

In reflection

For families who have supported eye or tissue donation

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This booklet was produced in partnership with DonateLife agencies as the original authors.

T 02 5156 6662

E enquiries@donatelife.gov.au

donatelife.gov.au

There isn't any preparation for the heartache which strikes when you lose someone you love. How does any family consider a total stranger in a time of such immense grief? This is the miraculous gift of donation.

Saying 'thank you' seems so inadequate. In your time of anguish, there is so much I am thankful for. Thank you for your compassion, thank you for considering me, my family, my friends and those who touch my life. Thank you for making the decision to donate and honouring someone you love.

I share an unimaginable bond with my donor. I have developed so many memories, had so many adventures, seen and shared so much since I received the gift of my corneas. These experiences were only made possible because of your very kind consideration.

As a recipient I feel privileged and humbled knowing someone cares so much to give such a special gift. I have formed close friendships with many donor families whose decision continues to bring them some peace and warmth. It is my sincerest hope your decision will also bring you this comfort.

A grateful transplant recipient

'There are simply no words in the dictionary that are strong enough to describe the gratitude that I have for our donor and their family. Thank you simply doesn't seem enough.'

Mother of a child who had a tissue transplant

A donor family story

Our brother was deaf and blind, but his life was as colourful and rich as any other.

When he was involved in a catastrophic accident, the DonateLife team approached us to discuss donating his organs and tissues. Unfortunately, he was unable to become an organ donor in the end, but to our surprise, he was able to donate his eyes. We never would have believed that through becoming an eye donor, he would be able to give the gift of sight to 2 other people.

Our brother donated both corneas to 2 different recipients for use in corneal transplants. He also donated his sclera, the whites of the eyes, which is used for reconstructive eye surgery for trauma or cancer patients and in people with glaucoma.

If there can be any joy arising from the sorrow that still shrouds our family, it's that our brother was able to give others a gift that he could never receive: the gift of sight.

We never discussed organ and tissue donation before that day. It was the hardest time of our lives, but donation is the one good thing that came from something so tragic. We are so proud that a part of our brother still lives on.



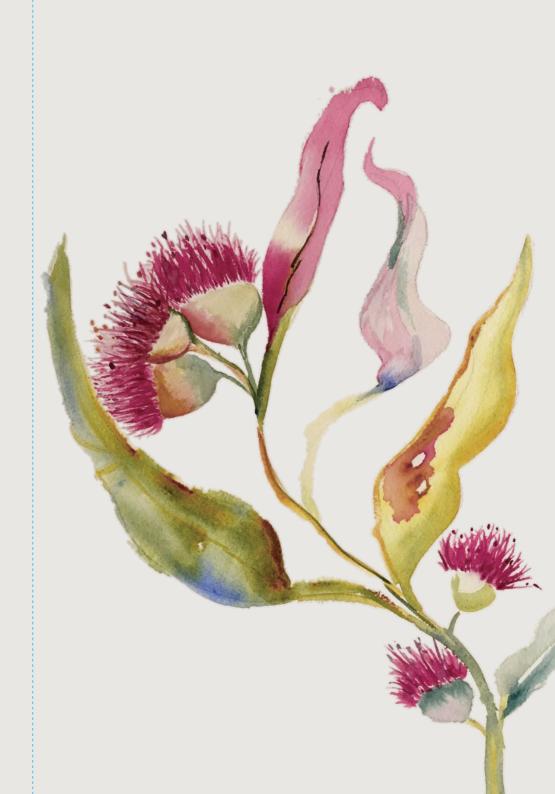
Introduction

This book has been written to support families and their friends whose lives have been touched by eye and tissue donation. Donor families and transplant recipients have generously contributed to this book by sharing their personal stories.

Your generosity at this very difficult time has made an enormous difference to the lives of others. We offer our sincere gratitude to you, your family and particularly to your family member for the precious donation you have given.

Every year the lives of many Australians are improved and saved through the transplantation of donated eye and tissue. Eye and tissue donation can make the difference between seeing and not seeing, and mobility and never walking again. It can make recovery from serious disease and trauma a real possibility for people who may otherwise have had little chance.

Your family's decision to donate was made soon after the loss of your family member. We realise the first few days are a stressful, difficult time. By sending you this information now, we hope to be able to answer any questions you may have since you agreed to donation. We also want to acknowledge the importance of this donation by telling you more about how other people may benefit.



