



# *Family Care Guide*

We honor life through donation.<sup>SM</sup>

# *This is not an easy time. We know.*

Our hope is that, through your grief, this can be a meaningful time for you and your loved ones as you consider the gift of organ and tissue donation.



At Gift of Life Michigan, we have the honor and privilege to work with families like yours who are facing an often unimaginable tragedy.

Yet through their grief, they're able to give life to others — something most people never have the opportunity to do.

As you begin this journey, we will be with you every step of the way, honoring the gift and your hero.

Please accept my deepest condolences for your loss.

A handwritten signature in black ink, appearing to read 'Dorrie Dils', with a stylized flourish at the end.

Dorrie Dils  
CEO, Gift of Life Michigan



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## *We're here to help you*

Please accept our sincere condolences on the loss of your loved one.

As your personal journey of grief begins, know that many people are invested in you, your family and your loved one.

We feel privileged to be able to offer more than sympathy and bereavement help to families experiencing loss. We offer the opportunity for your family to give life, sight and mobility to others in need.

Organ and tissue donation is the ultimate act of human kindness, and families of donors often are comforted knowing their loved one will live on through others.

With the help of this guide and our personal attention to your family, we will make sure you understand the process, timing and logistics of donation while caring for your well-being along the way.

This guide also will help you with what comes later — your stages of grief, resources available to you and how to reach out to your loved one's transplant recipients, if you desire.

If your loved one was a registered donor, we'll explain what happens next as we move to fulfill his or her wishes. If your family member isn't registered, you will have the opportunity to decide and we will support you no matter what decision you make.

# *Brain death and discontinuing care*

Discussions about donation often begin when a family asks about or starts to make end-of-life decisions.

The first step in exploring the possibility of donation is to make sure families fully understand how the injury or illness resulted in their loved one's death. Some severe injuries to the head and brain can cause blood to stop circulating in the brain. When that happens, death occurs. Unlike a coma, brain death is the complete and permanent loss of brain function. It is death, both medically and legally.

Testing to determine brain death is thorough and can take time, but it's an important step in understanding the condition of your loved one. Only a physician or designated clinician can determine if brain death has occurred.

Brain death is declared when physicians have tested the function of the entire brain and determined it no longer controls vital systems, including breathing. The brain has permanently stopped functioning and no longer sustains life.

Some patients' brains, although severely injured, function only at the most minimal level, but not enough to support breathing without help. Those patients require a ventilator to help them breathe. Without it, their heart and lungs will stop, and they will die. In that situation, families may decide to discontinue medical support and let their loved one go.

In either of these scenarios, organ, tissue and eye donation may be possible.



# *Two Pathways to Donation*

Organ donation occurs only for patients in a hospital setting, and only after death has occurred.

## **Donation after brain death**

Most patients who are declared brain dead are cared for by nurses and organ donation professionals from Gift of Life Michigan before they are transferred to Gift of Life's state-of-the-art surgical center for organ recovery.

The patient's ventilator remains on until he or she is in surgery to recover the organs. A moment of silence is held for your loved one in the operating room, and families can request that our staff play songs, read prayers, notes or letters there before surgery begins.

Families are welcome to travel to Ann Arbor, although most decide at this point to transition their time and energy to funeral planning and other pressing matters.

Following the recovery of organs or tissues at our surgical center, Gift of Life will make arrangements with the medical examiner or funeral home to transport your loved one's body.



## Donation after circulatory death

For donors whose brains have been severely injured but still have minimal function, the patient will remain at the hospital, and the ventilator will be stopped in the operating room by the healthcare team that has been caring for your loved one.

This is called donation after circulatory death.

The patient will be given medication and won't experience pain or discomfort. When all circulation and breathing have stopped, a physician or designated clinician pronounces the patient dead.

If the hospital's policy permits (most do), a family member may be with their loved one to say goodbye. Gift of Life Michigan helps arrange this, if possible.

When the patient is taken off the ventilator, and once death is pronounced, families are asked to leave so the organ recovery process can begin.

If your loved one doesn't pass away within a short period of time, he or she will not be eligible for organ donation. If that happens, family members can stay with the patient until death is declared.



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**8** life-saving  
organs



tissues &  
corneas  
that can  
improve **75**  
LIVES



## *What can be donated*

Many people who die in a hospital under the circumstances described on the previous pages are eligible for organ donation. However, criteria for each organ varies depending on condition.

In Michigan, more than 3,000 people are in desperate need of a transplant.

**Organ donors could give up to eight organs to patients waiting for a life-saving transplant:**

- heart
- lungs (2)
- kidneys (2)
- liver
- pancreas
- intestines

Tissue donors can give skin, bones, tendons, heart valves, bone marrow, pericardium, blood vessels, nerves, eyes and corneas.

