DonateLife

In reflection

For families who have supported organ and tissue donation

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

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The miracle of life

Today I witnessed the most incredible things. Today I saw a miracle! I saw the sunrise. I saw a child laugh. I saw a family kissing each other. I saw a flower in my garden. Each one of these was a miracle, because they are the miracle of my life.

And every day for the past 17 years I've enjoyed and appreciated the second chance at life that organ transplantation has provided to me.

On behalf of all transplant recipients I would like to give thanks to all those people who have donated organs and tissue. Through their love of life and decision to help others at the time of their death, they continue to provide life to other human beings.

Let us also acknowledge and give thanks to the families of all donors. People who, in times of trauma unimaginable to most, have the strength and compassion to see beyond the tragedy; who have respected the decisions of their loved ones or made decisions on their behalf; to allow others to live a life and have a quality of life that otherwise would not have been possible.

Every day, I give thanks to the 2 people who loved enough to give me – a total stranger – a heart that beats without missing a beat, so I can see the sun rise; feel the warmth of a hug; smell the fragrance of a flower; taste the freshness of a fruit; and hear the laughter of a child.

These are life's everyday miracles that most people take for granted. What is ordinary to some is extraordinary to me.

A grateful transplant recipient

‘When you are sorrowful, look again in your heart, and you shall see that in truth you are weeping for that which has been your delight.’

Kahlil Gibran

A donor family story

My dad passed away in early 2014. Today, and for all the years to come, we will live with the consequences of him being gone and while the pain is not the raw shock and denial it once was, that feeling of loss will always be there. Yet I still consider myself lucky as I have the comfort of knowing my dad was an organ donor and something of a hero to many, myself included.

The fear that you will never hear or see your loved one again can be overwhelming. My dad spent his last night playing cricket on the beach, laughing with his daughters over homemade shortbread ice cream, and watching *The Hobbit* with his son and wife. It was the perfect end to a brilliant life, almost as though he had designed his last night with us himself. But within hours we were faced with the question of whether or not we would donate his organs. Phrased like this it seems harsh, but for those who need that second chance at life it really does come down to yes or no.

I do not believe I have ever experienced such kindness as that from the doctors and nurses at the hospital. They cried with us as we said goodbye, held our hands as we sat in shock, and treated dad with the greatest respect through the entire process. Today we live with the relief that we made this decision. It offers hope against the finality of death and out of our loss came the ability to prevent another family from suffering the heartache that we have.

Organ donation is a beautiful creation, and one that stems from great tragedy. Perhaps this is what makes it the most precious gift of all and reminds me why my dad's life was so valuable. For those who have received an organ and those who make it possible, I want to say how grateful I am. You hold a very special place in my heart for letting my dad live on.