Section One

Grief

| What is grief? | 8 |
|--------------------------------|----|
| How will grief affect me? | 9 |
| Children and grief | 13 |
| How to cope with anniversaries | 14 |

What is grief?

The death of someone we love is a universal experience and the feelings of grief that accompany the loss cannot be avoided. It is particularly hard when the death is sudden or unexpected and there is no time to prepare – no time to say goodbye.

You may feel shocked, confused and frightened. The way you see the world suddenly changes. Your sense of safety and security is shaken, and a feeling of being in an 'unreal world' takes over. There may also be a feeling of anger and a strong need to blame someone for what has happened.

Many factors can influence how the death of a loved one impacts you. These include the age of, and relationship with, the person who has died as well as the circumstances surrounding their death.

How will grief affect me?

It is important to be aware that there is no specific 'pattern' to grief. There are no set time limits for when you should be 'feeling better' and no set sequence of 'stages'. As individuals, we all vary in the way we cope. However, there are some reactions that are commonly experienced by bereaved people. We have listed some below so you may recognise them in how you are feeling, and also some things that you might like to consider. Experiencing any of these is completely normal.

Emotional

- Often numbness and a feeling of disbelief help you to cope in the first few days or weeks. Don't be surprised if things feel worse when that numbness wears off.
- · A deep yearning and sadness for your loved one is normal.
- Feelings of anxiety, fear or panic are also a common response.
- Recognise that anger is a normal part of grief.
- Give yourself permission to grieve. Don't try to be strong for everyone around you.
- Let people know how they can be helpful. Suggest practical tasks as well as providing emotional support.
- You may fluctuate between needing the company of others and wanting some time on your own. Be open with people and make those needs known.
- It may be hard to concentrate for long on even simple tasks.
 Don't expect too much of yourself.
- You may experience strong emotions during bereavement, which can be alarming. This is not unusual, but if you are worried by the intensity and duration of your feelings, don't be afraid to seek professional help.
- Some people may experience grief dreams as part of their grief response.

Physical

- It is important not to neglect your health. You are under great stress and will be more vulnerable to illnesses. You may feel run-down.
- Some people may feel physically sick, experience severe pain or discomfort, digestive problems, energy loss, lack of concentration, or have weight fluctuations.
- Even if you are not enjoying or thinking about food, try to continue to eat regularly.
- Your sleeping patterns are likely to be disturbed. Try to take some time out during the day to rest when you can.
- Try to moderate and be mindful of your alcohol intake and the use of other substances.
- If you have symptoms that are worrying you, seek advice from your local doctor.

Social

- Friends and family are often most supportive in early stages of bereavement. As time goes by, it's important that you reach out to them for help if and when you need it. If you wait for them to guess how you are feeling, you might not be supported when you most need it.
- Grief can take a toll on relationships because it is primarily an individual experience. Intimate relationships may intensify or grow distant, so be aware of each other's pain and loss, and listen to what they have to say.
- Social gatherings may elicit feelings of anxiety, especially in the first weeks and months. Be gentle with yourself and choose to be with people you trust.
- During a period of grief it can be difficult to judge new relationships.
 It is hard to be objective about new relationships if you are still actively grieving. No one will be a substitute for your loss. Try to enjoy people as they are.

Financial

- Avoid hasty decisions. Try not to make major life decisions within the first year unless absolutely necessary.
- In general, most people find it best to remain settled in familiar surroundings until they can consider their future more calmly.
- Don't be afraid to seek advice from someone you trust.

Spiritual

- Personal faith may be a great source of comfort during bereavement.
- Some people experience a comforting dream, or touch, or sense of visitation from the person that has died.
- As we grieve, it is normal to consider and re-evaluate our beliefs and views about the way the world works and our place in the human condition.
- We may struggle with the meaning of our family member's death at this time.
- Some people can find their spiritual beliefs are being challenged.
 This can be be extremely upsetting for them.
- You may find it comforting to consider the emotional legacy of knowing and loving the person who has died.
- Your local minister or religious leader may be able to provide support.
- Some people report that transitioning from loving the person in presence to loving in absence is extremely helpful.

What may help?

