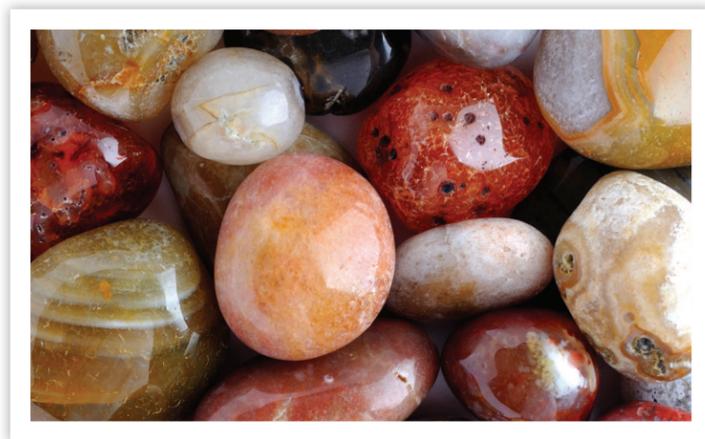


From Heartache to Hope
A JOURNEY OF GRIEF AND HEALING



*As in NATURE, as in ART, so in GRACE; it is rough treatment
that gives SOULS, as well as STONES, their LUSTER.*

– Thomas Guthrie

From Heartache to Hope

A JOURNEY OF GRIEF AND HEALING

Please accept our deepest sympathy on the death of your loved one. As you find yourself on a journey you likely did not expect to travel you may have questions about the grieving process and your loved one's gifts of donation. While your grief journey will be uniquely yours, our hope is that the following information and resources will be of comfort to you and your family.

As a donor family member you will receive support from LifeSource in the months and years to come, including invitations to participate in remembrance events and opportunities to connect with other grieving families whose loved ones gave the gift of life. We are honored to support you as you navigate this journey of grief and healing. Please contact us at any time by calling **1.888.536.6283** or by emailing us at **familyservices@life-source.org**. You can also find more information online at **www.life-source.org**.

The gifts of donation so generously given by your loved one and your family are precious, and we are honored to be stewards of these gifts. Transplantation would not be possible without your generosity. Thank you for putting your trust in us.

Please be assured that you, your family and your loved one will not be forgotten.

What is Grief?

Grief is the emotional suffering we experience when we lose someone or something that is important to us. It is a healthy and normal response and a necessary process for adjusting to living without the person we love. Grieving is the work we must do before we are able to fully embrace life again. Each of us grieves in our own way, and our expression of grief is determined by our culture, earlier experiences with loss, our gender and age. Some cultures permit and even encourage open expression of feelings, while others discourage it. People may demonstrate their grief differently because of the way they have been socialized. Children express grief as it relates to their level of understanding, their age and the way significant adults share their grief with them. Because each of us is different in our upbringing and experiences, it's important that we respect one another's ways of dealing with grief.

The Grieving Process

The grieving process involves several phases that are experienced by each of us in our own way and on our own timetable. Grief is a journey and you will find the path that moves you from heartache to hope in your own time. There is no right or wrong way to experience your grief. Please be gentle with yourself as you explore this new world of living without your loved one.

Most of us initially respond to a sudden death with shock and disbelief. We just cannot believe what has happened. This leads to a period of denial because we do not want to believe the person is gone. As we slowly begin to accept the reality of the death, we often feel confused. This confusion is made up of many feelings that seem to fight with one another.

In recognizing our feelings and expressing them we can begin to feel better. Dealing with our feelings helps us learn more about the meaning of our relationship with our loved one and the impact of their loss on our life. It is in this process that healing begins. With this healing comes a sense that life is beginning to feel normal again. The following is a description of common reactions and feelings you may experience as you grieve for your loved one.

Shock and Disbelief

Shock and disbelief are the most common reactions to the sudden death of a loved one. The general feeling at this time is one of numbness, which allows us to function and thereby helps us accomplish what we need to do regarding our loved one's death. This numbness is nature's way of protecting us from becoming overwhelmed by the impact of our loss.

