

## Focus Group Questions & Answers

### **Would, or could, a deceased organ donation go to a criminal?**

The organ allocation process is based on medical and geographic factors and is a fair and equitable system. Social status/characteristics are not considered when allocating organs.

### **Can my family refuse to honor my wishes to be a donor once I pass away?**

Donor designation is legal and binding if you have registered as a donor and are 18 years of age or older. If a potential donor is under the age of 18 and had registered as a donor on their driver's license, their parent or guardian must affirm their decision. If you have not registered as a donor, your family will be asked to make the decision on your behalf.

### **Is the donation process respectful?**

The people who work in donation take great care to respect the donor and treat each person with dignity.

### **Why are family members asked about donation so quickly after a loved one has passed away? (not given time to grieve)**

The ability to honor a person's or family's decision to donate is time-sensitive. For organs and tissues to be safely transplanted, the process must begin relatively soon after death has been declared. The process is medically and logistically complex, and can take hours to days to complete. In serving more than 9,000 grieving families over the years, we have often heard that donation helps the family in their grief journey.

### **Who does donation benefit?**

First and foremost, donation benefits the donor and the donor's family by honoring their decision and leaving a life-saving and healing legacy. Secondly, transplant recipients benefit by receiving the gift of organs, tissues or eyes. Finally, the entire community benefits when recipients can return to an active and full life and grieving families are supported.

### **Does anyone profit from donation?**

The field of organ donation is highly regulated in the United States. All organ procurement organizations, like LifeSource, are non-profit organizations which means that funds are reinvested in achieving the organization's mission of saving and healing lives.

### **If I registered as a donor but my organs can't be transplanted, would they be used for research? How could I specify that I want that to happen if that were the case?**

If LifeSource talks with your family about donation and there is potential for research, your family will be asked to decide about research. Therefore, share your wishes about research with your family.

Other opportunities include whole body donation, which must be arranged during your lifetime. Programs exist at the University of Minnesota Medical Center and Mayo Clinic.

### **If someone is a living donor is there a cost to the donor or the recipient?**

Medical expenses associated with living donor evaluation are covered by either the recipient's insurance or in certain circumstances, by the Transplant Centers Organ Acquisition Fund (OAF).

The actual donation surgery expense is covered by the recipient's insurance. The transplant center will charge the recipient's insurance an "acquisition fee" when he/she receives a transplant. The medical costs related to the donation procedure and required postoperative care are also covered by this fee.

Anything that falls outside of the transplant center's donor evaluation is not covered by insurance. These costs could include annual physicals, travel, lodging, lost wages and other non-medical expenses.

### **Where do I go to find information about getting an organ for a family member?**

If you or a family member need an organ transplant, or would like to be evaluated, you need to get a referral from your physician to one of the state's transplant centers. Here is a list of local transplant centers: <https://www.life-source.org/recipients/your-gift-of-life/transplant-centers/>

### **If I need to get a transplant will it fail (rejection)? Why does rejection happen and what causes compatibility issues?**

Rejection can happen when the body sees the transplanted organ or tissue as a foreign invader and attempts to destroy it. All organ transplant recipients must take immunosuppressant (or ant-rejection) medications that prevent the body from rejecting the transplanted organ for the rest of their life.

### **Can you choose who gets your donation? Can you decide in general or in a focused way? Can that be guaranteed?**

Direct donation, or donating to a specific person, can occur when a deceased donor's family identifies a person waiting on the national transplant list who they would like to receive their loved one's organ. A specific individual would need to be named by the donor family for a direct donation to occur - families cannot direct a donation to a group of people. If the person the family selects to receive the donation is not a match, the family would be asked to donate the gift to another person on the national transplant waiting list per allocation policy.

### **Can an adult give to a child or vice versa?**

Yes, adults can donate to children and children can donate to adults. The size of the body and the organ are considered when matching donors to recipients. That's why very small children most often receive donations from other young people - although older children and adults can often match. Sometimes, children can receive donations of partial organs such as a section of a liver or lung.

### **Does my decision to be a donor need to be in my will?**

Registering to be a donor is the only step necessary to be eligible to save lives. To register as a donor, check the box on your driver's license or state ID card, or register online at [DonateLifeMN.org](http://DonateLifeMN.org). Please share your decision with your family.

### **Does living kidney donation hurt? How long would it hurt?**

Living donation is major surgery. All complications of major surgery apply.

Donors usually stay in the hospital for four to seven days after surgery. Although recovery time varies, most donors can resume normal activity one month after surgery and can return to work within six weeks. It is important to talk to your doctor about what to expect.

The following resources will provide specific information about living donation:

The National Kidney Foundation (NKF): <https://www.kidney.org/transplantation/livingdonors#livingdonation>

The NKF brochure: [https://www.kidney.org/sites/default/files/11-10-7228\\_KBG\\_PatBro\\_BigAsk\\_LD2.pdf](https://www.kidney.org/sites/default/files/11-10-7228_KBG_PatBro_BigAsk_LD2.pdf)

United Network of Organ Sharing (UNOS) website: <https://transplantliving.org/living-donation/being-a-living-donor/>

UNOS living donation brochure: [https://www.unos.org/wp-content/uploads/unos/Living\\_Donation.pdf](https://www.unos.org/wp-content/uploads/unos/Living_Donation.pdf)

## **Am I too old to donate?**

People of all ages and medical histories should consider themselves potential donors. Your medical condition at the time of death will determine what organs and tissue can be donated.

