This guide is prepared in loving memory of

individuals and families who chose to give the gift of life
to others, even in the midst of their own tragic loss.

We hope this resource provides assistance

and comfort after the loss of a loved one,

when families can feel overwhelmed and lost.
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Message to Our Donor Families

Dear Donor Family:

LifeLink offers our sincere condolences on the loss of your loved one. We recognize the generosity of your loved one and honor your support of organ and tissue donation. We hope you find comfort from the wonderful gift your loved one has bestowed upon others.

This guide is meant to provide helpful information to assist you through this most difficult time. Please know the precious gift of life your loved one gave will benefit the transplant recipient and the recipient’s family, friends and community. The staff at LifeLink thanks you.

If you have any questions regarding the donation process and your loved one’s gift please contact our office.

With Sympathy,

From the LifeLink Family to Your Family
The Loss of a Loved One

This is a time of great sorrow for your family; it may be difficult to think clearly. If possible, we suggest you ask a family member or trusted friend to assist you. Be kind to yourself; ask for help; give assignments to others; rest and take time to grieve.

With Your Help, Life Goes On...

For those seeking guidance and understanding about organ and tissue donation, the following information may help. Please don’t hesitate to contact your LifeLink coordinator if you have questions.

Was everything done to save the life of my loved one?
As always, everything medically possible was done to save your loved one. Donation becomes an option only after there is no possibility for survival.

What is brain death?
Brain death occurs when blood no longer flows to the brain, causing the brain cells to die. This condition is irreversible. Although the brain has died, other organs and tissue can function for a short time if supported by artificial means, such as a mechanical ventilator.

Why and how long must the ventilator be kept on after death has been declared?
The ventilator is kept on to provide oxygen to the vital organs, because without oxygen, they stop functioning and are no longer suitable for transplantation. The ventilator is kept on until organ recovery is arranged and performed.

What will happen after the organs and/or tissues have been recovered?
After the donation, if the death falls within the jurisdiction of the medical examiner or coroner, they may exercise their right to examine the body or perform an autopsy. Otherwise, the funeral home will be contacted, as would be the case with any death.

Donation After Cardiac Death

Donation After Cardiac Death (DCD) may occur when a patient does not meet brain death criteria, but their injuries are not survivable and the patient’s family chooses to discontinue lifesaving measures. These circumstances could result in donation opportunities including organ, tissue and eye donation.
How are organs and tissue used?

Up to 8 PEOPLE may be saved by transplanting organs from one donor.

Heart    Kidney    Liver    Lung    Pancreas    Intestine

As many as 75 PEOPLE may be helped by the gifts from one tissue donor.

SKIN: primarily used to assist in the healing of burn patients

BONE: used for a variety of orthopedic and spinal procedures

TENDONS: often used for sports-related injuries

VALVES: used commonly in heart valve replacement surgeries

Organ and tissue donation surgery is performed under sterile conditions in an operating room. The body is always treated with dignity and respect.

How are recipients chosen?
Recipients are chosen by urgency of need, geographic location, compatibility of blood type, tissue matching and body size. Gender, race, religion and social status are not considered. Tissue is available to any patient in need based on medical suitability. Just as donors are of all ages and backgrounds, so too are recipients. Transplant recipients can be of any age, gender, race, religion or other unique characteristic.

How will I know if the transplants are successful?
LifeLink will send general information regarding the organ recipients shortly after their transplants. The names will be withheld to protect the privacy of all parties concerned. More information for corresponding with recipients can be found later in this guide.

Visit www.UNOS.org for more information about the national waiting list for an organ transplant.
Will I be charged any additional costs associated with the donation?
No. All costs relating to the actual process of organ and tissue donation will be covered by LifeLink. These costs include expenses incurred after brain death has been declared and/or authorization has been completed, through recovery. Funeral and burial arrangement costs remain the responsibility of relatives or persons in charge of the estate.

What do I do if I receive a bill I feel is associated with the donation process?
Although we work closely with hospital billing to minimize the occurrence, occasionally charges may appear on the hospital bill you receive that are actually our responsibility. If you have any questions or concerns regarding this process, or receive a hospital bill with charges you believe are related to organ or tissue recovery, please contact LifeLink. It is our pleasure to assist you in ensuring all charges related to donation are ultimately billed to LifeLink. While it sometimes takes as much as several months for the billing-accounting-payment process to be completed, please be assured you will not be expected to make any payment for services directly connected with the gift your loved one provided to others in need.

Will the funeral be delayed, and will the body appear disfigured?
Since every effort will be made to schedule surgery as soon as possible, there should be no unnecessary delay in making funeral arrangements. The donation of organs and tissue do not interfere with an open viewing funeral.