You may also experience physical symptoms in the first weeks, including aching in the chest and arms, heart palpitations, feeling as though you can't get a deep enough breath, or constant sighing. If your loved one was ill you may find that you are experiencing similar symptoms. Your appetite and sleep patterns may be affected and you may experience nightmares. Some people experience visions of their loved one, or think they hear them crying or calling out. If this happens, please know this is a normal response to the loss of a loved one and it lessens over time.

Denial

When we experience a tragedy we do not want to believe it has happened. This is why you may find yourself wondering, at times, if this is just a bad dream and you will soon awaken to find that it is not true. You may feel the need to tell the story over and over again, which can help convince you of its truth. Accepting the reality of your loved one's death will help you move forward in the grieving process. Acceptance comes in time and may increase your feelings of loneliness and sadness. When you can no longer deny your loved one's death, you may have a greater sense of the loss and its affect on your life.

Confusion

As the numbness wears off, many feelings begin to surface—strong feelings that seem to be all mixed together. At this point, we tend to feel unsure of what it is we think or believe because it seems to change from day to day. Our emotions feel out of control. Talking about your feelings and writing them down can be helpful in gaining some clarity during this period of confusion.

Feelings

The feelings that surface for us after a loss relate to the manner of death and our relationship to that person. If the death was expected, we may have had time to say “goodbye.” However, when death is caused by suicide, sudden illness, homicide or an accident, there is no time for “goodbye” or to take care of unfinished business with our loved one. These factors tend to complicate the grieving process and intensify feelings.



Fear

Fear is a normal reaction to the sudden and unexpected death of another person because we are confronted with how helpless we are in the face of death and that bad things can happen to us. The universe may no longer feel like a safe place. This sense of vulnerability is compounded by the fact that we must go on living without that special person. Since we do not know what this will be like, the future may seem uncertain and scary.

Anger

Anger stirs within us when someone we love has died. It is quite natural to be angry because we feel abandoned and victimized. Even when our loved one did not have control over his or her death, we are angry at him or her for leaving us. Some of us get angry at God, while others express anger toward the medical system for not being able to save the person. It is important that you express feelings of anger (in an appropriate manner); failure to do so can result in depression.

Guilt

Guilt is present when we feel that we “should have” or “could have” done something to prevent the death and when we have unfinished business with the person who has died. We often show our guilt by being angry at others when we are really angry at ourselves. You may find yourself saying things like: “If only I had not let him use the car that night” or “If only I had told her that I am sorry for what I said during our argument.” These statements may give you some insight about your feelings, which may help you process your experience.

Emptiness and Loneliness

Emptiness and loneliness occur because a part of us goes with our loved one. The emptiness is felt both inside ourselves and in the world around us. No one can fill the empty spot or take away the loneliness because the relationship you had with that person was unique. Learning to live without your loved one is the most difficult task of the grieving process.

Depression

Depression is the sadness that seems to stay with us for a long time after the death. It is characterized by low energy and a lack of interest in the pleasures of life. As you learn to accept and express your feelings, depression will begin to ease. You will realize that it is lifting when you are able to have a fairly good day and not cry every time you talk about your loss.

Be gentle with yourself and give yourself time. It may take several years for you to get to the point of feeling really good about life again. Within six months of the death, you should start to notice improvement in your sleeping habits and appetite, as well as an increased ability to concentrate, work and find pleasure in living. If you do not notice improvement in these areas or have thoughts about wanting to hurt yourself or die, you may be experiencing a depression that requires professional help.





Recovering After Your Loss

Learning to live without your loved one is the most difficult part of the grieving process. You learned to depend on his or her presence, and their death leaves a void that cannot be filled. As you become accustomed to their absence, you will develop a new routine and begin to feel like you are more in control. You will notice that your concentration has improved and the “good” days will begin to outnumber the “bad” ones. Life is of interest again and you may be forming some new relationships. You may even recognize some ways you have grown through this difficult time. The journey is uniquely yours.