Dedication

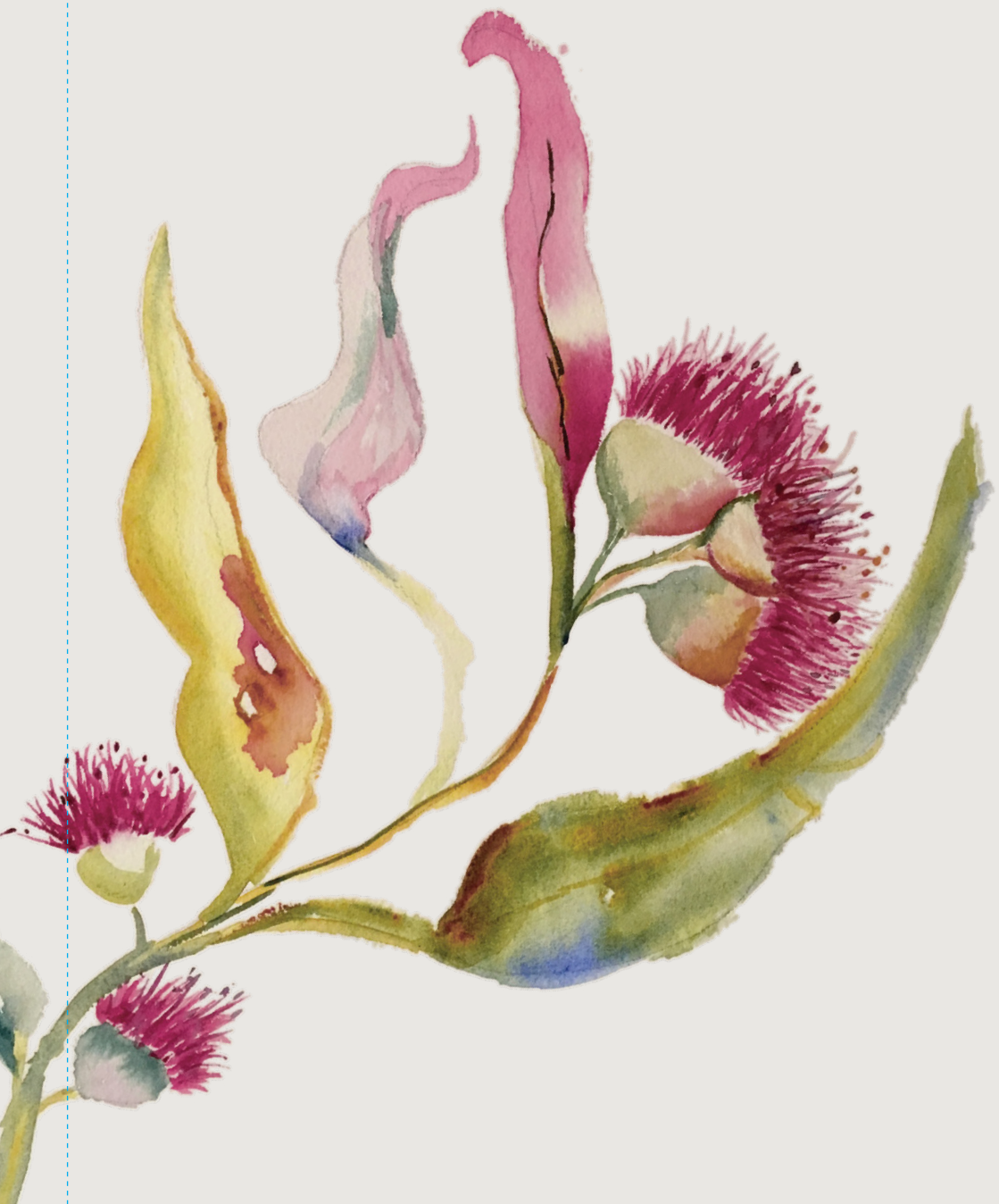
This book is dedicated to all organ and tissue donors and their families who, through their generosity, have changed the lives of others through transplantation.

It also acknowledges those whose wish to be a donor could not be fulfilled.

Introduction

This book has been written to help families and their friends whose lives have been touched by organ and tissue donation. We have included some information about organ and tissue donation that may answer any remaining questions.

Donor families and transplant recipients have also generously contributed to this book by sharing their personal stories. Although you may not feel up to reading it all right now, you will find some information on grief and bereavement which we hope will help you understand what to expect on your individual journey.



Section One

Grief

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 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 family member 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 own 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, 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 being challenged. This can 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 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 too. 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 – writing your feelings in a journal, visiting a special place that feels safe and may hold happy memories for you, 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.

Gradually over time you may notice you:

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

Each family member had his or her 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:

- take time to play with them and ask them to explain what they are doing - 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 the 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 will have 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

Family Support Service

The National DonateLife Family Support Service provides support to families who have agreed to donation. Support is provided in a number of ways and will vary depending on your needs now and in the future.

As part of the service, Family Support Coordinators are located in each state and territory DonateLife agency. The Family Support Coordinator is available to support you and your family during your time of loss. They are there to listen, to provide information and reassurance and to answer any questions or concerns you might have. You might find it is helpful to talk to someone outside your immediate family. The service may provide counselling or referral to local grief counsellors if preferred.

When transplants have occurred, your local DonateLife agency will inform you how many people have been helped by your decision to donate and how they are progressing. Families of donors and transplant recipients are both vulnerable and need time to heal and adjust to very different circumstances.

In Australia, correspondence between donor families and recipients is anonymous. Although the identity of recipients cannot be revealed, DonateLife will forward correspondence to you if you want to receive it. Similarly, you may wish to write to recipients or respond to their letters through the same anonymous channels.

If in time you feel that this is something you would like to do, your Family Support Coordinator can help you.

In the future if you would like an update on the progress of the recipients this can be facilitated through the Family Support Coordinator or your local DonateLife agency. Updates are not provided routinely, as not all families wish to know if circumstances change over the years.