It takes time to adjust to an environment where the person you love is missing. Things you least expect can trigger memories and may overwhelm you with emotion – a piece of music, an empty chair, the smell of a favourite perfume.

Learn to recognise what works for you. You will quickly identify family members or friends who will allow you to be yourself and express your grief in a meaningful way. Talk about the person who died and encourage others to share their memories. Sometimes people are hesitant to talk about the deceased for fear of upsetting you more. They may wait for you to give them permission.

You may find that spending some time on your own also helps – such as writing your feelings in a journal, visiting a special place that feels safe and may hold happy memories for you, or putting together a memory book. Different things might work for you at different times.

These feelings are complex. You may notice that at times it might seem they get worse rather than better.

Over time you may notice you:

- have more good days rather than bad days
- can share memories about the person who died and experience more pleasure more than sadness
- can actively begin to reinvest in life and plan for the future.

Each family member had their own special relationship with the person who died and will be impacted in a different way.

Children and grief

A child's understanding of death varies with age. Even young children will be aware something very bad has happened but may not be able to comprehend the seriousness of it.

Their home and family provide the only sense of security they know. They are likely to be very sensitive to sadness, grief and disruption among those they usually turn to for comfort. It is important that they feel loved and reassured.

You may notice that children's behaviour regresses. They may act as they did when they were much younger. For example:

- they may insist on staying close by you and be very fearful of being separated from you
- their sleep patterns may be disturbed and include bad dreams.

What might help?

There are things you can do to help, such as:

- taking time to play with them and ask them to explain what they are doing, as young children often express themselves through play
- being open and honest with them and explaining what is happening as simply as possible
- involving them they need to be able to 'do something special' for the person they loved. You could make a garden, plant a flower, or take something they have made to the cemetery
- letting their school know what has happened as soon as possible.
 This will give teachers time to plan how best to support them when they return to school
- knowing that some of these reactions are common, which can be reassuring for you as a parent. However, if at any time you are concerned about how your child is coping, do not hesitate to seek professional advice through your local doctor.

There are many excellent books for both children and parents. A list of some of these can be found in the 'Counselling support services' brochure available through the DonateLife agency in your state or territory.

How to cope with anniversaries and special days

Anniversaries and special days will never be quite the same without the person you loved. The first year can be especially painful. There is a sense of 'building up' to each important day with an increasing feeling of anxiety as to how you might 'get through it'.

What might help?

- Plan ahead. Everyone has different needs or expectations, which is why it
 is important to talk openly with family about the day.
- Children in particular will be seeking reassurance that family life will continue as normally as possible.
- Share the day with people you enjoy and with whom you feel comfortable.
- You may choose to make a change from the usual family ritual and create a new family tradition.
- · Try to make the day meaningful in some way.
- Allow others to help you plan, while remembering that it is your special time.
- Allow yourself to share both laughter and tears with those around you
 it may help them to express their feelings too.
- Be creative in remembering your family member light a candle, buy a special decoration for the Christmas tree, or buy something special that all the family can enjoy.
- Children may wish to draw a picture or write a letter for the person who has died.
- Be gentle with yourself set realistic goals.
- Treasure memories of your family member you will always carry them in your heart.

Section Two

Support

| Commemorating organ and tissue donors | 16 |
|---|----|
| Stories from donor families | 17 |
| Messages from recipients | 19 |
| Shared words from donor families and recipients | 22 |
| DonateLife contacts | 23 |
| State and Territory Coronial Service contacts | 24 |

Commemorating organ and tissue donors

Organ, eye and tissue donation agencies throughout Australia have developed special ways of acknowledging the generosity of all organ and tissue donors and their families.

DonateLife Services of Remembrance

Annual DonateLife Services of Remembrance provide a forum for acknowledgement of and gratitude to donors and their families. They are an opportunity for all those touched by organ and tissue donation to meet with others whose lives have also been changed by this experience.

Donation stories

Across Australia, thousands of lives have been touched by organ and tissue donation. This includes donors and their families and people who receive transplants and their families.

We have an inspiring collection of stories on the DonateLife website that donor families and transplant recipients have shared with us. You can read these stories and find out how to share your own at donatelife.gov.au/all-about-donation/donation-stories

Stories from donor families

Families have generously shared their personal experiences with us.