Transplantation and therapy are the primary uses of recovered organs and tissue. If organs and tissues are unable to be used for transplantation, they may be donated for education and research, which can lead to new treatments and cures for those suffering from diseases such as diabetes, cystic fibrosis, ALS and many more.



## Donated tissue and how it helps others:

- Bone can be formed into different sizes and shapes and is used in surgeries to replace or restore function, mobility and structural support.
- Tendons are used to repair ligament injuries caused by sports injuries and trauma.
- Cartilage can be used in reconstructive, periodontal and dental transplantation.
- Nerves can ease pain, restore sensory feeling and muscle or organ function.
- Heart valves can be transplanted to save the lives of those suffering from defects or damage.
- Veins and arteries are used to rebuild those that are damaged by surgery or infections.
- Skin grafts can save the lives of burn victims as well as ease their extreme pain. In addition, skin is used for cleft palate, gum surgeries and wound repair, breast reconstruction after a mastectomy, hernia and much more.
- Corneas restore eyesight for those who suffer from disease or injury. Eyes help in research and development projects, trainings and ocular patch grafts.





# *Donation Costs Nothing*

Your family will incur no costs associated with your loved one's life-saving gifts. You also won't be paid for the donation; that would violate state and federal laws. Families are responsible for hospital charges not associated with the donation and for funeral arrangements.

If your family member becomes a donor and you receive a bill from a hospital or a funeral home that you believe includes questionable costs, please contact Gift of Life immediately. You will be asked for a copy of the invoice and, if we are responsible, the bill will be paid.

# *Is your loved one registered?*

## **If your loved one is registered**

Gift of Life always checks to see if a patient has added their name to the Michigan Organ Donor Registry.

Millions of people in the state have signed up to help others. This is sometimes a surprise for family members who have never talked about donation with their spouses, partners, parents, children, siblings and others. But learning that their loved one already made the decision for themselves usually is a relief for families struggling with the tragedy and related stresses.

Your family member's decision to help others is a legal, binding document of his or her wishes. Family members cannot revoke that decision.

If your loved one is registered, it is our job to help fulfill those wishes to help others.

## **If your loved one isn't registered**

Your family member might have been a supporter of donation, and talked about that with friends and family members, but simply didn't get around to registering. If that's the case, your decision is probably a little easier.

But death isn't a topic most people like to think about or discuss even with close relatives, so it might not be surprising that your loved one didn't register and that you don't know their feelings about it.

As you consider donation, keep in mind that saving the lives of others would become a beautiful part of your family member's legacy.

Take a little time to ask questions. Gift of Life Michigan will be available to help you every step of the way.

You may call us anytime at **800-482-4881**.

# *What we will need from you*

Families are an important part of a successful donation process, whether authorization for donation was offered to your family or decided by your loved one.

You'll be asked to answer important medical and social questions about your loved one that will help determine if donation can happen.

We'll find a quiet, private place to talk with you and other members of the family who might also have answers.

Some of the questions we are required to ask are personal so we can ensure the highest level of health and safety for transplant recipients. All answers are kept confidential.

If we believe your family member is a good candidate for donation, you can stay at the hospital if you like. Please also consider your own well-being — get some rest and make sure you're eating and staying hydrated.

If you decide to go home for a break, our on-site staff can keep you updated. Please know that your loved one will never be alone. Gift of Life Michigan and hospital staff will be there around the clock to care for them.

# Notes

It can be overwhelming to absorb all the information you're being given right now. Please use this space to write down any questions you want to ask or other information you'd like to remember.

# *Timing, transportation and your loved one's funeral*

As with any medical procedure, the length of the process can vary and will be determined by many factors such as which gifts your loved one is able to give, the location of recipients and more.

## **Organ recovery**

As mentioned earlier, your loved one likely will be moved to Gift of Life's surgical center for organ recovery. We will discuss this with you ahead of time.

Once we determine which organs can be transplanted, we begin communicating with the doctors taking care of potential recipients and arranging the details leading up to the transplant.

Gift of Life Michigan will work with your family to accommodate any specific timeframes you need. This may include waiting until distant family arrives or to honor funeral arrangements or cultural rituals that are important to you. Share your needs with us and we will help.

## Tissue recovery

If your loved one is also a tissue donor, the process will take a little longer. We'll work with the tissue recovery specialists to keep you informed.

## Cornea and eye recovery

Eversight is the organization responsible for coordinating the eye tissue recovery process with healthcare staff and organ procurement organizations. Eversight's staff travels to hospitals and other facilities to recover tissue.