Testing For Antibodies To The Human Immunodeficiency Virus (HIV)

In accordance with local applicable statutes and/or national regulatory requirements, all organ and tissue donations require blood testing to detect the presence of antibodies to HIV, the virus that causes Acquired Immunodeficiency Syndrome (AIDS).

Testing will be performed for antibodies to HIV. The test is important to ensure that the appropriate evaluation can be undertaken to prevent transmission of the virus to others.

Blood tests for the virus, which is the cause of AIDS, are not 100% accurate and these blood tests sometimes produce false positive or false negative test results. All confirmed positive results will be reported in accordance with state law.

A positive test may indicate the following:
- An exposure to the virus that causes AIDS and this exposure may or may not cause the development of AIDS in the future.
- The result may be a false positive.

A negative test may indicate the following:
- No exposure to the virus that causes AIDS.
- An exposure to AIDS, but where antibodies have not yet developed to produce a positive test.
- The result may be a false negative.

If the test results are positive, tissue will not be acceptable for transplant. In certain circumstances, organs may still be recovered for transplant.

The test results will remain confidential, except that the test results may be disclosed to those directly involved in the care of the person tested, and as is otherwise allowed by law.
What Happens Now

The Donation Process

Every donor, and every donation process, is unique. There is no standard timeline by which each phase of the donation process takes place. Below is a basic guide of what can be expected during the donation process.

1. A potential donor is referred to LifeLink.
2. LifeLink evaluates to determine if donation is possible.
3. If donation is possible, LifeLink checks the applicable state registry to determine if the potential donor is registered.
4. LifeLink meets with the donor’s family to discuss and confirm donation plans and review medical and social history.
5. The search for transplant recipients begins. Donor organs are matched by blood type, weight, age, severity of patient illness and time on the waiting list.
6. Matches are found and organ donation begins.
7. After organ donation is complete, if your loved one is also a tissue donor, tissue recovery will take place.
8. Many unexpected deaths are Medical Examiner cases. Medical Examiner investigations take place after the donation process is complete. Donation does not adversely impact the Medical Examiner investigation.
9. Funeral arrangements proceed as planned.
Donation should not delay funeral or memorial services planned for your loved one.

Delays, such as those caused by adverse weather, scheduling or transplant center logistics happen sometimes, and you will be kept informed of changes in the donation timeline.

Not only will LifeLink reach out to you throughout the donation process, you are welcome to contact LifeLink at any time, or to remain at the hospital or bedside with your loved one.

After a loved one has died, you may choose to:

- Contact your clergy.
- Notify other family members and ask key family members to assist in contacting extended family and friends.
- Select a funeral home and discuss with close family.
- Call employer(s)/school(s).
- Locate and review will/trust for burial instructions (it may be necessary to contact the family attorney for a copy).
- Contact insurance company to obtain burial funds (there may be other burial benefits available through government assistance).
- Call military if applicable (if deceased was a member of the armed forces, special military service may be available).
- Write obituary.
- Contact local newspapers to place public announcement. Your funeral home may assist.
- Have a family member or family friend stay with you to help, or be available to assist with your needs.
Funeral Arrangements

- Make an appointment with the funeral home of your choice.
- Notify the funeral home director that your loved one is an organ, tissue or eye donor — LifeLink is happy to answer any questions they may have.
- Decide the type of funeral service and its location.
- For an open casket service, bring clothes and other items to the funeral home.
- Request several certified copies of the death certificate.
- Inform the funeral home director if you want flowers or if you prefer donations to a charity in the name of your loved one.
- Notify family and friends of the funeral arrangements.

Some families want to include information about their loved one’s organ, tissue or eye donation in their funeral. You may consider:

- Include information on donation in your loved one’s obituary.
- Request donation information and materials to be available for attendees at your loved one’s funeral.
- Plan to mention your loved one’s organ, tissue or eye donation during the funeral service and encourage attendees to register as an organ, tissue and eye donor in memory of your loved one.
- Request contributions be made to LifeLink Legacy Fund in memory of your loved one, in lieu of flowers.
Obituary for Funeral

The obituary is a summary of your loved one’s life and an important connection for those the decedent has left behind. It is generally published in newspapers where your loved one lived and there may be a fee for publishing, although many families choose to place obituaries online. Many funeral directors will facilitate the obituary process for you. Important considerations include:

- Size requirements
- Photo specifications
- Photo return policy

Information you may want to include in the obituary:

☐ Full name
☐ Birth date
☐ Date of death
☐ Cause of death
☐ Education
☐ Marriage information
☐ Spouse or partner’s full name
☐ Children’s names
☐ Church/civic connections
☐ Career/business accomplishments
☐ Surviving relatives (list immediate family)
☐ Personal interest/hobbies
☐ Preceded in death by (list immediate family)
☐ Funeral date and service location
☐ Internment site
☐ Family message
☐ Special thanks to caregivers, etc.
☐ Information about your loved one being an organ, tissue or eye donor. If you would like to include the Donate Life logo in your announcement, contact LifeLink and we will provide it to you.