What to Tell Children

Adults often try to protect children by sheltering them from information or participation in death rituals. What you choose to share with your children or the children in your family may vary depending on the age of the child, their prior experience with loss, their relationship to the deceased and the cause of death.

Generally, children need simple explanations of the truth. They can sense when adults are not being truthful, which can result in a loss of trust and security. It's better to tell them in simple terms that the person has died. If you show that you are open about your feelings and are interested in their feelings, they will be more comfortable asking questions and expressing themselves. This is what they may need in order to learn about death and feel secure.

Many younger children (age three to five) see death as reversible. You may have to repeat the conversation about the death several times in order for them to begin to understand. The distinction between any accident and a tragic accident may not be comprehended. Attention to the child's questions, with repeated simple and consistent messages, should increase their understanding. Encouraging younger children to express their emotions is important.

Children age six to twelve will require a more detailed explanation of the death. For example, describing the difference between routine illness and terminal illness may be important. Sharing your emotions with children this age may be helpful for them to identify and express their own feelings. Adults should also reassure children that they do not bear any responsibility for the death.

Explaining the death and helping teenagers understand emotions is important. Many adults assume teenagers will take care of themselves. Adult support is necessary to allow teenagers to discuss any anger, guilt or responsibility they feel.

Explaining suicide and murder to children requires thought. Honesty remains an underlying requirement. Anger toward the loved one is natural in suicide, and children should be advised that feeling angry does not mean you did not love the person. Older children will probably seek a more detailed explanation, which should be provided as appropriate.

In explaining murder to a child, the explanation should be as simple as possible as to what happened and who did it and why, if known. A suggestion for explaining the murder of a loved one is: “A terrible thing happened over which we had no control.”

Withdrawal, regressive behavior, problems in school, misbehavior, appetite and sleep problems are normal in children after the death of a loved one. Children may also fear that remaining family members will abandon them. If these or other problems persist, it may indicate the child would benefit from professional help.

Suggestions to Help with Your Grieving

1 *As you already know, grief is work. Get plenty of rest and eat a nutritious diet.*

2 Avoid the use of alcohol, tranquilizers, sleeping pills and other drugs. These give only temporary relief and may complicate the grieving process. Feeling the pain is one of the necessary tasks of grieving your loss.

3 Try to get some daily exercise, even if it is just a short walk. Exercise can help you manage your anger and frustration.

4 *Ask for and accept support from family and friends. They will be eager to help but are often unsure about what to do. Let them know what you need.*

5 KEEP A JOURNAL OF YOUR THOUGHTS AND FEELINGS. THIS PROVIDES YOU WITH A WAY TO EXPRESS YOURSELF AND A PERSPECTIVE ON YOUR PROGRESS.

6 Talk about your feelings and thoughts with someone who listens well and will not tell you how you should be feeling.

7 *Speaking with your religious leader or clergy may be helpful.*

8 IF YOU FIND YOURSELF PREOCCUPIED WITH YOUR LOVED ONE'S GIFTS OF DONATION OR THE PROCESS OF ORGAN, EYE, OR TISSUE DONATION, PLEASE GET IN TOUCH WITH ONE OF OUR DONOR FAMILY ADVOCATES.



9 Be gentle with yourself about your grief journey. When people indicate that “you should be over this,” gently remind them that everyone experiences grief differently and tell them how they can help you.

10 Avoid getting over-involved with work or other activities. While work provides some necessary relief and structure, you also need time to think and experience the pain of your grief. If all the hours of your day are filled with activities, leaving no time for anything else, you may be avoiding your feelings. Try to find balance.

11 Reading books on grief related to the type of loss you have experienced can be very comforting and provide you with a deeper understanding of your grief experience. Our Donor Family Advocates can provide references.

