TALKING ABOUT TRANSPLANTATION

How to Find a Living Donor

Make Your Transplant Happen

UNITED NETWORK FOR ORGAN SHARING UNOS

Who are UNOS and the OPTN?

United Network for Organ Sharing (UNOS) is a non-profit, charitable organization that serves as the Organ Procurement and Transplantation Network (OPTN) under contract with the federal government. The OPTN helps create and define organ allocation and distribution policies that make the best use of donated organs. This process involves continuously evaluating new advances and discoveries so policies can be adapted to best serve patients waiting for transplants.

All transplant programs and organ procurement organizations throughout the country are OPTN members and are obligated to follow the policies the OPTN creates for allocating organs.

Table of Contents

2 **Why do I need to learn about living donor transplantation now?**

3 **What is living donor transplantation?**

3 **Why living donor transplantation?**

4 **What if asking for an organ from someone seems unthinkable?**

5 **Learn about living donor transplantation**

5 Where is the best place to learn about living donor transplantation?

6 What will my transplant center teach me?

9 **Get support and spread the word**

9 What if I feel a little overwhelmed by all of this?

10 How do I get my story out?

13 Stay positive and carry on – no matter what

14 **Know the living organ donation process**

14 What happens when someone says they might be interested in being my living organ donor?

16 What if the person who wants to donate to me or to my child is not compatible?

18 Learn more

19 **Take action**

19 Your “To Do” list to help a living organ donor find you

20 Some issues to talk about with your transplant center

21 Some issues to talk about with a potential living organ donor

I have so much to do and I don't feel well – why do I need to learn about living donor transplantation now?

When you hear you need an organ transplant, things can feel really out of control.

One of the best ways to get a sense of control back in your life is to learn all your options. A very important option is living donor transplantation.

Taking the time to read this brochure will help you learn:

- What living donor transplantation is and why it is an important option for you
- How to get comfortable talking about your need and living donor transplantation with others
- Why it is so important to involve your family and friends - right away
- How important it is for you, your family and friends to tell your story everywhere you can
- The best ways to get more information about living donor transplantation

What is living donor transplantation?

Living donor transplantation is when a living person donates an organ or a part of an organ that is transplanted into another person.

The organ most often donated by a living person is a kidney. The other organ most commonly donated by a living person is a portion of the liver.

Why living donor transplantation?

Many people can wait years for a kidney transplant from a deceased donor. People can also spend years waiting for a liver transplant.

A living donor transplant can shorten your wait

Only about half of the people in the United States sign up to donate their organs when they die. This number is different in every state and region, so the wait can be longer depending on where you live.

Every year, thousands of people get removed from the waiting list because they have grown too sick to make it through a transplant.

Living donor transplantation can help shorten or eliminate the wait by:

- Giving you more options about where and when a transplant happens
- Helping you get an organ transplant even before you begin dialysis if you are a kidney patient

"When we found out my brother needed a transplant, we also learned that African Americans are more likely to have medical conditions that lead to kidney disease. More than anything, I wanted my brother to get off of dialysis and get back to his life. For me, the best way to do that was to be his living kidney donor. I'd do it again in a heartbeat."

– David

Living donor transplantation can improve your chances of success

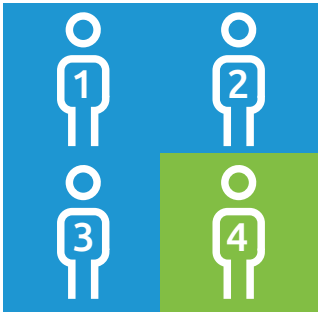
Kidneys from living donors generally have high success rates:

- More than 98% of transplanted kidneys from living donors are still working well one year after transplant
- On average, living donor kidney transplants work longer than kidney transplants from deceased donors
- On average, living donor liver transplants also have as good or better outcomes compared to liver transplants from deceased donors

*Living organ donors make about **6,000** transplants possible each year.*

What if asking for an organ from someone seems unthinkable?

Most of us don't even like to ask for a ride. The idea of asking someone to be a living organ donor - to give a kidney or a part of a liver - seems unthinkable.