If you choose to offer the option to contribute to LifeLink, the following language could be included in the obituary.

- In lieu of flowers, memorial contributions can be made in your loved one’s name to LifeLink Legacy Fund and mailed to 9661 Delaney Creek Boulevard, Tampa, Florida 33619. Contributions may also be made online at [www.LifeLinkLegacyFund.org](http://www.LifeLinkLegacyFund.org).

- LifeLink Legacy Fund is a separate non-profit organization in support of LifeLink Foundation that provides funding assistance to pre- and post-transplant patients, organ and tissue transplantation related research and community grants/scholarships.
After the Funeral

☐ Send thank you letters to family and friends.
☐ Check with the Social Security office about benefits.
☐ File insurance claims.
☐ Consult an attorney for advice about a will and other financial matters.
☐ Check with the IRS about the paperwork you will need to file.
☐ Contact other government agencies (i.e. Department of Motor Vehicles) to inform them of your loved one’s death.
☐ Contact your local bank or other financial institutions.

Documents you may need for changing official records

☐ Social Security number
☐ Marriage certificate
☐ Copies of death certificate
☐ Copy of will
☐ Birth certificates of dependent children
☐ Copy of insurance policies
☐ Copy of certificate of honorable discharge
☐ Complete list of property
☐ Bank account number
☐ Car title
☐ Property title(s)
Experiencing Grief

Grief presents itself in different forms. Some characteristics of grief are:

- Distress, including emotional distress
- Hostility
- Guilt
- Blame
- Fear
- Preoccupation with image of deceased
- Loss of usual pattern of behavior
- Emotional withdrawal/isolation
- Depression
- Anger

Coping With Grief

You may need time alone or you may choose to spend time with others you trust. Every person deals with grief differently. It can take months and sometimes years to feel and understand the emotions which accompany the loss of your loved one. Grief is an individual experience and you will cope with your grief in your own time and manner. Others should not tell you how to cope with grief or push you “to be over it by now.”

There are many resources available to help guide your family through the grieving process, and organizations in Florida, Georgia and Puerto Rico which provide grief support groups to those who have lost a loved one. Bereavement support groups may include those who have suffered the loss of a parent/guardian; loss of a child/sibling; loss of a spouse; loss through homicide; survivors of suicide; and many others. There are specific support groups which target adults, while others specialize with children and adolescents.
Hospice organizations have bereavement support groups for those who have lost a loved one and are open to the public. For information on a hospice support group nearest to you, please contact your local hospice organization.

Hospitals may provide bereavement support groups as well. Please call the Chaplaincy Program or Pastoral Care at your local hospital for further information about the support groups offered.

Houses of Worship are an additional resource for many bereavement support groups and can help your family or refer you to other support services in your area even if you are not a member. Please contact a local House of Worship for further information about the types of bereavement support groups offered.

Funeral home representatives are helpful and may provide information on local bereavement resources as well as private counseling.

If you are unable to locate a grief support group in your area or one which can address your specific needs, please contact LifeLink so that we may assist you.

Books and other grief literature are available at local libraries, as well as most book stores. Many publications may address your specific loss, such as the loss of a child, parent, spouse or sibling.

Visit www.lifelinkfoundation.org/donor-families or the National Donor Family Council at www.donorfamily.org for more information on support and literature.
Future Correspondence from LifeLink

Sympathy Card
Your family has our deepest sympathy for your loss and you will receive a card with our sincere sentiments.

Family Services Letter
You should receive this approximately two weeks from the date of organ donation. This letter will remind you that charges associated with the donation process are not your responsibility, and how you may contact LifeLink if you receive a bill with charges you feel are associated with donation.

Family Letter
You should receive this letter within approximately one month from the date of donation. This letter will share some information about the recipients of your loved one’s organs and/or tissues. You will also receive a grief resource booklet.

Donor Medallion Packet
Each donor family receives a specially designed medallion commemorating the gift of life their loved one provided. This should arrive approximately 60 days after donation.
Survey
We want to ensure your experience with donation was positive. You will receive a survey approximately three months after donation. We appreciate your feedback so that we can continuously improve our support for families like yours.

Donor Quilt Square Project
Information about submitting a quilt square in memory of your loved one will accompany your survey. LifeLink has memorial quilts in Florida and Georgia and this project is ongoing.

