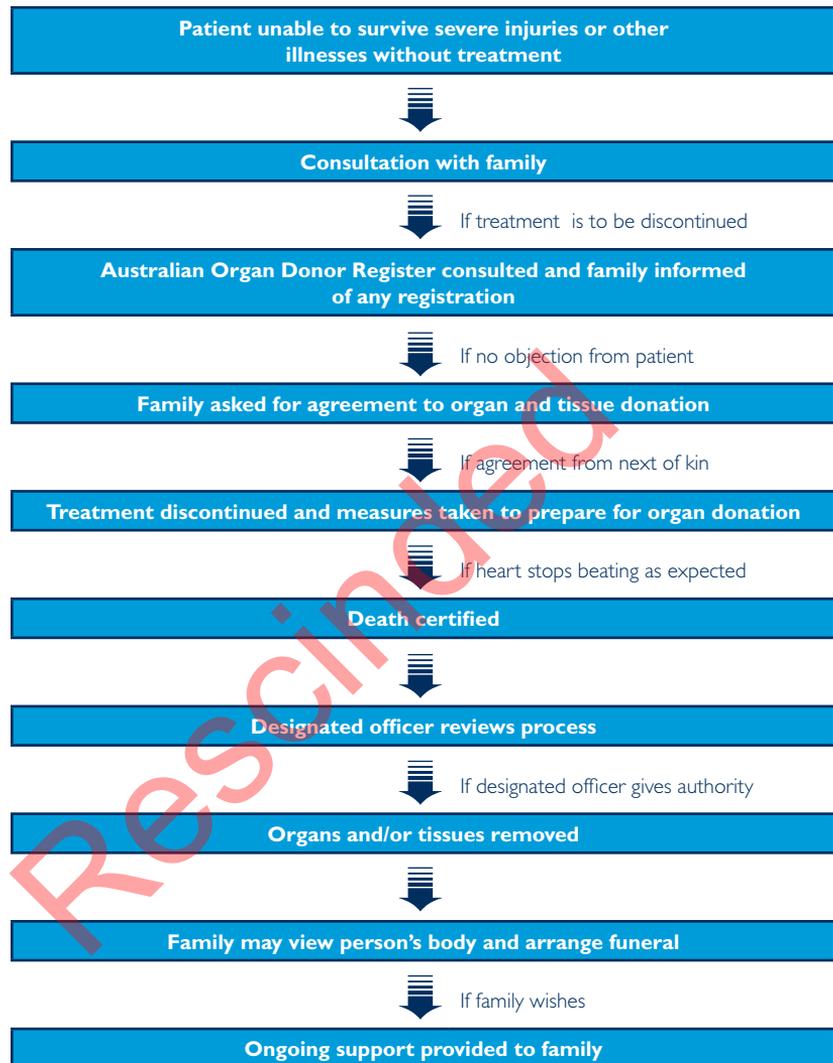
Some families may wish to see their family member after the operation. Viewing of the person's body or an open coffin at the funeral is also possible.

Organ donation following loss of all brain function*



* This framework is meant as a guide only. The actual sequence of events will depend on individual circumstances.

Organ donation following loss of circulation*



* This framework is meant as a guide only. The actual sequence of events will depend on individual circumstances.

WHO IS INVOLVED?

Donors and their families are cared for by a range of health professionals before, during and after the donation.

- A specialist medical team, including intensive care specialists and nurses, does everything possible to save the life of the critically ill person. If this is not possible and the person dies, the team will continue to support the family.
- An experienced and trained health professional will approach the family about organ and tissue donation and help them to understand the process of consent and donation.
- The donor coordinator has an important role in coordinating the donation process and works with the family, completing the consent process and providing continuing support.
- In some hospitals a nurse may be the contact between the hospital and a donor coordinator located somewhere else (this position is sometimes called a link or area nurse).
- Others in the hospital may be involved who will take into account the cultural and religious sensitivities of the donor and the family.

WHAT HAPPENS WITH TISSUE DONATION?

The same ethical and legal standards apply to tissue donation. The relatives of the deceased person will be approached (usually by telephone) by a donor coordinator or a coordinator from one of the tissue banks to record consent to remove specific tissues. If the family wishes, counsellors may also be involved.

