DonateLife

Understanding death and donation

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. The generosity of organ donors can help others who need a transplant.

Some families have discussed organ and tissue donation and may already know their family member's wishes. Families who have not discussed donation will need to decide whether their family member will become a donor. This booklet provides information to help you and your family make a decision about donation that is right for your family member and you.

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 donation specialists. These people are available to support you and provide you with further information.

It is important to know that donation will only happen if a patient or their senior next of kin agrees.

Organ and tissue donation

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 sclera.

Death must have occurred before donation can take place.

Death can be determined in 2 ways:

- Brain death, which occurs when a person's brain permanently stops functioning.
- Circulatory death, which occurs when the circulation of blood in a person permanently stops.

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

Brain death

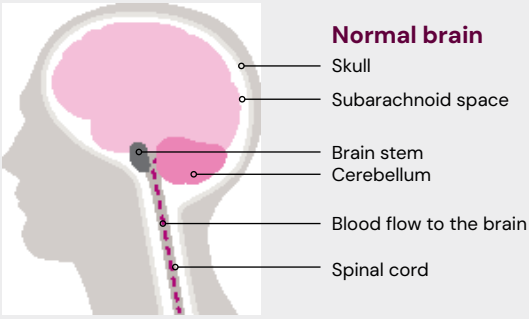
Brain death occurs when the brain has been damaged to the point that it completely and permanently stops functioning. This can occur as the result of severe head injury, a stroke from bleeding (haemorrhage) or blockage of blood flow in the brain, brain infection or tumour, or following a period of prolonged lack of oxygen to the brain.

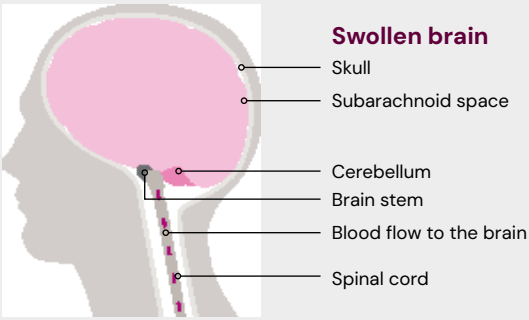
Just like any other part of the body, when the brain is injured, it swells. The brain is contained within a rigid 'box' (the skull), which normally protects it from harm but also limits how much the brain can expand. This is different to other parts of the body, such as an injured ankle, that can continue 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 brain stem where the brain joins with the spinal cord at the back of the neck. The brain stem 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 blood is unable to flow to the brain (see diagram on next page). Without blood and oxygen, brain cells die. Unlike many other cells in the body, brain cells cannot regrow or recover. If the brain dies, that person's brain will never function again, and the person has died. This is called 'brain death'.

The brain and brain stem 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 blows oxygen into the lungs (ventilation). The oxygen is then pumped around 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. This can make it difficult to accept that death has occurred. However, even with continued artificial ventilation, the heart will eventually stop functioning.

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

People who are critically ill in 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 the normal response of the pupils to light, loss of the ability to cough, inability to breathe without the ventilator, and reduced 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 of the following:

- response to a painful stimulus
- pupil constriction when a bright light is shone in the eye
- blinking response when the eye is touched
- eye movement when ice cold water is put into the ear canal
- gag reaction when the back of the throat is touched
- cough when a suction tube is put down the breathing tube
- ability to breathe when the ventilator is temporarily disconnected.

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 reaching the heart with the assistance of the ventilator.

A doctor or nurse may ask family members if they would like to be present for the clinical brain death testing. Viewing the clinical testing can help family members understand that the person has died, but it can also be confronting. As this is a personal choice, there is no pressure for family members to be present for the testing.

There are times when the person's injury or illness means that clinical brain death testing cannot be done. For example, facial injuries may limit examination of the eyes or ears. In these circumstances, medical imaging tests are done to determine if there is any blood flow to the brain (a cerebral angiogram or cerebral perfusion scan). The hospital staff will provide further information if such a test is necessary.

What happens after brain death has been confirmed?

The person will remain connected to the ventilator while members of the healthcare team speak with the person's family about next steps. These will include the person's end-of-life wishes, the opportunity for organ and tissue donation and when to remove 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 an extended period of time to make the necessary arrangements for donation.

Some families find that the extra time with their family member is valuable. You may like to speak to the healthcare team who can make suggestions about how you might like to use this time with your family member.

The person will remain connected to the ventilator and medications will be provided to support blood pressure and keep oxygen circulating to the organs. Increased medical activity may be seen around the person, due to further tests such as chest X-rays. If it becomes clear that organs are not suitable for donation, the senior next of kin will be notified. It may still be possible for the donation of tissue including eye, heart, bone and skin to occur.

When arrangements for donation have been made, the person will be moved to the operating theatre for the donation operation. 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. Their skin will become cold and pale because blood is no longer being circulated around the body.