Remembrance Card
The anniversary of the death of your loved one may be very difficult. We are thinking of you and your family during this time and you will receive a sentiment of support near the first anniversary of donation.

Letters Received From Transplant Recipients
Correspondence from recipients will be forwarded to you upon receipt.

Periodic Follow-up Letters
Contact LifeLink to request an update on the recipients of your loved one’s organs. We will mail them upon your request.

Note: If you requested not to obtain correspondence from LifeLink, you will not receive any of these items. However, if you change your mind and request the correspondence at a later time, we will provide it to you.
Guidelines for Writing to the Transplant Recipient(s)

Do you wish to correspond with the recipients of your loved one’s organs?

- Please address your correspondence to Transplant Recipient(s) (i.e. Dear heart recipient.)

- Identify yourself only as a donor family.

- On another sheet of paper, please write your name, donor’s name and the date of the donation so that LifeLink will know which transplant recipient(s) to send it to. This sheet will not be sent with your correspondence.

- Mail the letter to LifeLink.

- LifeLink will mail the letter to the transplant center, which may forward the letter to the transplant recipient(s), if appropriate. All confidentiality will be maintained.

- LifeLink reserves the right to remove personal information if it can be used to identify the donor and/or recipients.
Information you may want to include in your letter:

Talk about yourself and your loved one:
- Your/their job or occupation
- Your family situation (spouse, children, grandchildren)
- Your/their hobbies or interest
- The state in which you live
- Describe your loved one — did he/she play a sport, work, have children, etc.
- Since the religion of the recipient’s family is unknown, please consider this when making religious comments.

Talk about your donation experience:
- Use simple language
- Please write in a sensitive manner
- Explain how the donation has helped you deal with your loss
- Explain what has happened in your life since the donation.

Closing your card or letter:
- Sign your first name only
- Do not reveal your email address, home address, city, phone number, social networking sites or the name of the hospital where your loved one died.

Will I hear from the transplant recipient(s)?
You may or may not hear from your transplant recipient(s). Many transplant recipients want to receive correspondence from their donor family. They often times feel very close to the donor family. Others are overwhelmed with emotion and have difficulty expressing their gratitude.

Some transplant recipients, even though they are grateful for the donation, may not write to their donor family. They may not be able to express their feelings, have feelings of guilt or may need time to fully recover emotionally and physically. Remember, just as some donor families prefer to remain private, so do some transplant recipients.

Keep in mind, it may take several months or even years before a recipient feels comfortable writing to their donor family.
Volunteer Information

LifeLink volunteers come from many different walks of life. Some are members of a donor family, others are organ and tissue recipients, and some are people who have been touched by the story of a successful transplant. As a result of their experiences, volunteers share their stories with others. The mission of the volunteer group is simple: to increase donor designations by educating the community about the importance of organ and tissue donation.

More than 100,000 Americans are waiting for an organ transplant while hundreds of thousands more await tissue and corneal transplants. Eighteen people die each day waiting for an organ transplant.

LifeLink understands that a large majority of the public is aware of organ and tissue donation and transplantation, however most are unsure of the necessary steps to be a donor. Volunteers help clarify the donor designation process.

We invite you to learn more about the LifeLink volunteer program. Our public affairs department staff will gladly speak with you.

Visit www.lifelinkfoundation.org/volunteers to learn more about volunteering at LifeLink.

Without the love of a stranger I would not be here today.
I want to do all I can to make a difference in this life because someone made such a difference in mine.

- Heather, recipient
Now that Will has received his transplant, we are free to do normal family activities like evening walks around our neighborhood. The focus of every day used to be keeping Will alive, now our focus is really living.

- Mother of Will, recipient

Everyone else’s tomorrow was always more important to him than his own. We carry Joshua’s memory forward by continuing to help others.

- Monica, donor family mom
My new heart literally pumped life into my tired body and has inspired me to be the best I can be...keeping my gift going. Without my transplant, I would not have seen my children become successful adults. My donor and his family are never out of my mind. I think of them every day and want to honor my donor’s memory and help his legacy live on.

- Sherrell, recipient

In your darkest hour, you thought enough about the well-being of others to give the gift of life. A gift that will allow for birthdays and anniversaries to be celebrated, softball and basketball games to be attended, and the births of sons and daughters to be witnessed.

Please know that the death of your loved one was not meaningless, as a part of them, as well as their spirit, lives on in others. We recipients thank you and honor you!

- Quincy, recipient
Notes
To my donor family I would like to say that the last 11 years for me has been the most loving gift that I could have received. My comfort and joy every day is to thank God for the Gift of Life and my “Ben” who I carry with me every day. Thank you.

- Camille, recipient
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