A parent's story

Our daughter was suddenly taken from us in a road incident involving a young man driving under the influence of marijuana and alcohol. She was just 23 years old.

As a family we had discussed organ donation around the kitchen table so were aware of her wishes. At the hospital, staff informed us that organ donation was not possible because she had died at the scene. We requested the eye bank be contacted immediately.

We have never regretted our decision as we knew it was what she wanted. At the time it helped us enormously to know that her donation would make a difference in someone else's life. Later we received a letter of thanks from one of the cornea recipients, which was another positive step towards adjusting to the great change in our life.

Our lovely daughter had dreams and aspirations that sadly never eventuated. However, it is our hope that those who knew her and have become aware of her final special gift of sight, will be inspired to talk to their families about their own wishes.

The legacy of sight

My family's donation story started a few hours after my dad passed away, when we were contacted by the eye bank and were given the opportunity of tissue donation. Dad had made the decision to be an organ donor some years earlier and although he was not in a position to donate organs, he was able to donate eye tissue and so as a family we were able to honour dad's wishes.

Dad had lovely blue eyes that saw a lot of the world, and when we received the letter from the eye bank saying dad's corneas had been successfully transplanted into a man and a woman, it actually took me at least 3 tries at reading it as I couldn't see through my tears.

To say we were happy that the transplants were successful is describing it mildly. Dad's sister, his wife, his 3 daughters and his son-in-law were so proud of him, and some day his grandson will be too when his mother tells him what his grandfather did. The fact that as result of his donation 2 people have been given the gift of sight just seems such a fitting legacy.

Messages from recipients

A vision of gratitude

There are 2 families I thank every single day without fail.

I don't know who they are but their generosity inspires me.

These 2 families gave me the greatest gifts in highly emotional circumstances by donating the corneal tissues of their loved ones who had passed away.

My 2 diseased corneas had left me legally blind – in my left eye as a 15-year-old high school student, and in my right eye 6 years later as a budding journalist.

I am now a 31-year-old double corneal transplant recipient with perfect vision in one eye and exceptional sight in the other.

The decision by these 2 families restored not only my sight but my quality of life.

To them I am forever indebted, and they are who I thank for the privilege of my drivers licence, for my passion in photography, for allowing me to witness my best friend get married in Bali, for my university degree, and for my ensuing career as a journalist which has seen me report on news, sport and entertainment events throughout Australia.

It is to these families that I am eternally grateful to for giving me the privilege to see my beautiful daughter as she grows up.

I can't personally thank these families, but I'd love to tell them I take nothing for granted and am grateful for everything I have seen and will get to experience in the future thanks to their selfless decision.

The benefit of tissue donation

At 28 years old, Jenni was diagnosed with a malignant tumour in her right leg. She underwent 3 months of chemotherapy before she had major surgery to remove the bone tumour, during which she received a large bone graft. The surgery took 15 hours, saving her leg from amputation. Following surgery, Jenni underwent weeks of further chemotherapy treatment.

Jenni knows she would not have been able to save her leg without receiving the bone graft, something she says has made a huge difference in her life. She is especially grateful to the donor family who agreed to donation after losing a loved family member; but also to her surgeon, the bone bank and for the great support she received from family and friends.

After 5 years of annual check-ups, Jenni was given the all clear and has since led a very fulfilling life. She returned to full time work, and has managed to maintain a good work/life balance, still doing all the things she was able to do before the surgery.

Jenni has been married now for 16 years and has 2 healthy children: Rebecca who is a very keen jazz pianist and classical guitarist, and Thomas who is a passionate soccer player.

Jenni's mother Jan has had 2 hip replacements, and each time she has donated her femoral head to the bone bank Jan didn't hesitate when asked if she would like to donate, knowing that she could help someone else in need, just as Jenni had been helped by a generous stranger.

Both Jan and Jenni actively promote donation.

Jenni said, 'I will be forever grateful to the donor family and everyone involved in my surgery, and feel that organ and tissue donation is something that the whole family should discuss and support."

A family's miracle

Dane is our fourth child and a surprise baby! He was born with an infection that attacks the inside lining of the heart, called bacterial endocarditis. It's a very rare illness in newborn babies and usually is fatal. We spent 5 weeks in hospital watching him fight this horrible sickness. There were lots of complications and from day one we were told that Dane was most likely going to die from this condition.