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

DonateLife Services of Remembrance are 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.

Donor family support pin

This lapel pin has been specially designed for families of organ and tissue donors.

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

Two families have generously shared their personal experiences with us.

A son's lasting impact

On an overcast mid-July day a few years ago, I discovered by telephone that my beloved elder son had died instantly after sustaining a head injury. It was the result of a motor vehicle accident that occurred on his way home from work.

Some hours later, his young widow, being inconsolable when approached by the donor coordinator to discuss possible tissue donation, was unable to make the decision required.

Not being aware that my son had registered as a donor, but knowing him as a loving, thoughtful, sincere and compassionate, spiritual being in life, I had no hesitation in giving permission for tissue retrieval as requested. Stating that if this were his wish, we hadn't the right to deny him his choice to donate in the event of this, his untimely death.

Following the tissue donation, we were able to view his body and found him to look just as he always had, when asleep. Some time later, I received a heart-warming beautiful letter from the donor coordinator thanking me for the donation of tissue from my son.

I'm proud to share that my son donated his eyes, heart valves, leg bones and Achilles tendons. I'm also honoured to share that his donation resulted in a male and female both in their mid-30s having their sight restored, and 17 other people receiving bone grafts – 5 of them being children.

My son died before he could father a child but I couldn't be more proud of him. In death, due directly to his gifts, he has enhanced the lives of many people – not only the individuals who received the tissue grafts, but their families and extended families too. I'm sure they all delight in the improved quality of life their relatives now enjoy.

This knowledge is a constant comfort to my family and myself.

The gift of life through loss

Life, as we knew it, changed for us several years ago. It was early one morning, I was awake contemplating another new day when suddenly I could hear crying from the next room. It was my teenage daughter. She said to me, 'Mum, my head it feels like it's going to explode. Call the doctor. There's something wrong!'

Within 15 minutes she was unconscious. While I was calling the ambulance she stopped breathing, so I breathed for her until the ambulance arrived. She was in hospital within 45 minutes of me hearing her cry. A parent's worst nightmare had begun.

It was several hours before we had any idea what the problem was. After a CT scan they discovered that she had had a brain haemorrhage. Four hours after her admission to hospital she was in intensive care and we were able to visit her. She looked so 'normal' as though she were asleep. She was warm. Her chest was rising and falling. There was no visible sign that there was anything wrong at all. We could not believe what had happened in those past few hours.

The doctors had the first family conference soon after we saw her in intensive care. They told us that they didn't know why she had the bleed but it was so catastrophic that there was virtually no hope of recovery. Having heard that, my first thought was that she had to be still 'alive' so her dad and older sister, who were both working interstate, could get there to say goodbye. Next, I said that she would want to be an organ donor. However, the doctors quickly told me that this would not be discussed until brain death was established and the tests would not be performed for another 24 hours.

We had discussed organ donation when she went for her learner's permit for her drivers licence and she had said then that it was the right thing to do. I was lucky - there was no doubt in my mind that she would approve. I had always believed that organ donation was the only way for some good to come from a terrible situation but had never really thought that it could happen to us. Her dad and sister arrived later that day and we all had lots of time with her. Her younger sister brought in her Walkman and we played her favourite CDs. Her boyfriend talked to her about all the plans and

dreams that would now not be fulfilled. I sat and held her hand and hoped and prayed that she was still 'there' to hear how much we loved her and would miss her.

The brain death tests the next day confirmed our worst fears and the process commenced for organ donation. There were times when I thought to myself that we had given up on her too soon – after all, people wake up from comas and are OK. Then I would talk to the nurses and remember the stringent tests and realise that no matter how long she stayed on the ventilator she would not be waking up.

Watching the lift doors close on her as she was taken to theatre for the organ donation was heart breaking, but we were sure that it was the right thing to do. Even though we were in such terrible pain, it was comforting to know that somewhere out there people were rejoicing that their relative was being given a second chance at life.

Many people have been affected by my daughter's death, and although nothing makes it OK that she is not here to fulfil her dreams, the legacy she has left behind is far-reaching. There was nothing we could do to prevent her dying, but organ donation meant that her death was not meaningless. The recipients will never know who she was, but I am sure she will always be remembered by these strangers who have a second chance at living because of her 'Gift of Life'.