Once the donated tissue arrives at the Ann Arbor lab, it is carefully evaluated to ensure it is safe for transplantation. Thanks to advances in tissue-preservation methods, corneas can be transplanted up to 14 days after donation. In the United States, there is no waiting list for a cornea transplant.

After donation, Gift of Life will make transportation arrangements with the funeral home of your choice.

## Medical examiner involvement

A medical examiner might be involved, if the law requires it. Sometimes, the medical examiner will order an autopsy to determine the cause and manner of death. That can cause a slight delay in the release of a loved one to a funeral home.



## *After donation and writing to the recipients*

To extend our deep appreciation for your generous decision or support of your loved one's decision, you will receive a letter four to six weeks after the donation. The letter will contain information about what your loved one was able to donate.

Within two months, you will receive a letter inviting you to provide feedback on your experience with the donation process.

It is possible to contact the recipients of the gifts. Gift of Life will help with the exchange of anonymous correspondence between you and your loved one's recipients until both parties agree they are ready to exchange contact information. We also can help arrange for you to meet or contact each other directly by email or phone.



Dear Donor Family  
After a bad skateboarding accident when I was 13, my femur had a "missing piece out of its puzzle." My surgeon told my family I received what's called a "matched graft," a large piece of bone tissue to repair my injury. I am now 17 and doing well. Thank you for letting your loved one become a donor. This blessing means so much to me and my family.  
Sincerely,  
Samy Ward



## Writing to transplant recipients

The decision to write to the recipients of your loved one's organs and/or tissues is a personal one. Some donor families say it helps them in their grief process, but the choice to write or respond to a letter from them is yours.

You may or may not hear back from the recipient, even if they welcome the correspondence. They simply might not be ready to communicate. Many recipients have indicated difficulty in adequately expressing their gratitude in words and need time to deal with the overwhelming emotions associated with receiving an organ or tissue.

Correspondence is anonymous and kept confidential until both you and the recipient would like the other's contact information. Then you can correspond directly after signing release forms from Donor Family Services.

### Things to consider writing in your letter:

- Share general information about you and your loved one's life, occupation, hobbies, friends and interests.
- Sign only your first name.
- Refer to your loved one by their first name only.
- Please do not include specific information about him or her (i.e. last name, address, city, phone number, email address, etc.).

When your letter is complete, place your card or note in an envelope, unsealed. On a separate piece of paper include the donor's full name, date of donation as well as your address and phone number. Place both in an envelope and mail to:

**Attn: After Care Services  
Gift of Life Michigan  
3861 Research Park Drive  
Ann Arbor, MI 48108**

# *Other things to think about*

Here are checklists to help you navigate what comes next as you deal with post-funeral matters:

- Check with the Social Security office about survivor's benefits.
- File claims for insurance, if applicable. This may include life insurance, credit card insurance, mortgage or loan insurance, insurance on bank accounts, accident insurance, auto and homeowner's insurance, and insurance provided by your loved one's employer.
- Re-establish bank accounts and safe-deposit box in the appropriate name. Call before going to the bank to be sure that you have the necessary papers to make these changes. It may be desirable to have a co-signature on all accounts. If so, make arrangements with the person of your choice.
- Consult an attorney for advice about a will and other financial matters. If you do not have an attorney, the Lawyer Referral Service of the local bar association provides a list of attorneys. If you cannot afford an attorney, the Legal Aid Society can help you find legal assistance at reduced rates.
- Check with the IRS about the paperwork you will need to file with your tax return.
- The title of the car owned by the deceased may need to be changed. Contact your local Secretary of State office.

## Documents and official records you might need:

- Social Security number
- Marriage certificate
- Death certificate
- 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



## *Donor family resources*

**Gift of Life Michigan** can provide additional information regarding organ and tissue donation and transplantation.

We offer many opportunities to volunteer in the community and can train you to speak in public about your experience.

**The Donor Family Advisory Committee (DFAC)** is composed of people who have lost a loved one who has given the gifts of life, sight and/or mobility. DFAC is overseen by Gift of Life Michigan with the support of Eversight. The committee meets approximately four times a year to provide input to both organizations on best practices to support and honor donors and their families. All donor families are welcome to join the DFAC at any point after their loss.

To learn more, visit [golm.org](http://golm.org) or call **866-500-5801**.

**Eversight** is in Ann Arbor. Its mission is to preserve and restore sight through transplantation, research, education and partnership.

To learn more, visit [eversightvision.org](http://eversightvision.org) or call **800-247-7250**.