The infection had destroyed Dane's aortic valve and eaten a hole from the left ventricle to the right atrium of his heart. Dane was dying and needed urgent open heart surgery to replace his valve and repair the hole. When Dane went into surgery he was given a 10% chance of surviving.

Six hours later he was the recipient of a donated aortic valve and the hole had been repaired using donated heart tissue. He was pink and warm; it was like he was born all over again. Dane's recovery has been described as a miracle but the miracle wouldn't have happened without the donated valve and tissue, regardless of how hard he had fought.

There are simply no words in the dictionary that are strong enough to describe the gratitude that I have for our donor and their family. 'Thank you' simply doesn't seem enough!

Shared words from donor families and transplant recipients

'Thank you for all your caring and kind words it made such a difference."

— Donor family

'The fact that our loved one was able to help others through transplantation has been a great comfort to us. Happiness to them always.'

- Donor family

'All the support we received helped us to deal with our loss and showed how much you cared.'

- Donor family

'Just to say "thank you" seems so inadequate.'

- A very grateful recipient

DonateLife contacts

DonateLife ACT

T (02) 5124 5625

E organ.donation@act.gov.au

DonateLife NSW

T (02) 8566 1700

E otds-familysupport@health.nsw.gov.au

DonateLife NT

T (08) 8922 8349

E donatelife@nt.gov.au

DonateLife QLD

T (07) 3176 2350

E donatelife@health.qld.gov.au

DonateLife SA

T (08) 8207 7117

E donatelifesa@sa.gov.au

DonateLife TAS

T 03 6166 8858

E donatelife.tasmania@ths.tas.gov.au

DonateLife VIC

T (03) 8317 7400

E donatelife@redcrossblood.org.au

DonateLife WA

T 1800 950 155

E donatelifewa@health.wa.gov.au

State and Territory Coronial service contacts

Australian Capital Territory

Coronial Counselling

15 Napier Close, Deakin ACT 2600

T 1300 364 277

Enquire at racr.org.au/services/coronial-counselling/

New South Wales

Coroners Court

Forensic Medicine and Coroners Court complex 1A Main Avenue, Lidcombe NSW 2141

T (02) 8584 7777

E lidcombe.coroners@justice.nsw.gov.au

Northern Territory

Coroner's Office

Darwin Local Courts Nichols Place, Corner of Cavanagh Street and Harry Chan Avenue Darwin NT 0800

T (08) 8999 7770

E nt.coroner@nt.gov.au

Queensland

Coronial Family Services

T (07) 3096 2794 or 1800 449 171 (toll free)

E fss.counsellors@health.qld.gov.au

South Australia

Coroner's Office Counselling and Support Service

302 King William Street, Adelaide SA 5000

T (08) 8204 0600

E coroner@courts.sa.gov.au

Tasmania

Southern Coroners Office

27 Liverpool Street, Hobart 7000

T (03) 6165 7127 | (03) 6165 7134

E coroners.hbt@justice.tas.gov.au

Northern Coroners Office

73 Charles Street, Launceston 7250

T (03) 6777 2920

E coroners.hbt@justice.tas.gov.au

Victoria

Coroners Court of Victoria

State Coronial Services Centre 65 Kavanagh Street, Southbank VIC 3006

T 1300 309 519

E courtadmin@coronerscourt.vic.gov.au

Western Australia

Coronial Counselling Service

Coroner's Court of Western Australia Department of Justice Central Law Courts Level 10, 501 Hay Street, Perth WA 6000

T (08) 9425 2900 | Freecall 1800 671 994

For information on additional support contacts, please refer to the 'Counselling support services' brochure available through the DonateLife agency in your state or territory.



Section Three

Donation

| Information about eye and tissue donation | 28 |
|--|----|
| Information about eye and tissue transplantation | 32 |
| Acknowledgements | 35 |

Information about eye and tissue donation

When a family member dies there are many issues to consider. You may have been given information about eye and tissue donation at the time your loved one died or shortly after. As the weeks go by, people often begin to remember events more clearly and may wish to get further information or simply confirm what they already understand.

Why do we contact you at such a difficult time?

The time involved in eye and tissue retrieval is very short. The donation process takes a number of hours to coordinate, and the eye and tissue for transplantation only remains suitable for a short period after death.