Shared words from donor families and 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

Letters from recipients

To our special donor family,

We can't put into words what your decision has meant to us and our little man, now aged 4. He had been given only a week to live after his liver failed for no apparent reason. It was a huge shock to us, as he had always been so healthy. After a short stay in our local hospital he later received his life-saving transplant. If it weren't for your decision, he would have died. That decision tore at our hearts, as while we were praying a donor would become available, we knew someone was to lose a relative.

Our cheeky, lively little boy is now back to full health and living like a normal 4-year old. We and our families thank you so very much.

We hope this letter brings you some comfort in your time of grieving. You didn't only save our son, you saved a brother, grandson, cousin and nephew.

Dear donor family,

I am a mother and about 18 months ago I realised my eyesight was deteriorating. Just before Christmas, I woke to very smoky and hazy vision, which was so scary. I rang my GP who sent me straight to an eye specialist who diagnosed Fuchs Dystrophy Syndrome, a hereditary eye disease that would require a corneal transplant in both eyes. Looking back, my vision had been going slowly and I remember trying to read to my daughter and finding it so difficult. I had to hold up a torch so I could read to her.

My father had the same disease and had corneal transplants, so I sort of knew a little about the procedure, but was still very nervous and scared. The phone call came only 4 months after being on the waiting list, and although terrified, I was so hoping to one day be able to see again and read to my daughter.

It has now been 10 months since my corneal transplant and not a day passes by that I don't think of and thank my donor, who has given me a chance to see. Had the family chosen not to donate, I would not be able to tell you my thoughts and give thanks for what I have been given.

I am able to read to my 6-year-old and help her learn to read. Last week I saw freckles on her nose for the first time. I simply cannot express how wonderful these little experiences are.

The love and thanks I feel for this family and their relative is unexplainable. Their generosity and selfless love has given me the sight to see my daughter. I cannot thank them enough, just to know that out there somewhere, they have made me the happiest mum in the world. Without donation, I would not be able to write this letter.

From the bottom of my heart, thank you. Thank you for the gift of sight. Although we will probably never meet, this family will always be in my thoughts and prayers. THANK YOU!

Words from a donor mother

Dear recipient,

In my line of work I travel large distances, which gives me ample time for contemplation. While travelling home last night I was wondering how the people who had received one of our child's organs were faring. Imagine my delight in finding your letter. In reply, it gives me great pleasure to wish you well in the future.

I like to think that a portion of my child's spirit lives on with you. They were a truly lovely person – very caring, made friends readily, generous of spirit, and a good sportsperson who loved anything to do with the outdoors. While we are deeply saddened at the suddenness of departure, the memories are so very sweet.

May I make a request? Simply that you tell your family and close friends that they are loved. I was fortunate to have been told 'I love you, mum' in a special moment, completely out of the blue only a very short while ago and it is one of my most precious memories.

Take care and God bless.