## **Why is the wait to receive a transplant so long?**

Most candidates, except those with living donors, wait for an organ due to the shortage of donor organs. Because each candidate's situation is unique, waiting times can vary, depending on several factors such as: how well you match with the donor, how sick you are, and how many donors are available in your local area compared to the number of patients waiting.

## **Information about the national transplant waiting list. (Who manages it, how does it work, is it fair?)**

When transplant hospitals accept patients onto the waiting list, the patients are registered in a centralized, national computer network, managed by the United Network for Organ Sharing (UNOS) that links all donors and transplant candidates. A national system matches available organs from the donor with people on the waiting list based on blood type, body size, how sick they are, donor distance, tissue type and time on the list.

The organs are distributed locally first, and if no match is found they are then offered regionally, and then nationally, until a recipient is found. Every attempt is made to place donor organs.

For each organ that becomes available, the computer program generates a list of potential recipients ranked per objective criteria (i.e. blood type, tissue type, size of the organ, medical urgency of the patient, time on the waiting list, and distance between donor and recipient).

Each organ has its own specific criteria. Ethnicity, gender, religion, and financial status are not part of the computer matching system.

After printing the list of potential recipients, the coordinator from the OPO contacts the transplant surgeon caring for the top-ranked patient (i.e. patient whose organ characteristics best match the donor organ and whose time on the waiting list, urgency status, and distance from the donor organ adhere to allocation policy) to offer the organ. Depending on various factors, such as the donor's medical history and the current health of the potential recipient, the transplant surgeon determines if the organ is suitable for the patient. If the organ is turned down, the next listed individual's transplant center is contacted, and so on, until the organ is placed.

## **Would my age effect my ability to donate?**

People of all ages and medical histories should consider themselves potential donors. Your medical condition at the time of death will determine what organs and tissue can be donated.

## **Can I donate if I have diabetes? Multiple sclerosis? Other diseases?**

Even with an illness or a health condition, you may be able to donate your organs and/or tissues upon death. At the time of death, doctors determine whether you are medically suitable for donation. Only a few conditions would absolutely prevent a person from becoming a donor—such as active cancer or a systemic infection. People with diabetes, HIV, hepatitis, and cancer CAN sometimes donate their organs.

## **What medical issues prevent someone from being able to donate?**

Only a few conditions would absolutely prevent a person from becoming a donor—such as active cancer or a systemic infection. It is even possible for individuals who are HIV-positive to donate to HIV-positive transplant candidates.

## **How much does race matter when matching organs from one person to another?**

Although organs are not matched per race/ethnicity, and people of different races frequently match one another, all individuals waiting for an organ transplant will have a better chance of receiving one if there are large numbers of donors from their racial/ethnic background. This is because compatible blood types and tissue markers—critical qualities for donor/recipient matching—are more likely to be found among members of the same ethnicity. A greater diversity of donors may potentially increase access to transplantation for everyone.

## **Can I donate things besides organs?**

Yes. The list of organs and tissues that can be successfully transplanted continues to grow. So does your ability to save and heal lives as a donor.

Organs: Heart, lungs, kidneys, pancreas, liver and intestines.

Tissue: Corneas, skin, veins, tendons, bone, heart valves and connective tissue.

## **Does it cost my family any money if I become a donor after I die?**

No. Your decision to be an organ, eye and tissue donor will NOT result in any medical expenses associated with donation.

## **I'd like to know all the information available (about donation). I'd want to know the pros and cons of the information.**

Visit the LifeSource website: <https://www.life-source.org>

Donate Life Minnesota: [www.DonateLifeMN.org](http://www.DonateLifeMN.org)

Email us with specific questions at [info@life-source.org](mailto:info@life-source.org) or call us at 612.800.6100 (toll free: 1.888.5.DONATE)

## **Other information:**

Many group members shared that they do not like the word “harvest” to describe what happens to a person if they become an organ donor. Neither do we. The removal of organs for transplant is a respectful, surgical procedure. “Organ Recovery” or “Surgical Recovery” are the words and phrases used by Organ Procurement Organizations like LifeSource to describe this process because they maintain the dignity of the donor and the donor’s family. After all, donors are heroes.

## Additional Resources:

- You can always call your local (MN) donation community liaison: Lindsey Williams [lwilliams@life-source.org](mailto:lwilliams@life-source.org), office: 612.800.6295 or cell: 651.329.4211
- Visit the LifeSource website: <https://www.life-source.org>
- Visit the Donate Life America website: <https://www.DonateLifeAmerica.org>
- Contact a local Transplant Center <https://www.life-source.org/recipients/your-gift-of-life/transplant-centers/>
- The U.S. Department of Health and Human Services <https://optn.transplant.hrsa.gov/learn/> and <https://www.organdonor.gov/about/process.html>