Eye, heart, bone and skin tissue donations must occur as soon as possible, often only hours after death. That is why families are contacted soon after the death of their family member to consider donation.

Families tell us they appreciate the opportunity to consider donation, even when they decide not to agree.

Why do we ask you so many questions?

You may have wondered why we asked about your family member's health and lifestyle when you decided to donate.

Every precaution must be taken to avoid the risk of passing on any infection or illness when transplanting tissue. Although we undertake a range of tests, a crucial part of our safety procedure is to conduct a rigorous examination of the medical and social history of the donor. It is important that we obtain as much information as possible about the person who is donating to ensure the safety of the tissue and to enable the best possible outcome for recipients.

The same list of questions is asked about every person who is going to donate eye or tissue and they are very similar to the questions people are asked before donating blood. These questions help us identify any infection or illnesses that might prevent them from being able to donate.

Donation

We appreciate you discussing these sometimes very intimate matters with one of our staff members. Please be assured the information you provided is only used to ensure the donated tissue is used safely and appropriately and is treated in the strictest confidence by all concerned.

Agreeing to donation

You may have been approached in person to agree to donation, in which case you will have signed a consent form. Or, you may have received a call from a donor coordinator and agreed over the telephone, which allowed us to arrange the retrieval, processing and transplantation of your family member's donated tissue.

Although this is legal consent under Australian transplantation legislation, some states and territories also require us to request your written agreement. The donor coordinator will inform you if we require this.

Consent for research

When families are asked to consider donating tissue, the primary focus is for transplantation. However, you may have also been asked to consider giving consent for research in the event that the donated tissue could not be used for transplantation. Researching donated tissue can lead to scientific discoveries that help countless people.

Final medical suitability of the tissue is not always known until after the tissue has been retrieved and laboratory tests are reported. In some instances, donated tissue may be unsuitable for transplantation, but with the family's permission, may still be used for research. Tissue donated for scientific and medical research is equally important as tissue donated for transplantation. It can lead to the treatment and prevention of disease and improvements in patient care, such as prevention of blindness or heart disease.

Eye and tissue retrieval

Donors are always treated with the utmost respect and dignity.

The retrieval is performed by specially qualified and trained health professionals. There will be surgical wounds which are carefully sutured like in any surgical procedure.

Do we find out who the recipients are?

In Australia, all health professionals who are involved in donation and transplantation are bound by laws that enforce confidentiality. Donor families are not given identifying information about recipients, and recipients are not given identifying information about their donor or donor's family.

Depending on the circumstances of donation, there may be an opportunity for anonymous correspondence between recipients and donor families. The process for corresponding with recipients is arranged through the DonateLife agency in your state or territory.

How are transplant recipients selected?

For patients requiring tissue transplants, selection and waiting time is based on the urgency of their medical procedure and availability of bone tissue, heart tissue and skin stored in a tissue bank. For patients waiting for a cornea or eye tissue, the order of selection may be determined by their position on a waiting list or the urgency of their medical condition. Tissue typing is not required for tissue transplants.

The coronial process

Your donation experience may have involved the Coroner.

Most states and territories have counsellors attached to the Coroners Court. who will provide information regarding the processes involved and provide support to you and your family. The coronial counsellors work exclusively with families of people who die suddenly or unexpectedly, and where their death must be reported to the Coroner.

Donation

The counsellors always attempt to make early contact with families to let them know where the body of their family member has been taken and to explain the Coroner's role.

Contact details for your State Coroner are listed under the Support Section of this book. If you have any difficulties contacting the counsellors please contact the eye bank, tissue bank or DonateLife agency in your state or territory for assistance.

The role of the Coroner

The role of the Coroner includes investigating the circumstances surrounding deaths that are required by law to be reported. The Coroner must be informed of any deaths from unnatural causes such as accidents, suicides, instances where the cause of death is unknown and deaths such as those occurring in an institution or in police custody.

Role of the police

When a person's death is reportable, the Coroner must be satisfied as to the identity of the person. In most states and territories this may involve the family confirming the identity of the person in the presence of a police officer at the hospital.

Coronial autopsy

An autopsy may be ordered by the Coroner to establish the cause of death. The coronial process is quite complex and a delay may be experienced in obtaining a final report. The coronial counsellors can provide you with assistance in relation to autopsy findings, the final report and other issues.