Contacts

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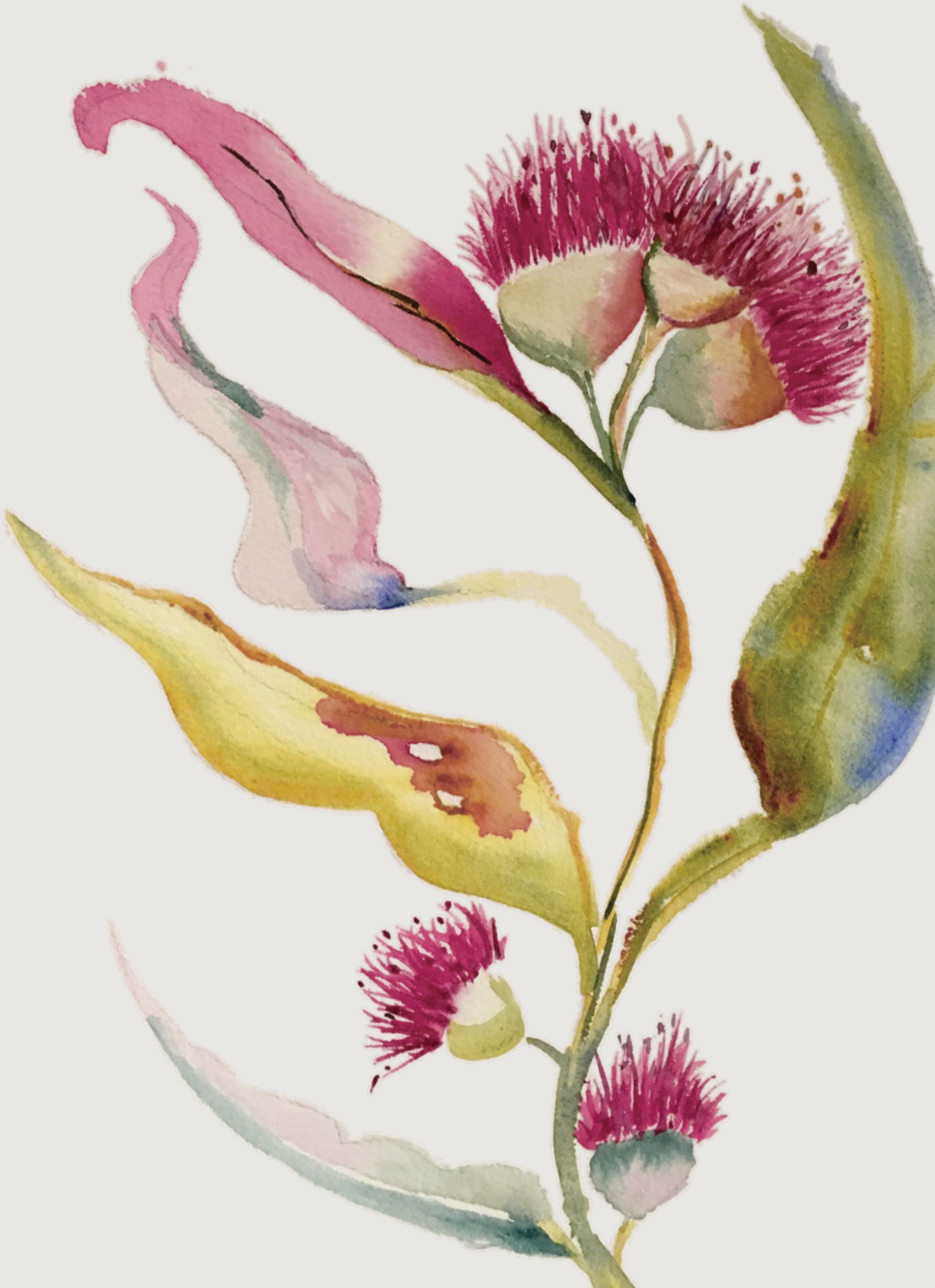
For information on additional support please refer to the 'Counselling support services' brochure available through the DonateLife agency in your state or territory.



Section Three

Donation

Donation

During the donation process you and your family will have received a lot of information at a highly stressful and emotional time. As time passes, people often begin to remember events more clearly and may wish to get further information or simply confirm their understanding of the processes that took place. The following pages provide information and answers to some common questions families and friends ask about donation.

Pathways to organ and tissue donation

There are 2 pathways in which it is possible to donate organs and tissues after death.

Death must have occurred before donation can take place. Death can be determined in 2 ways:

- **Brain death** occurs when a person's brain permanently stops functioning.
- **Circulatory death** 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

What is 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, 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 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 blood is unable to flow to the brain. 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 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 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 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 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.

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.

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 would have provided you with further information if such a test was necessary.

Once death has been confirmed, members of the medical team speak with the person's family about the next steps, including removing the ventilator.

Every family's experience is slightly different, but it will have been around this time that the medical team began speaking with you and your family about the possibility of organ and tissue donation.

Circulatory death

What is 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, terminal heart or lung failure, or a very severe spinal injury where the person cannot move or breathe unassisted.

When doctors have determined that the person's life cannot be saved, the priority is then to support them with care, comfort and compassion at the end of their life. The withdrawal of life supports 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 patient'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 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 that 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.

Every family's experience is slightly different, but it will have been when doctors believed that your family member was not going to recover that the medical team began speaking with you and your family about the possibility of organ and tissue donation.

Information and common questions asked about donation

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.

Does 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 in any other operation.

Are funeral arrangements affected?

Organ and tissue donation does not affect funeral arrangements. Viewing your 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.

Is the person's family expected to pay for the cost of donation?

No, there is no financial cost to the family for the donation. If you have received any accounts in relation to organ or tissue donation, please contact your state or territory DonateLife agency or donor coordinator.

Which organs and tissues are donated?

The donation specialist staff discusses with the family which organs and tissues may be possible to donate. This depends 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 are asked to sign an authority form with this information.