But, **one out of four** people say they would be willing to donate an organ.

People donate organs to:

- A family member
- A good friend
- Sometimes, someone they've never even met

About **90 to 95 out of every 100 donors say they would not change anything about their decision to donate.** They would make the same decision to help someone. They would go through all the screenings, tests, and the surgery. They would take time away from their lives, jobs, and other commitments to recover. They would do all of that to help someone.

Learn About Living Donor Transplantation

Where is the best place to learn about living donor transplantation?

Your transplant program is the best place to learn whether a transplant from a living donor might be right for you. Talk to your transplant center staff about living donor transplantation during your first visit. If you've already had your first visit, call your transplant center staff and ask for a conversation about living donor transplantation. They will be happy you asked.

You can also find a lot of information on the internet – on websites, or on social media. Some websites have useful information about living donor transplantation and living donation. Others can be wonderful sources of social support. In fact, most transplant centers have information about living donor transplantation on their websites. Some use social media, too.

As with any subject, some places on the internet can also have information that isn't true. Sometimes, even well-meaning friends unknowingly pass on incorrect information from these sources. Knowing what information to trust can be a challenge. Always check in with your transplant center staff if you have read or heard anything that leaves you with questions.

What will my transplant center teach me?

The point of living donor transplantation education is simple. It is to help you learn about the potential for a living donor transplant and to help you and your family and friends become more comfortable talking about living donor transplantation and organ donation. Getting comfortable with talking about your need for an organ donor is important, because telling your story is where everything starts.

You will get the facts from transplant professionals, such as doctors, nurses and social workers. Talking about living donor transplantation and organ donation is one of the most important things transplant center staff do every day.

You will get medical information about:

- Risks and benefits of living donor transplantation
- Risks and benefits for living donors
- Living donor testing
- Living donor surgery and transplantation
- Living donor recovery

You will also get non-medical information, such as:

- Potential costs to donors for things like travel and lodging
- How much time a donor might need to take off from work

Once you learn the facts about living donation and transplant, it's easier to talk about it with others.

Transplant Centers have different ways to help you learn

Here are some of the different ways your transplant center may help you learn about living donor transplantation. Your center may have others. Transplant centers are always working to come up with new ways to make it easy for people in your shoes to learn.

- **Education for your support team.** Sometimes, transplant center staff can meet you in a comfortable place with plenty of room for your support team, such as a community center, a library or your home. When friends and family learn with you, it helps them get comfortable sharing your story, too. Your support team could include:
    - o Friends and family
    - o Neighbors

- o Co-workers
- o People at your place of worship
- o Anyone else who hears about your need and wants to support you

- **Conversations with people who've looked for a living organ donor.** Some transplant centers may be able to connect you with people who have also looked for a living donor. Learning how others told their story helps you do the same.
- **Conversations with living organ donors and with people who have received an organ from a living donor.** Some transplant centers can arrange for you to talk with living organ donors and/or living donor transplant recipients. Hearing others' experiences can help you feel more at ease about the idea of someone donating to you. They can help you learn about things like:
  - o Surgery for the donor and recipient
  - o Recovery of donor and recipient
  - o Quality of life after transplant and donation

If you are considering living donor kidney transplantation, the National Kidney Foundation can help connect you to someone who has been there. Call the National Kidney Foundation's PEER Program at 855-653-7337 (855-NKF-PEER) or send an email to nkfpeers@kidney.org to get more information.

Some living organ donors and transplant recipients have shared their "Stories of Hope" with UNOS. A link to where you can read their stories is in the "Learn more" section.