12 DELAY MAJOR DECISIONS UNTIL AFTER THE ACUTE STAGE OF GRIEF WHEN YOU WILL BE ABLE TO THINK MORE CLEARLY. MOVING OR CHANGING JOBS MAY DRAIN YOU OF ENERGY AND COMPLICATE THE GRIEVING PROCESS.

13 *Find ways to take a break from your grief, like going to a funny movie or reading a good novel. It is okay for you to laugh and have fun. Finding enjoyment can provide relief and help create balance in your life.*

14 Share memories about your loved one. This can help you feel closer to them and ease your pain. Putting together a picture album of your loved one's life can provide comfort and also creates a nice keepsake.

15 *If after six months you are seeing no improvement in your ability to function, or at any time you have thoughts of wanting to hurt yourself or die, you may be experiencing a depression that requires professional help. Talk with a mental health professional about the difficulties you are having.*

16 *Holidays and special days, such as the anniversary of your loved one's birth or death, can be difficult because the person's absence is more pronounced. This may be true for many years. Plan ahead for how you will spend this time and develop some rituals for remembering your loved one. For example, light a candle at mealtimes or play his or her favorite music.*

17 *YOUR LOVED ONE'S BELONGINGS CAN PROVIDE COMFORT AND HELP YOU FEEL CLOSE TO HIM OR HER. DECIDING WHAT TO DO WITH YOUR LOVED ONE'S BELONGINGS SHOULD OCCUR WHEN YOU ARE READY.*

18 *If your loved one died by suicide, you may tend to isolate yourself due to feelings of guilt and shame. You may want to consider seeking the help of a support group to better understand your feelings and receive support. Our Donor Family Advocates can assist you in locating grief resources or support groups.*

19 *Obtaining counsel from an accountant or lawyer regarding your loved one's estate or will can help you feel confident that these matters are being handled properly, which may help reduce your stress.*

20 *BEING TOUCHED, HELD, OR HUGGED BY SOMEONE WHO CARES ABOUT YOU CAN BE VERY HEALING. A MASSAGE CAN HELP REDUCE THE EFFECTS OF STRESS ON YOUR BODY AND PROVIDE COMFORT.*

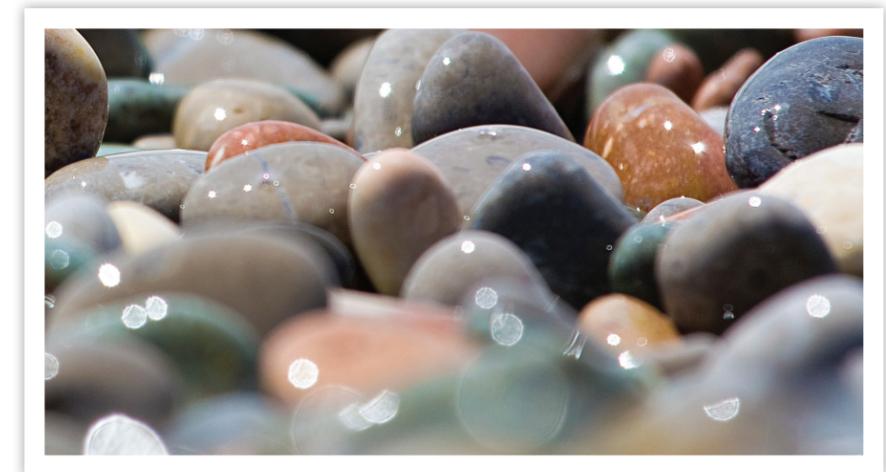
21 *Spiritual readings in line with your beliefs may help give you some perspective and sustain you through this time.*

Organ, Eye and Tissue Donation

"Donation was our bright spot. You know all of the good things about your child, and this is their last good thing."