Jonation

Information about eye and tissue transplantation

One donor can change the lives of many people. Eye and tissue donation can be the difference between mobility and never walking again, seeing and not seeing, or a quick rather than protracted recovery from trauma, cancer or disease.

Each year the lives of hundreds of Australians are improved and often saved through the transplantation of donated eye and tissue. Any one of us could one day find ourselves needing this life saving or life enhancing procedure. The following pages provide information on the different tissues that can be donated and the reasons some people need a transplant.

Why do some people need transplants?

Adults and children need transplants for a range of reasons, including:

| Eyes/corneas | Blindness, eye trauma, disease and infection |
|--------------|---|
| Bone | Bone cancer, spinal deformities in children and teenagers, joint replacement surgery and trauma |
| Heart valves | Valve disease, infection and children born with heart valve problems |
| Skin | To dress severe burns, unhealed wounds and injuries resulting in significant skin loss |

Eye tissue

Donation of eye tissue allows corneal transplantation and scleral grafts. The cornea is the clear tissue which covers the coloured part of the eye. It allows light to pass through to the retina, giving sight. When problems develop in the cornea, vision rapidly deteriorates. Donated eye tissue can prevent blindness and restore sight to people who are partially or completely blind due to corneal damage following a genetic condition, illness or injury.

Donation

The sclera is the white part that surrounds the eye. Scleral grafts are performed to prevent blindness due to injury, or in people who have had cancer removed from their eye, or to repair integrity of an eye that has had a corneal perforation.

Bone and tissue (such as tendons and ligaments)

Donated bone and tissue can be grafted to replace bone and tissue that has been lost due to tumours or through other disease or injury. Your family member's donation could save a limb of a person who has developed cancer and would otherwise face limb amputation, aid fracture healing, strengthen hip and knee joint replacements, or repair spinal deformities in children and teenagers.

Bone is the second most commonly used donated tissue in the world. Only blood is more regularly donated and received. Some 20 to 30 people can benefit from a single bone and soft tissue donation after death.

Skin tissue

Skin grafting is often a life-saving procedure. Skin grafts are the most effective way to treat people with severe burns. They are also used where there has been extensive trauma or where skin has been destroyed as a result of infection. It is also medically recognised as the most effective way to minimising scarring and promote healing for burn victims.

Ideally, these grafts would be taken from unburnt parts of the patient's own body. Unfortunately, in some circumstances, people do not have enough of their own skin available for this procedure. In these cases skin grafts from a donor are vital.

When skin is donated, only a thin layer is retrieved, similar to skin that peels in sunburn. On average, skin from 3 donors is needed for one person with severe burns.

Heart tissue

Heart tissue donations are primarily used to repair congenital defects in young children and babies. The tissue is also used to replace diseased valves in adults. Heart tissue donation markedly improves quality of life, and can sometimes save lives.

While artificial valves and some animal tissue can also be used, human heart tissue is preferable because it is more resistant to infection and can also enable the recipient to lead a life without the need for blood thinning medication. Human heart valves are also much safer for women of childbearing age. One heart tissue donor can help up to 10 people.

Heart tissue, bone and skin tissue can be safely stored for up to 5 years. Eye tissue is usually transplanted within one month of donation.

Donation

Acknowledgements

We would like to thank the following people for their valuable contributions in creating this book:

- Families of eye and tissue donors for their courage in sharing their own personal experiences.
- Transplant recipients for sharing their stories and words of gratitude.
- Representatives of organ and tissue donation agencies, eye banks, tissue banks and counsellors whose collective experience supporting donor families and recipients has helped to create and shape this book

In particular we would like to acknowledge Teresa Spencer Plane – a pioneer of the modern hospice movement in Australia, bereavement counsellor and educator. Her personal experience of organ donation inspired her to write the first book for families of donors, *Caring Strangers*. Her dedication has inspired us to build upon her original work.

On behalf of the DonateLife Network, our community and transplant recipients, we thank you for your generosity in thinking of others.





Contact

Organ and Tissue Authority

(O2) 5156 6662 | enquiries@donatelife.gov.au

- f DonateLifeAustralia
- DonateLifeToday
- DonateLifeToday
- in Australian-Organ-and-Tissue-Authority

donatelife.gov.au