Does the donor'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. 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.

Are the person's organs definitely transplanted?

When donation is supported by the family, everything possible is 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 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.

Does the family receive information about people 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 will be discussed with families, and families can request further updates from their local DonateLife agency. Donor families and transplant recipients can write anonymous letters to each other through their local DonateLife agency and transplant units.

Information and common questions asked about transplantation

Organ and tissue donation can save and significantly improve the lives of many people who are sick or dying. For many people with a serious or critical illness related to organ failure, organ transplantation is the only hope for a healthy life. The following pages will provide some information on the different organs and tissues that can be donated, and the reasons some people need a transplant.

Heart donation

The heart pumps blood around the body, and the blood carries oxygen to all other organs. If the heart cannot pump blood properly, the rest of the body can become sick very quickly. Some people with heart failure, viral infection, or a congenital heart defect, require a heart transplant to survive. Heart transplants are performed when all other forms of medical treatment have failed.

Artificial hearts can be used temporarily until a human heart is available. If the whole heart cannot be transplanted (e.g. if there are no matching recipients) heart valves can still be donated.

Lung donation

The lungs provide oxygen to the blood and remove carbon dioxide. Lung transplants are often needed by people with cystic fibrosis or emphysema whose own lungs cannot provide enough oxygen to their bodies. The 2 lungs can be transplanted together into one recipient or separated and transplanted as single lungs into 2 recipients.

Many people believe that smoking will prevent lung donation. However, this is not true. There are tests that can be done in intensive care to check how well the lungs work and these results determine suitability for donation.

Kidney donation

The main function of the kidneys is to filter waste products from the blood. When the body has taken what it needs from food, waste is sent to the blood, filtered by the kidneys, and leaves the body as urine. If the kidneys are damaged or diseased and not able to filter the blood properly, wastes begin to build up in the blood and damage the body.

People with severe kidney failure are put on dialysis, which filters waste products from the blood when the kidneys cannot. However, many of these people will need a kidney transplant to stay alive. The 2 kidneys can be transplanted together into one recipient, or separated and transplanted into 2 people.

Liver donation

The liver is a complex organ with many functions. Its main functions are to maintain a balance of nutrients (e.g. glucose, vitamins and fats), to remove waste products and to regulate blood clotting. People with metabolic liver disease, Hepatitis B or C and congenital liver defects such as bilateral atresia can all require liver transplants to stay alive.

The liver is a unique organ as it can regrow. This means that an adult liver can be reduced in size and transplanted into a small child, where it can then grow with the child. Alternatively, the liver can be divided and transplanted into 2 recipients.

Pancreas donation

The pancreas contains cells called islets that produce insulin to regulate the body's blood sugar levels. In people with type 1 diabetes, the pancreas produces little or no insulin, and it can be extremely difficult to control blood sugar levels even with insulin injections. Currently, most pancreas transplants are performed on people who have type 1 diabetes, which can also cause kidney failure. For this reason, the pancreas is often transplanted with a kidney from the same donor.

Pancreas islet donation

Sometimes it is not possible to transplant the pancreas as a whole organ. However, the insulin-producing islet cells of the pancreas can be transplanted separately as a treatment for diabetes.

Eye tissue donation

Donation of eye tissue can allow transplantation of the cornea and the sclera. 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. Corneal transplants restore sight to people who are partially or completely blind due to corneal damage following a genetic condition, illness or injury. 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.

Bone donation

Donated bone tissue can be grafted to replace bone which has been lost as a result of tumours or through other disease or accidents. It is also used to aid fracture healing, strengthen hip and knee joint replacements, and to repair curvatures of the spine (scoliosis) in children and teenagers. Depending on the type of transplant required, over 10 people can benefit from a single bone donation.

Skin donation

People who have suffered extensive trauma, infection damaging or destroying the skin, or severe burns can require skin grafts to become healthy again.

When skin is donated, only a thin layer is retrieved, like the skin that peels in sunburn. It is usually retrieved from the person's back and the back of their legs. On average, skin from 3 donors is needed for one recipient.

Heart tissue donation

While the heart can be donated as a whole organ, heart tissues can also be donated separately. Donated heart tissues such as heart valves are primarily used to repair congenital defects in young children and babies. The tissue is also used to replace diseased valves in adults.

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‘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

DonateLife

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