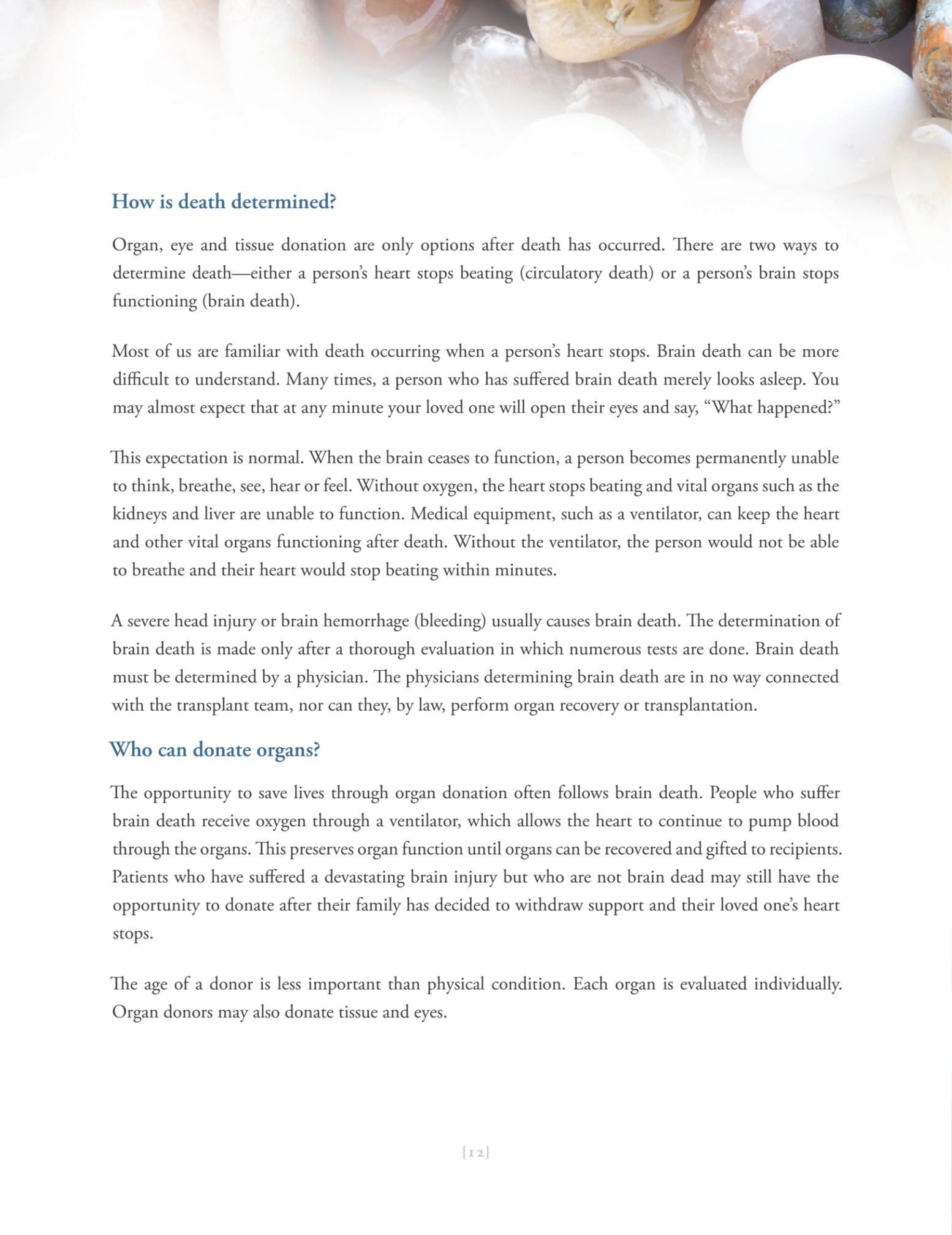
– Kim, donor mom

As a donor family member, you are part of a precious group of people whose loved ones continue to provide life and healing to others. We understand you may have questions about your loved one's gifts of donation and we hope the information on the following pages will help. If you have any questions about your loved one's gifts, the process of donation or anything else, please do not hesitate to get in touch with us.