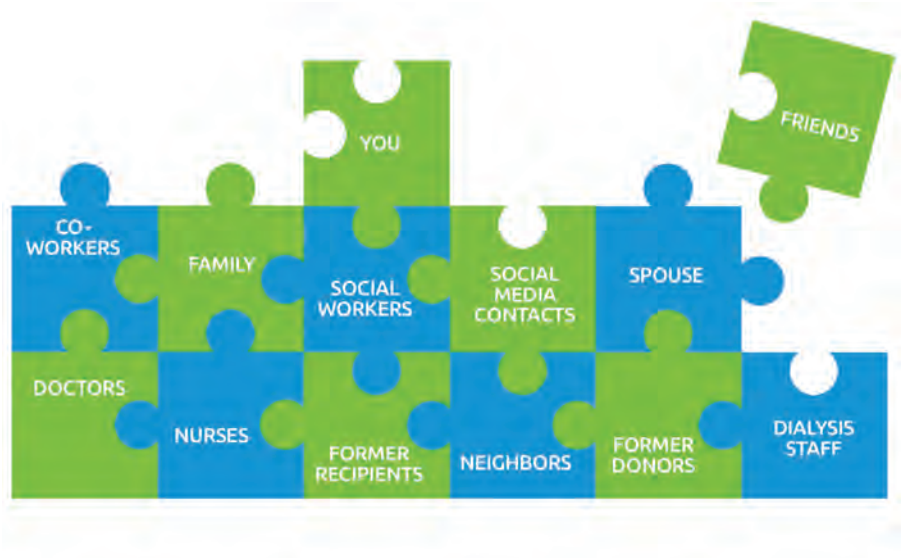
- **Education for your Living Donor Champion.** Some transplant centers help educate your living donor champion so that they can help spread the word about your need for an organ donor. Everyone needs a champion sometimes. There's no better time to let someone be yours. Your champion can learn:
    - How to talk about living donation and transplantation
    - How to identify your social network
    - How to tell your story

If your child needs a transplant, you can be your child's Living Donor Champion. Learn how to tell your child's story and spread the word about living donation.

Each of these approaches may increase the chance that someone will start thinking about being a living donor, and in some cases, lead to a transplant. Take advantage of all the education your transplant center can offer.

Get Support And Spread The Word

What if I feel a little overwhelmed by all of this?



Build a Support Team

Everyone needs a support team. When you need a transplant, there is a lot to learn and a lot to do. At times, it can all feel like it's just too much.

Becoming a transplant candidate or being the parent of a child who needs a transplant is much easier when you don't try to do it all alone. You need support. When you learn about living donor transplantation, bring family and friends with you. In fact, your transplant center will expect that you have support from family or friends. Including your family and friends will:

- Help you remember what you need to do
- Let others know the best way to help you
- Increase the number of conversations that happen about your need and living donor transplantation

The more your family and friends learn about living donor transplantation and organ donation, the more they will talk about it with others. Every conversation increases the chance that a potential living donor will learn about your or your child's need.

How do I get my story out?

Share your story in **any and every way** that is comfortable for you:

- At work
- In a community group or club
- In a place of worship
- On social media
- On a sign on your car
- Any other place where you or your family and friends can reach people

"My mom was like she's always been. Talked and shouted about my need – this time for a living donor – from the rooftop. And here I am, enjoying life after my living donor transplant."

- Elizabeth

A word about social media

A great way to get support and to maintain hope is for you or your friends and family to share your journey with kidney or liver disease on social media. Social media lets you share your story with the world simply, quickly, and at no cost.

Just one message can have an endless reach with shares and likes. Sharing your story on social media may increase the chance that someone will step forward to consider being your living donor.

If you need help setting up a social media account, ask family, friends or your transplant center if they know someone who can help. It's easy. It's free. And people like to help.

Share the right information

Talk with your transplant center staff about how to tell your or your child's story in a way that is safe, effective and ethical.

For example, you may wish to share information such as:

- Your or your child's journey with kidney or liver disease
- How the need for a transplant has changed your or your child's life
- A little about your family
- Whether your family has tested to donate and perhaps why they can't donate

Other details you may want to share include:

- What organ is needed
- Blood type
- How long the wait may be
- Why a transplant from a living donor is better than a transplant from a deceased donor
- The state where you live
- Your transplant center contact

Share the good and the bad

A transplant requires just one donor, so keep sharing.

Sharing all your news keeps your story and your need fresh on everyone's minds. It reminds people that they matter and that you still need their help to spread the word.

Sharing also helps you celebrate the good days. And get the support you need to get right back up after the bad days. You will have both.