# Bereavement

Shock, anger, fear, hope, sadness, denial and eventually acceptance are typical emotions, but keep in mind there is no right way to feel after losing someone close to you. Accept each emotion as it comes, and if any feeling or emotion worries you, please ask for help in understanding what you're experiencing.

You will likely be experiencing acute grief. This means you may feel physical and emotional sensations that are scary and confusing. A few signs of physical symptoms include: fatigue, restlessness, stomach pain, headache, crying and nausea. A few emotional symptoms include: sadness, numbness, anxiety, panic, fear, irritability, anger and loneliness.

## Ways to manage your grief

**Stay physically aware and healthy:** Depending on what kind of grief you experience, it can be a trying physical experience. It is essential to maintain the best diet, sleep schedule and exercise.

**Honor the loss:** Give yourself time and space to feel the loss and honor the passing of your loved one. Find ways to honor them. Trust that process and feel the peace it brings you.

**Don't judge your feelings:** We all experience death differently. You feel what you feel. Each person has their own personal journey. Be kind, loving and nonjudgmental with yourself. Surround yourself with people who lift you up and support you.

## Bereavement resources in Michigan

This list is a sampling of services available and does not suggest endorsement.

### General

#### Hello Grief

Community-based grief blog offering memorial boards and information about local support.

[hellogrief.org](http://hellogrief.org)

#### New Hope Center for Grief Support

Serving Michigan. Offering grief support to the community.

248-348-0115

[newhopecenter.net](http://newhopecenter.net)

#### Hospice of Michigan

Serving Michigan.

888-247-5701

[hom.org](http://hom.org)

### Parents

#### Bereaved Parents of the USA

Serving Copper County and Macomb County.

[bereavedparentsusa.org](http://bereavedparentsusa.org)

#### Parents of Murdered Children, Inc.

Serving Detroit, Flint and Saginaw.

[pomc.com](http://pomc.com)

### Children and Teens

#### Ele's Place

Serving Ann Arbor, Grand Rapids and Lansing. Support for grieving children and teens.

[www.elesplace.org](http://www.elesplace.org)

#### Michigan Network for Grieving Children

Raising awareness about the needs of grieving children and teens and providing education and resources for those who support them.

[childrengrieve.org](http://childrengrieve.org)

#### SandCastles Grief Support Program

Serving metro Detroit. Grief support for children and families.

313-874-6881

[aboutsandcastles.org](http://aboutsandcastles.org)

### Suicide

#### American Foundation for Suicide Prevention

For prevention and survivors.

[afsp.org](http://afsp.org)

# *Gift of Life Michigan organ and tissue partners*

Gift of Life Michigan works with the following organizations to process and distribute life-changing tissue grafts.

## **Axogen, Inc.**

For-profit, domestic and international organization dedicated to nerve recovery and transplantation.

[axogeninc.com](http://axogeninc.com)

## **CellRight Technologies**

For-profit, domestic and international company producing bone, tendon, cartilage, ligament and skin grafts.

[cellrighttechnologies.com](http://cellrighttechnologies.com)

## **Community Tissue Services (CTS)**

Not-for-profit, domestic and international company producing bone, tendon, cartilage, ligament, skin and vein grafts.

[communitytissue.org](http://communitytissue.org)

## **CryoLife, Inc.**

For-profit, domestic and international company producing heart valve and vein grafts.

[cryolife.com](http://cryolife.com)

## **IIAM**

Not-for-profit, division of the Musculoskeletal Transplant Foundation (MTF) that provides human organs and tissues for medical research, education and development.

[iiam.org](http://iiam.org)

## **LifeCell**

For-profit, domestic and international company producing skin grafts.

[lifecell.com](http://lifecell.com)



## LifeNet Health

Not-for-profit, domestic and international company producing bone, tendon, cartilage, ligament, heart valve and vein grafts.

[lifenethealth.org](http://lifenethealth.org)

## MTF Biologics

Not-for-profit, domestic and international company producing bone, tendon, cartilage, ligament and skin grafts.

[mtf.org](http://mtf.org)

## National Disease Research Interchange

Not-for-profit, domestic company that distributes organs for medical education and research.

[ndriresource.org](http://ndriresource.org)

## Pinnacle Transplant Technologies

For-profit, domestic and international company producing bone, tendon, cartilage, ligament and skin grafts.

[pinnacletransplant.com](http://pinnacletransplant.com)



*When there is a donor,  
life springs from death, sorrow turns to hope,  
and terrible loss becomes a gift.*



3861 Research Park Drive  
Ann Arbor, MI 48108

[golm.org](http://golm.org)

800-482-4881



4889 Venture Drive  
Ann Arbor, MI 48108

[eversightvision.org](http://eversightvision.org)

800-247-7250