*I alone cannot CHANGE THE WORLD,
but I can cast a STONE across the waters to CREATE MANY RIPPLES.*

– Saint Teresa of Calcutta



How is death determined?

Organ, eye and tissue donation are only options after death has occurred. There are two ways to determine death—either a person’s heart stops beating (circulatory death) or a person’s brain stops functioning (brain death).

Most of us are familiar with death occurring when a person’s heart stops. Brain death can be more difficult to understand. Many times, a person who has suffered brain death merely looks asleep. You may almost expect that at any minute your loved one will open their eyes and say, “What happened?”

This expectation is normal. When the brain ceases to function, a person becomes permanently unable to think, breathe, see, hear or feel. Without oxygen, the heart stops beating and vital organs such as the kidneys and liver are unable to function. Medical equipment, such as a ventilator, can keep the heart and other vital organs functioning after death. Without the ventilator, the person would not be able to breathe and their heart would stop beating within minutes.

A severe head injury or brain hemorrhage (bleeding) usually causes brain death. The determination of brain death is made only after a thorough evaluation in which numerous tests are done. Brain death must be determined by a physician. The physicians determining brain death are in no way connected with the transplant team, nor can they, by law, perform organ recovery or transplantation.

Who can donate organs?

The opportunity to save lives through organ donation often follows brain death. People who suffer brain death receive oxygen through a ventilator, which allows the heart to continue to pump blood through the organs. This preserves organ function until organs can be recovered and gifted to recipients. Patients who have suffered a devastating brain injury but who are not brain dead may still have the opportunity to donate after their family has decided to withdraw support and their loved one’s heart stops.

The age of a donor is less important than physical condition. Each organ is evaluated individually. Organ donors may also donate tissue and eyes.

How do vital organs help people?

There are many more people waiting for a transplant than there are donated organs. Sadly, every day people across the country die because they did not receive the organ they so desperately needed. If your loved one was an organ donor, they provided a second chance at life for the grateful recipients they so generously helped.

- Our *heart* delivers oxygen and nutrients to all the cells in our bodies. Patients who need a heart transplant will not survive without this precious gift, often waiting in the hospital or at home for many months.
- Our *lungs* move oxygen into the body and carbon dioxide out of the body. Lung transplants most often benefit people with cystic fibrosis, emphysema and pulmonary hypertension.
- Our *liver* cleanses our blood and removes waste and toxins from our bodies. People in liver failure are often jaundiced, which means that their skin and eyes have yellowed because this vital organ is no longer working. The liver can be split and transplanted into two people.
- Our *pancreas* regulates blood sugar through the production of insulin. Patients with diabetes benefit from a pancreas transplant.
- Our *kidneys* are the filtration system of the body. Kidney failure may be a result of kidney disease, diabetes or high blood pressure.
- Our *intestine* breaks down the food we eat and allows the body to absorb nutrients. People with digestive disorders benefit from an intestine transplant.

How does tissue and eye donation help people?

Tissue and eye donation are incredible gifts that restore life, sight and hope to grateful recipients. If your loved one was a tissue donor they may have the opportunity to help someone with a single, unique gift or provide dozens of health-restoring gifts months to years following donation. Cornea transplants typically happen days or weeks following recovery.

- Our *corneas* are the clear, contact lens-shaped tissue covering the eye. A cornea transplant restores or improves sight following injury, infection or disease.
- Our *tendons and ligaments* are examples of *connective tissue*. These types of transplants restore mobility, reduce pain and promote healing in patients with injury.
- Donated *bone* can be used to repair bone damage or loss after serious injury, crippling diseases of the bone, or bone cancer.
- Our *heart valves* regulate blood flow in the heart. Transplanted valves replace damaged or defective valves.
- Our *veins* carry blood to all the parts of our body. Donated veins help restore blood flow in people whose own veins are badly damaged because of disease or injury and can help prevent amputation.
- *Skin* is our body's external protection against injury and infection. Donated skin can help people who have been severely burned or injured or help restore function after surgery.