Share safely and legally

Ask your transplant center staff for any advice about how to share health information safely and carefully. You will want to do it in the right way – because you can never erase anything you share on the internet. Think it through before you share. If in doubt, say less. You can always share more some other day.

Remember that it is illegal to give money or any other item of value in exchange for a donated organ. Your transplant center staff will be able to talk to you about what expenses are often covered by insurance and what expenses a living donor can get help with. These include travel, lodging and possibly lost wages.

Let people know they can talk to your transplant center privately

Let people know that they can contact your transplant center directly and privately if they are interested in learning more about donating. They don't even need to tell you. Sometimes, people wish to be tested without telling anyone at all.

Stay in touch with your transplant center

Let your transplant center know that you plan to share its contact information in advance so that they can be prepared. No one knows what will happen when you share your story. Sometimes no one steps forward. Sometimes many people do. Staying in touch with your center will help the process work well for everyone.

Stay positive and carry on – no matter what

Finding a living donor might take a long time and a lot of effort. Every road to transplant is different. Expect ups and downs.

Be patient

Someone might step forward to be a donor right away. Or, the right donor may come forward only after your family and friends spend a lot of time working hard to find one.

Don't be surprised if someone who wants to donate is not able to, for medical, social, or other reasons.

Don't be surprised if you feel discouraged from time to time. Feel it and talk about it. Then carry on. No matter what.

*When people who know your story spread the word, they just might end up finding a donor for you **and** for someone else.*

Know The Living Donation Process

What happens when someone says they might be interested in being my living organ donor?

Once someone says they're interested in being a living donor, a long process begins with education. The potential donor and the transplant center have to figure out if living donation is right for that person.

1. Someone says they might want to donate

2. The potential donor talks to your transplant center

3. The potential donor and transplant center decide whether to test or whether it's not right for any reason

4. If both agree, testing begins

5. After testing, the potential donor and transplant center think about whether donating is right for that person and talk more

6. The potential donor may decide not to donate up until the time of surgery

7. Donation and transplant

When someone steps forward to consider living donation, they are really stepping forward to learn more about the process from transplant professionals. The education process also lets your transplant center staff learn about that person. Decisions about whether living donation is right for that person are still a long way off for both the potential donor and the transplant center.

The living donor team

The transplant center assigns the person a living donor team, including their own:

- Nurse
- Medical doctor
- Surgeon
- Social worker
- Independent living donor advocate

The team's job - and primary focus - is to educate the potential donor about the benefits and risks of living donation, and to assess if donation is safe for this person. For the donor evaluation team, success is not whether a transplant happens. Success is getting to the right decision. Sometimes, the right choice is the potential donor deciding not to move forward with donation at that time. Sometimes, the right outcome is the transplant center deciding living donation is not right for the person who had expressed interest.

The first steps

Basic information. The first step is often as simple as the potential donor giving the transplant center's staff some basic information by phone or email or even online. This might include the potential donor's relationship to you and some very basic medical history.

Testing. After that, if both the potential donor and the transplant center think it makes sense to continue, the living donor team will do testing to make sure that the potential donor does not have medical or other issues that make living donation too risky.

Education. The transplant center will talk about all aspects of living donation to be sure the potential donor understands everything in order to make the right decision. This includes:

- Surgery
- Risks
- Benefits
- Recovery

- Possible non-medical costs related to living donation, and how to get help if needed
- The importance of following up with the transplant center after donation and lifelong healthy habits and medical check-ups.
- How donating could affect a person in the future

During this time, the transplant center will not give you any information about the donor or test results. This is to protect the potential donor's privacy. In fact, it's possible for someone to be tested without you even knowing. The transplant center will only tell you if the potential donor asks the center to let you know.

The decision

The decision about donation only happens after all the needed medical tests and conversations.

Even if the transplant center approves the living donor and that person wants to donate, the living donor may continually consider the decision and whether or not to donate right up until the day of donation.

"Living donors are often called selfless. I don't think I was. There was something giant in it for me. My brother."
- Matthew

After the team decides the potential donor is acceptable, the decision to go forward with donation always belongs to the donor.