WHAT HAPPENS TO THE ORGANS AND TISSUES?

If donated organs and tissues are medically suitable, they are allocated to recipients. Several people may receive organs and tissues from a single donor, depending on what the person wished to donate, their medical condition and the number of suitable recipients at the time.

Organs and tissues are allocated fairly, to benefit those most in need and to make best use of donated organs and tissues.

Allocation is not made on the basis of race, religion, gender, marital status, sexual orientation, social status, disability or age (except where age may affect the outcome).

What happens to organs and tissues that can't be used?

Every attempt is made to ensure that organs and tissues are suitable for transplantation before they are removed from the person's body. However if the organs and tissues are donated but then can't be used because there is no recipient with the matching blood and tissue type, there are specific rules for what may happen to them.

The organs may only be used for research if specific consent has been given (this is separate from consent to donation). Any research has to be approved by an ethics committee.

If they are not being kept for research, the organs are disposed of lawfully (this may mean that they can be buried or cremated with the person's body).

WHAT HAPPENS AFTERWARDS?

What happens after the donation process depends very much on what the family wants.

Records of who donates organs and tissues and who receives transplants are confidential. Hospital staff cannot provide information about the people involved. There is no obligation for the donor family to have any further contact with staff.

However, if the donor family requests it, the donor coordinator will send them information about which organs and tissues were transplanted and how the recipients are progressing. If families wish, donor coordinators will keep in touch — sometimes this happens for many years.

Letters may also be exchanged between donors and recipients, through the donation agency. Letters are only passed on if the person has agreed to receive them. No information that might identify the people involved may be included. There is no obligation for either party to write.

There are no costs to the family resulting from organ or tissue donation.

Grief counselling is usually available through the hospital. The organ and tissue donation agency in each State and Territory can also provide assistance after the donation has taken place.

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5 VIEWS THAT MAY INFLUENCE CONSENT OR OBJECTION TO DONATION

FURTHER INFORMATION

- Medicare Australia can provide information about registering as an organ and tissue donor and information about organ and tissue donation in general (see page 6).
- Australians Donate is the peak national body for organ and tissue donation for transplantation. The website includes information for potential donors and links to other relevant organisations including State/Territory organ donation organisations, tissue banks and eye banks (www.organdonation.org.au).

Why people may choose to register consent to donation

- After my death, I'd like to do something to help others in medical need.
- Once I'm dead, I don't need my organs and tissues any more so someone else might as well have them.
- It may comfort my family to know that some good has come from my death.
- Waiting lists are long and there is a real need for more organ donors.
- Transplantation is generally successful and can improve the quality or length of life.
- I feel okay about organ and tissue donation because it is allowed by my religious faith.
- Being offered the opportunity to consider organ and tissue donation after my death may give some comfort to my family.

Why people may choose to register an objection to donation

- Organ and tissue donation is too invasive.
- I feel that it is wrong to take organs and tissues from a dead body.
- I don't accept that brain death is equivalent to death.
- It will upset my family too much to think about it when I've just died.
- I'm not sure how my religious faith views donation.
- Organ and tissue donation is not consistent with my beliefs about the body after death.

6 BEFORE YOU DECIDE

This booklet has tried to guide you through some of the issues to consider when making a decision about organ and tissue donation. Here are some questions you might like to consider.

Do I think that donating organs and tissues for transplantation is worthwhile?

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

What do my family and friends think about organ and tissue donation?

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

How do I feel about my body once I am dead?

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

Do I feel that once I'm dead, I don't need my body anymore and it should be used to help others?

Do I feel that even when I'm dead my body is still me and should remain intact for cremation or burial?

Do my family and friends know what I want to happen with my body after I die?

OTHER NHMRC PUBLICATIONS

- Organ and Tissue Donation After Death: Guidelines for Ethical Practice for Health Professionals
- Making a Decision about Living Organ and Tissue Donation
- Organ and Tissue Donation by Living Donors: Guidelines for Ethical Practice for Health Professionals

These publications are available from the NHMRC at nhmrc.gov.au



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