Understanding death and donation
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If you are reading this booklet it may be because someone you love has died, or it is expected that they will die soon. You may have been asked to consider organ and tissue donation. This is an important and rare opportunity that can help others in need of a transplant.

Some families have discussed organ and tissue donation and may already know their loved one’s wishes. Other families who have not discussed donation will also need to make a decision about whether their loved one will become a donor. This booklet provides information to support you and your family to make a decision about donation that is right for you and your loved one.

There are many people who can support you and your family through this process. In addition to the medical and nursing teams, you may have already met other support staff in the hospital such as social workers, pastoral carers or organ and tissue donation specialists. These people are here to support you and can provide you with further information.

It is important to know that donation will only proceed if consent is given by a patient, a patient’s family, or in some states by a Designated Officer of the hospital if the family cannot be reached.
Organ and tissue donation involves removing organs and tissues from someone who has died (a donor) and transplanting them into someone who, in many cases, is very ill or dying (a recipient). Organs that can be transplanted include the heart, lungs, liver, kidneys, intestine and pancreas. Tissues that can be transplanted include heart valves and other heart tissue, bone, tendons, ligaments, skin and parts of the eye such as the cornea and or sclera.

This booklet will provide you with some information about organ and tissue donation, and the physical aspects of understanding what it means to die.

Death must be determined before donation can take place.

Death can be determined in two ways:

- Brain death occurs when a person’s brain permanently stops functioning.
- Cardiac death occurs when a person’s heart permanently stops functioning.

It is important to understand the difference between brain death and cardiac death. The way a person dies influences how the donation process can occur and which organs and tissues can be donated.
Brain death

Brain death occurs when the brain has been so badly damaged that it completely and permanently stops functioning. This can occur as the result of severe head injury, bleeding in the brain such as a stroke or haemorrhage, brain infection or tumour, or lack of oxygen to the brain.

Just like any other part of the body, when the brain is injured, it swells. The brain is contained within a rigid box, the skull, which normally protects it from harm but also limits how much the brain can expand when it starts to swell. This is different to other parts of the body, such as an injured ankle, that can continue to swell without restriction. If the brain continues to swell, pressure builds up within the skull causing permanently damaging effects.

The swelling places pressure on the brainstem where the brain joins with the spinal cord at the back of the neck. The brainstem controls many functions that are necessary for life including breathing, heart rate, blood pressure and body temperature.
As the brain swelling increases, the pressure inside the skull increases to the point that the blood vessels going to the brain tissue are squashed. Eventually the blood, which contains the oxygen, stops going to the brain (see Diagram 1). Without blood and oxygen, brain cells die. Unlike many other cells in the body, brain cells cannot regrow or recover. If the brain cells die, that person’s brain will never ever function again, and the person has died, which is called “brain death”.

**Diagram 1**

- **Normal brain**
  - Skull
  - Subarachnoid space
  - Brain stem
  - Cerebellum
  - Blood flow to the brain
  - Spinal cord

- **Swollen brain**
  - Skull
  - Subarachnoid space
  - Brain stem
  - Cerebellum
  - Blood flow to the brain
  - Spinal cord
The brain and brainstem control many of the body's vital functions, including breathing. When a person has suffered a brain injury, they are connected to a machine called a ventilator, which artificially circulates oxygen into the lungs. The oxygen is then pumped around the rest of the body by the heart. The heartbeat does not rely on the brain, but is controlled by a natural pacemaker in the heart that functions when it is receiving oxygen.

While a ventilator is providing oxygen to the body, the person’s chest will continue to rise and fall giving them the appearance of breathing, their heart will continue to beat and they will feel warm to touch. These signs can make brain death difficult to understand. However, even with continued ventilation, the heart cannot continue to beat forever and will eventually stop functioning.

**How do doctors know that a person’s brain has died?**

People who are critically ill in the hospital are under constant observation by the specialist medical and nursing teams caring for them and are closely monitored for changes in their condition. There are a number of physical changes that take place when the brain dies. These include loss of pupillary reaction to light, inability to breathe without the ventilator, and reduced heart rate, blood pressure and body temperature.
When the medical team observes these changes they will perform clinical brain death testing to confirm whether the brain has stopped functioning or not.