How does the donation process work?

The information you or a trusted friend or family member provided us about your loved one's medical and social history was combined with extensive medical testing, a physical examination and multiple laboratory tests to determine which of your loved one's organs, eyes and tissues were able to be recovered and gifted to others. The testing included screenings routinely performed on all donors to avoid the spread of infectious diseases to recipients.

If your loved one was an organ donor, a LifeSource coordinator worked with the United Network for Organ Sharing (UNOS) to match your loved one's organs with waiting recipients. After the organs were accepted, transplant teams from each facility traveled to the hospital where your loved one died for organ recovery surgery. Organ recovery is a surgical procedure and the utmost respect was given to your loved one and their precious gifts of donation. Once recovery was complete, the organs were transported to the recipient's transplant center for transplantation surgery.

If your loved one was a tissue or eye donor, those gifts were recovered by highly trained technicians. After recovery, your loved one's gifts were sent to our carefully chosen partners to be prepared for transplant. Eye tissue can be transplanted up to two weeks following donation. Tissue may be transplanted months to years following donation. Great care and respect was shown to your loved one during and after recovery.

Did my loved one experience pain?

No. Once a person has died the nerve pathways that conduct the feelings of pain no longer work. Therefore, no pain is experienced.

Is there any cost to my family?

No. There is no cost to your family for your loved one's gifts of donation. If you have questions about your hospital bill, please contact us as soon as possible at **612.800.6100** or **1.888.5.DONATE**.

Who received my loved one's gifts?

You should have received information explaining which of your loved one's organs, eyes or tissues were recovered, as well as general information about the organ and/or eye recipients who benefited from your loved one's gifts. To respect the confidentiality of your family and your loved one's recipients, names are not revealed.

Your loved one's gifts of tissue may be shared with others months to years following donation. Please be assured that your loved one's generosity will always be remembered by the recipients who so gratefully benefited from their gifts.

How were my loved one's organs matched with waiting recipients?

The United Network for Organ Sharing (UNOS) keeps a national list of everyone in the United States waiting for an organ transplant. The LifeSource coordinator who worked with your family communicated with UNOS to find the best matches between your loved one's organs and waiting recipients. The system is designed to fairly distribute organs based on medical urgency, genetic matching, waiting time and geography. Factors such as race, gender, income or celebrity status do not influence who receives a transplant.

Will I hear from my loved one's recipients? Can I contact them?

Whether or not you receive a letter from your loved one's recipients, please know that their gifts of donation are received with hope. Occasionally, transplant recipients choose to send cards or write letters to their donor's family, which we will forward to your family. If your loved one was an organ or eye donor, you may choose to write a letter to those recipients. Because the gifts of tissue donation may not be shared for some time, we are unable to forward letters from tissue donor families to recipients until a recipient has initiated contact.

The decision to communicate is a personal one for both donor families and transplant patients. In responding to a letter from a recipient, we encourage you to do what is most comfortable for you. As an organ or eye donor family, if you choose to write a letter, please send it to one of our Donor Family Advocates who will review your letter and then forward it to the appropriate transplant partner, who will then forward it to the recipient. Please feel free to send a greeting card, a letter or photos.

For more information on writing to transplant recipients visit our website at www.life-source.org/families or get in touch with one of our Donor Family Advocates.



My loved one had ‘donor’ marked on their driver’s license or in an online donor registry. What does this mean?

Your loved one made a generous decision to give the gifts of life and sight through organ, eye and tissue donation by marking ‘donor’ on their driver’s license or in an online donor registry. Their decision meant that upon their death they agreed to donate their organs, eyes and tissues to people in need. It’s a decision we were honored to help fulfill.