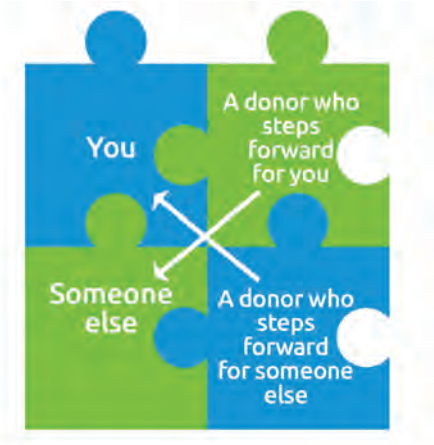
What if the person who wants to donate a kidney to me or to my child is not compatible?

If you or your child needs a kidney transplant and find a willing living kidney donor but medical tests show that person is not compatible based on blood type or other factors associated with high risk of organ rejection, you may still be able to have a transplant.

Ask your transplant center to explain your options if someone wants to be a living donor but is not compatible. And, if one of these options is right for you, it could help someone else's living donor transplant happen as well.

Kidney paired donation

Living kidney donation and the power of computers helps match willing donors and recipients who may live nearby or even across the country. Think about it as a swap or an exchange. Here's how it works:



1. A living donor who is willing to help you or your child is matched to another compatible transplant candidate

2. A special computer then finds someone else's willing donor who is compatible with you or your child

Matching patients with compatible living donors allows hundreds of people to get transplants each year. Participating in an exchange may also help you or your child receive a transplant more quickly.

Using an incompatible kidney

Another option may be for a transplant center to prepare your body to receive an organ from an incompatible donor. This includes getting medical treatments before transplant to help the body accept the organ. Talk with your transplant center about the availability, risks and benefits of these options.

Learn more

Read more

Here are some organizations that provide trustworthy information about organ disease, living donation and organ transplantation:

- United Network for Organ Sharing (UNOS): **unos.org** and **transplantliving.org**
- UNOS' Evidence Supplement about Living Donor Education: **https://optn.transplant.hrsa.gov/resources/living-donation**
- UNOS' "Stories of Hope" by living donors and transplant recipients: **https://transplantliving.org/community/stories-of-hope/browse-stories/**
- U.S. Department of Health and Human Services: **https://organdonor.gov/about/process/living-donation.html**
- List of Transplant Centers: **https://optn.transplant.hrsa.gov/members/member-directory/?memberType=Transplant%20Centers**
- National Kidney Foundation: **livingdonors.org**
- American Liver Foundation: **liverfoundation.org**
- National Institutes of Health: **nih.gov**
- National Living Donor Assistance Center: **livingdonorassistance.org**

Talk more

The United Network for Organ Sharing (UNOS) has a toll-free patient services phone number. Call **1-888-894-6361** to:

- Find a transplant center in your area that does living kidney or liver transplants
- Understand donation and transplantation policies and data
- Talk about concerns or problems

When you want even more facts about living donation and organ transplant, ask your transplant center to point you in the right direction.

Take action

Your "To-Do" List to Help a Living Donor Find You

- ☐ Call your transplant center
- ☐ Ask transplant professionals to help you learn about living donor transplantation
- ☐ Involve your family and friends right away, and at every step of the way
- ☐ Share your story by talking about your need, everywhere possible
- ☐ Grow your support team using social media or other methods
- ☐ Ask someone - your champion - to tell your story far and wide
- ☐ Get support by sharing your news, both good and bad
- ☐ Stay positive. Carry on. No matter what

Here are some issues to talk about with your transplant center

Benefits of early transplant

Wait times on the list

Risks of living donation

Benefits of living donation

Where to find helpful resources

What to share on social media

Here are some issues to talk about with a potential living donor

Saying yes now is only saying yes to learning more

The first step is a conversation with a transplant center

Potential donors get evaluated extensively–transplant centers say no to anyone for whom it's too risky, medically or otherwise

Donors can decide it's not right up until surgery–no rushing decisions

Our mission is to unite and strengthen the donation and transplant community to save lives.

follow us

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