Two senior doctors will independently conduct the same set of clinical tests at the bedside. The doctors performing the brain death testing will be looking to see if the person has any:

- response to a painful stimulus
- response to light by the pupil of the eye
- blinking response when the eye is touched
- eye movement response when ice cold water is put into the ear canal
- cough or gag reaction when the back of the throat is touched
- ability to breathe when the person is disconnected from the ventilator.

If a person shows no response to all of these tests, it means that their brain has stopped functioning and the person has died. Although they have died the heart will still be beating because oxygen is still getting to the heart with the help of the ventilator.
There are times when the patient’s injuries mean that they are not able to have all of these clinical brain death tests done. For example, severe facial injuries may restrict access to the eyes or ears. In these circumstances, medical imaging tests are done to check if there is any blood flow to the brain. These may include tests like a dye test of the blood vessels in the brain (a cerebral angiogram or cerebral perfusion scan). The hospital staff will provide further information if these tests are necessary.

**What happens after brain death has been confirmed?**

Once brain death has been confirmed, the patient will remain connected to the ventilator while members of the medical team speak with the person’s family about the next steps. These will include the person’s end-of-life wishes, the opportunity for organ and tissue donation and timing of removing the ventilator.

If the family supports donation, everything possible will be done to make sure those wishes are fulfilled. Timeframes can vary as every circumstance is different. It can take up to 24 hours for the necessary arrangements for donation to be made. The person will remain connected to the ventilator during this time to keep blood and oxygen circulating to the organs. In some cases medications are necessary to ensure organs remain suitable for donation. If it becomes clear that organs are no longer suitable for donation, it may still be possible for donation of eye, heart, bone and skin tissues.
When the arrangements for donation have been made, the person will be moved to the operating theatre for the organ and tissue retrieval surgery. The ventilator will be removed during the operation.

If donation is not supported, the doctor will speak with the family about removing the ventilator. When the ventilator is removed, the person’s heart will stop beating due to a lack of oxygen and their skin will become cold and pale because blood is no longer being circulated around the body.

Care and respect are always maintained during the end of life process, irrespective of whether or not donation proceeds.
Cardiac death

Cardiac death occurs when a person stops breathing and their heart stops beating. This can occur after a sudden illness or accident, or can be the final stage of a long illness. It can also occur when a person suffers a head injury that does not cause their brain to die, but is still so severe that the person cannot breathe properly to sustain a heartbeat on their own. During such a time, a ventilator can artificially breathe for them to keep the heart beating and circulate oxygen around the body.

In these circumstances, withdrawal of active treatment is only made when continuing treatment provides no prospect for recovery, death is inevitable and the patient is at the end of life. The priority is then palliative care with the relief of suffering and compassionate end of life care. The withdrawal of active treatment is always discussed and agreed with the family (and patient if possible). Only when this decision has been made, is there any discussion about donation after cardiac death.
What happens after the doctors believe the patient’s heart is going to stop beating?

When doctors have determined that the ongoing treatment with the ventilator is not going to make the person better, they will speak with the person’s family about the next steps. This will include discussion on the person’s end-of-life wishes and taking away the things that are not working such as the ventilator.

When the ventilator is removed, the person’s breathing will not be able to get oxygen to the heart. The heart will stop beating because it is no longer receiving oxygen and then all the other organs stop working, including the brain and the person will die.

If the doctors expect that the person will stop breathing and die within 90 minutes of taking away the ventilator, there may be the opportunity for organ and tissue donation.

Donation after cardiac death is only possible within this 90 minute period, because when the ventilator is removed, oxygen and blood stop being circulated around the body. Organs and tissues will then begin to deteriorate as they require blood and oxygen to remain suitable for donation.
If the family supports donation, everything possible will be done to make sure those wishes are fulfilled. It can be very difficult to predict the exact time it will take for a person to die following removal of the ventilator and other drugs that may be supporting them. Some patients die within 10 or 20 minutes and donation may be possible. Others may not die until some hours later. If this occurs, organ donation will no longer be possible but donation of eye, heart, bone and skin tissues may still be possible.

If donation is not supported by the family, the doctor will speak with the family about removing the ventilator. When the ventilator is removed the person’s heart will stop beating due to a lack of oxygen and their skin will become cold and pale because blood is no longer being circulated around the body.