Care, dignity and respect are always maintained during end-of-life care, whether or not donation proceeds.

Circulatory death

Circulatory death occurs when a person stops breathing and their heart stops beating (ie. there is no blood flow in the body). This can occur after a sudden illness or accident, or can be the final stage of a long illness.

Organ donation is sometimes possible after circulatory death although only in particular situations, as organs quickly deteriorate once blood flow to them stops. The usual circumstance is when a person is in an intensive care unit following a severe illness from which they cannot recover, and the doctors and family agree it is in the person's best interests to remove artificial ventilation and any other life supports. This may occur following a very severe brain injury resulting in permanent severe disability, people with terminal heart or lung failure, or people who have suffered a very severe spinal injury where they cannot move or breathe unassisted.

When doctors have determined that the person's life cannot be saved, the priority is then to support the person and their family with care, comfort and compassion at the end of their life. The withdrawal of life support is always discussed with and agreed upon by the family (and patient if possible) and this decision is made prior to and independently of any consideration of donation. Only when this decision has been made, will donation be raised.

What happens after the doctors believe the person's heart is going to stop beating?

When the family and the doctors agree that continuing treatment is not in the patient's interests, they will speak about next steps. This will include discussing the person's end-of-life wishes and the removal of the ventilator and other treatments, with a focus on providing comfort and pain relief.

If the doctors expect that the person will stop breathing and circulatory death will occur a short time after taking away the ventilator and any other life supports, there may be an opportunity for organ and tissue donation.

If the person and 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 life supports. Some people die within an hour and donation may be possible. Others may not die until many hours later. If this occurs, organ donation will no longer be possible, but donation of tissues may still be possible. If death does occur soon after removing life supports, the person will need to be moved quickly to the operating theatre so the donation operation can occur before the organs become damaged.

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. Their skin will become cold and pale because blood is no longer being circulated around the body.

Care, dignity and respect are always maintained during end-of-life care whether or not donation proceeds.

The donation process and further information

When donation is able to occur, the person who has died will be moved to an operating theatre for the donation operation. Some information about this part of the donation process is below.

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 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 up to 8 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 family member after the operation, this can be arranged by the donation specialist staff.

Will the person look different?

When a person has died and blood and oxygen are no longer circulating around the body, it is usual for them to appear pale and for their skin to feel cool. 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 with any other operation.

Will funeral arrangements be affected?

Organ and tissue donation does not affect funeral arrangements. Viewing the family member and an open casket funeral are both possible. If a Coroner's investigation is required, this may delay funeral arrangements, whether or not donation has occurred.

When is a Coroner's investigation required?

Some deaths, such as those following an accident or due to unnatural causes (e.g. poisoning, suicide), are required by law to be reported to the court and investigated by a Coroner. Any decision about donation does not influence whether a Coroner's investigation is required. The hospital or donation specialist staff will discuss with the family if the circumstance of the death means it is reportable to the Coroner.

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

Can the family change their minds about donating?

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

What are the religious opinions about donation?

All major religions support organ and tissue donation. If a family has any questions they would like to discuss, the donation specialist staff can provide them with additional information and help them contact their religious leader.

Will the donor's family be expected to pay for the cost of donation?

No, there is no financial cost to the family for the donation.

Which organs and tissues will be donated?

The donation specialist 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 donate. They will be asked to sign an authority form with this information.

Does the person's family have a say in who receives the organs and tissues?

No. Organ and tissue allocation is determined by transplant teams in accordance with national protocols[1]. These are based on a number of criteria, including who will be the best match and waiting lists, 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 medically suitable for transplantation. The donation specialist staff will discuss this with the family if it arises.

Is transplantation always successful?

Australia is internationally recognised for its successful transplants and having excellent long-term survival of recipients. Most people who receive a transplant benefit greatly and are able to lead full and active lives. However, transplantation is not without risk. This includes the transplant surgery and ongoing treatments required after transplantation.

1 Transplantation Society of Australia and New Zealand (TSANZ) Clinical Guidelines for Organ Transplantation from Deceased Donors tsanz.com.au/guidelinesethics-documents/tsanz-clinical-guidelines.htm

Will the family receive information about the patients who have benefited from the donation?

Health professionals involved in donation and transplantation must keep the identity of donors and recipients anonymous by law. Initial outcomes of the donation operation will be discussed with families while maintaining anonymity. Families can also request further updates from the their local DonateLife agency. Donor families and transplant recipients can write anonymous letters to each other through their local DonateLife agency and transplant units.

What support services are available for donor families?

Donation specialist staff will keep in contact with the family and provide ongoing support and information. State and territory DonateLife agencies can provide donor families with access to bereavement support and care.

You can find contact details for your local DonateLife agency at the back of this booklet. Additional resources containing more information will also be sent to you by mail.

Contacts

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DonateLife NSW

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DonateLife

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