Are there opportunities for remembrance?

Your loved one’s generous gift provides hope to someone else – hope for a chance at living a healthier, more productive life. To recognize and pay tribute to their selfless act, gifts given with love and received with hope, we are proud to offer opportunities for you to honor your loved one’s legacy.

Available opportunities include our Memorial Wall, Garden Bench, Gallery of Hope, and Donor Family Quilt. You are invited to participate in any combination of tributes that feels right for your family, in time that is healing for you. Each donor may be included once in each opportunity, and we encourage family members to consider collaborating and submitting their tributes as a group.

We understand that these recognition opportunities will be helpful for some families and difficult for others. Please do what is best for your family. These opportunities are ongoing, available at any time, and do not have to be completed all at once. You can find more information at www.life-source.org/legacy.

LifeSource also hosts remembrance events to provide an opportunity for donor family members to come together and share memories of their loved one. Your family will be invited to these events, and we hope you will join us.

From Heartache to Hope

As you travel this journey of heartache to hope, we want you to know that we are here for you and your family. While the path is uniquely yours, our Donor Family Advocates are here to answer your questions and provide support and resources. If there is anything we can do for you or your family, please get in touch with us at 612.800.6100 or 1.888.5.DONATE or by email at familyservices@life-source.org.

We wish you continued peace and comfort.



Resources

Visit our website

Please visit our website for more information and resources. At www.life-source.org/families you will find information about legacy opportunities, writing to transplant recipients, and resources. You can also learn about our Donor Family Advocates who will be caring for you and your family in the months and years to come. Information about donor family events can be found on our event calendar.

Connect with us on Facebook

Follow us on Facebook at facebook.com/lifefsource.donate. We also offer three public Facebook communities, one for each of the three states we serve. You can search Facebook for “Donate Life Minnesota,” “Donate Life North Dakota,” and “Donate Life South Dakota” to connect with us.

We are also pleased to offer a private Facebook community for donor families to connect and share with one another. You can find instructions for joining at www.life-source.org/families.

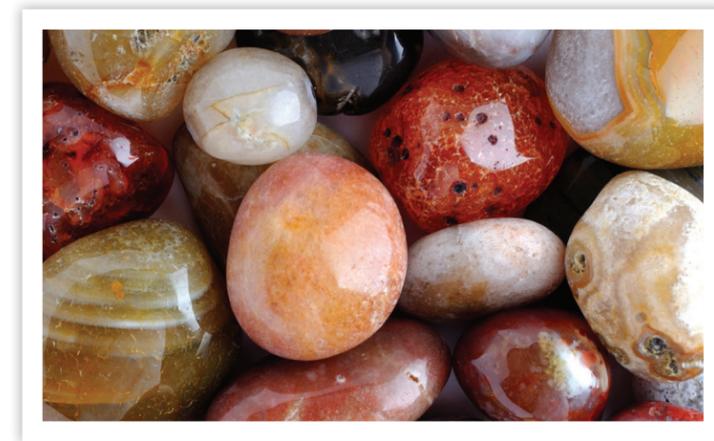
Follow us on Twitter

Follow us on Twitter to get brief updates on our activities, events and news stories.
[@DonateLifeMN](https://twitter.com/DonateLifeMN) or twitter.com/donatelifemn

Watch us on YouTube

On our YouTube channel you’ll find inspirational videos about donation and transplantation, including local donor family members and transplant recipients sharing their stories as well as our public education campaigns.

youtube.com/LifeSourceMN



We are grateful for the talented team at LifeNet Health who developed and shared the information in this valuable resource. The sections regarding the grief cycle, feelings related to grief, suggestions for self-care and information on talking with children have been adapted from LifeNet Health’s book “A Gift for Life: A Guide for Families.”

LifeSource

ORGAN, EYE AND TISSUE DONATION

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