Care and respect is always maintained during the end of life process irrespective of whether or not donation proceeds.
The donation process and further information
When donation is able to proceed, the person who has died will be moved to an operating theatre for surgery. Below is some information on the donation process.

**What does the donation operation involve?**

The donation operation is conducted with the same care as any other operation, and the person’s body is always treated with respect and dignity. This operation is performed by highly skilled surgeons and health professionals. Specialist doctors and their teams may be called in from other hospitals to perform the operation.

Similar to other operations, a surgical incision is made in order to retrieve the organs and this incision will then be closed and covered with a dressing. Depending on which organs and tissues are being donated, the operation can take from three to eight hours to complete.

**What happens after the operation?**

Following the operation, the donated organs will be transported from the operating theatre to the hospitals where transplantation will occur. If the family would like to see their loved one after the operation, this can be arranged.
**Will the person look different?**

When a person dies it is usual for them to appear pale and for their skin to feel cool, as blood and oxygen are no longer circulating around the body. The donation operation does not result in any other significant changes to the person’s appearance. The surgical incision made during the operation will be closed and covered as in any other operation and will not be visible beneath the person’s clothes.

**Will funeral arrangements be affected?**

Organ and tissue donation does not affect funeral arrangements. Viewing the body and an open casket funeral are both possible. If a Coroner’s investigation is required, this may delay funeral arrangements.
When is a Coroner’s investigation required?
Some deaths, such as deaths from unnatural causes or where the cause of death is unknown, are required by law to be investigated by the state or territory Coroner. In these circumstances, a coronial autopsy may be required. The hospital staff will discuss this with the family if it arises.

Most state and territory Coroner’s Offices provide access to counsellors who can provide more detailed information and support about the process when a coronial investigation is required.

Can the family change their minds about their donation decision?
Yes. The family can change their minds about donation at any point up to the time when the patient is taken to the operating room.

What are the religious opinions about donation?
Most major religions are supportive of organ and tissue donation. If a family has any questions they would like to discuss, the hospital staff can provide them with additional information and assist them in contacting their religious leader.
Will the person’s family be expected to pay for the cost of donation?
No. There is no financial cost to the family after death has been formally certified.

Which organs and tissues will be donated?
The hospital staff will discuss with the family which organs and tissues may be possible to donate. This will depend on the person’s age, medical history and the circumstances of their death. The family will be asked to confirm which organs and tissues they agree to be donated. They will be asked to sign a consent form detailing this information.

Does the person’s family have a say in who receives the organs and tissues?
No. The allocation of organs and tissues is determined by transplant teams in accordance with national protocols.¹ These are based on a number of criteria, including waiting lists and who will be the best match, to ensure the best possible outcome of the donation.

Will the person’s organs definitely be transplanted?
If the family supports donation, everything possible will be done to make sure those wishes are fulfilled. At the time of the donation it can sometimes become clear that organs intended for donation are not in fact medically suitable for transplantation. The hospital staff will discuss this with the family if it arises.

Is transplantation always successful?
Australia is internationally recognised for its successful transplants and its long-term survival of recipients. As with any operation, there are some risks associated with transplantation surgery, however, the majority of recipients benefit greatly from their transplants and are able to lead full and active lives as a result.

Will the family receive information about the patients who have benefited from the donation?
Australian law restricts identifying information being shared between donor and recipient families. The donation staff will provide donor families with ongoing information about which organs and tissues were transplanted, and the progress of the recipients. Donor families and transplant recipients can write anonymous letters to each other through the state or territory donation agency.
**What support services are available for donor families?**

The donation staff will keep in contact with the family and provide ongoing support and information. State and territory donation agencies can provide access to bereavement support and care.

You can find contact details for the donation agency in your state or territory at the back of this booklet.
Contacts

DonateLife ACT
Canberra Hospital,
Building 6, Level 1
Yamba Drive, Garran ACT 2605
Phone: 02 6174 5625
Fax: 02 6244 2405
organ.donation@act.gov.au

DonateLife NSW
Level 6, 4 Belgrave Street
Kogarah NSW 2217
Phone: 02 8566 1700
Fax: 02 8566 1755
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1st Floor, Royal Darwin Hospital
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donatelifenta@nt.gov.au

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Level 6, 45 Grenfell Street
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DonateLife VIC
Level 2, 19-21 Argyle Place South
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