



UNIVERSITY of MARYLAND
MEDICAL CENTER

Living Donor Transplant Champion Guide

Supporting Kidney & Liver Living Donor Transplant Recipients



WHAT'S INSIDE

Living Donor Champions:
An Overview

About Living Donation

Overview of the Living
Donation Process

Getting Started as a
Living Donor Champion



Introduction

Today, more than 90,000 people are on the kidney transplant list,¹ and 14,000 people are on the liver transplant list.² People can spend years on the list, and some unfortunately die before they're transplanted. But you can help.

As a living donor champion, you can help your family member or friend find a living kidney or liver donor — fast tracking your loved one's journey back to health. People who have a living kidney or liver donor get their transplants faster and generally have great outcomes.

You may not be able to donate a kidney or a portion of your liver yourself, but as a living donor champion, you **can** help save a life.

In this guide, you'll learn what a living donor champion does and why it is important. You'll gain insight into the living donor transplant process. The guide also provides ideas on ways to get started as a living donor champion, including strategies you can use to get the word out and find a donor.

Finding a living kidney or liver donor is a journey no one needs to take alone. By becoming a living donor champion, you can bring hope and healing to your loved one, giving the gift of a longer, healthier life.



Living Donor Champions: An Overview

WHAT IS A LIVING DONOR CHAMPION?

A living donor champion is a person who **supports** the person seeking a living kidney or liver donor and who **acts as a spokesperson** for the prospective organ recipient. While living donor champions may not necessarily donate the organ to the recipient themselves, they have a crucial role to play. Living donor champions are by the recipient's side every step of the way and help the recipient find a living donor.

BENEFITS OF HAVING A LIVING DONOR CHAMPION

Living donor champions increase the recipient's chance of finding a living kidney or liver donor. They can activate their friends and family network, which expands the number of people who may choose to be evaluated for possible donation.

While the recipient can talk with friends and family as well, the recipient is also dealing with late-stage kidney or liver disease. This can make it difficult for the recipient to devote time and energy to finding a living donor — the recipient needs to focus on his or her own health. And as time passes, the recipient may become sicker, making the process even harder. A living donor champion, on the other hand, can share the recipient's story and spread the word far and wide. The champion uses his or her energy and motivation to find a living donor.

In many cases, the recipient may feel uncomfortable or awkward asking people directly for a kidney or part of their liver. It is a big ask. A living donor champion can have those conversations more easily, because the champion is advocating for someone he or she cares about.

BENEFITS OF BEING A LIVING DONOR CHAMPION

When someone you care about needs a kidney or liver transplant, that person is in a fight for his or her life. It is natural to want to help. Even if you are not the donor, you can play a valuable role in the recipient's journey. Being a living donor champion is a great way to get involved and help the recipient get the transplant he or she needs as quickly as possible.

WHO CAN BE A LIVING DONOR CHAMPION?

Virtually anyone! A living donor champion can be anyone in the recipient's life:

- A close family member, like a spouse, child, sibling, or parent
- An extended family member, like a cousin or in-law
- A friend or neighbor
- A coworker

Some people choose to become living donor champions if they are unable to be living donors themselves, while others simply want to help and have decided that serving as a living donor champion is the best way for them to get involved. The most important factor in whether you can be a living donor champion is whether you can dedicate some time and energy to helping save the recipient's life by finding a living donor.

WHAT DOES A LIVING DONOR CHAMPION DO?

A living donor champion has two main duties:

1. **Finding a donor** – The living donor champion shares the recipient's story and spreads the word to as many people as possible, asking them to be evaluated as a possible living donor. The champion is the spokesperson in the search for a living donor.
2. **Providing emotional support to the recipient** – The living donor champion offers encouragement and helps keep the recipient hopeful and motivated to take care of his or her health while searching for a donor.



About Living Donation

WHAT IS LIVING DONATION?

If you are like many people, when you think about organ donation, you think of waiting for a matching organ from a deceased donor. Although that is still how most organ transplants happen, living donation is an increasingly popular option for both kidney and liver transplants.

Living kidney donation is possible because most people have two kidneys, and a healthy person only needs one. Although the donated kidney does not grow back, a single kidney can easily meet the body's needs.

Living liver donation is possible because the human liver regenerates (regrows). Doctors can take a portion of a healthy person's liver and transplant it into a person whose liver is failing. The donor's remaining liver grows back to normal size within a couple of months, and the recipient's portion also grows to full size.

BENEFITS OF LIVING DONATION

Living donation offers real benefits to the recipient. They include:

- **Shorter wait time for a transplant** – Once a living donor is found, the recipient can get a transplant in just a few months. In contrast, many people wait years for a new kidney or liver, getting sicker as time goes on. Some people even die waiting.
- **Great organ function** – An organ from a living kidney donor typically performs better than an organ from a deceased donor, increasing the recipient's chance of making a full recovery. An organ from a living liver donation performs similarly in the long-term to a deceased liver donation.³
- **Better outcomes** – Because the transplant happens sooner, the recipient is healthier, boosting the odds of a positive long-term outcome after transplant.
- **Convenient scheduling** – When you wait for a deceased donor organ to become available, you could get a call any time of the day or night. But with a living donor, the transplant surgery is scheduled for a mutually convenient date and time.

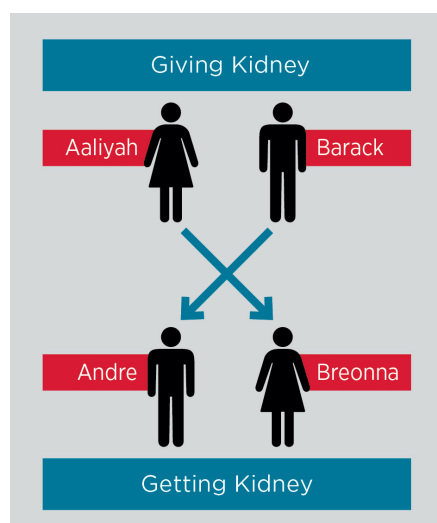
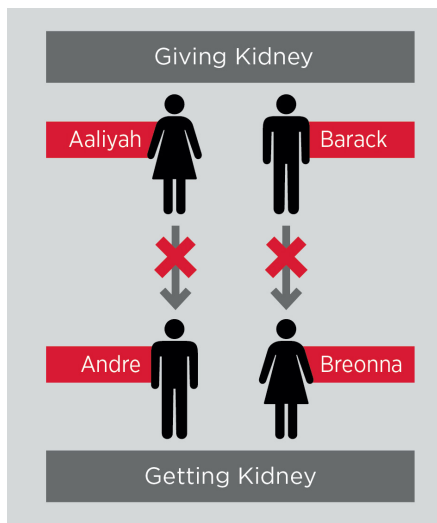
Living donation offers benefits for other people, too:

- **The living donor** gives a profound and selfless gift. Knowing that he or she saved a life, and that his or her gift goes beyond the recipient to the recipient's family and loved ones as well, creates a deep feeling of happiness and satisfaction – one that many living donors say never diminishes, no matter how much time passes.
- **The living donor champion** also feels contentment and fulfillment for helping save the recipient's life.
- **Other people on the transplant list** have a greater chance of receiving a kidney or liver, because the living donation recipient is no longer on the list. This means the available organs in the United States can go farther, saving more lives.

Overview of the Living Donation Process

TYPES OF LIVING DONATION

1. **Directed donation** – In a directed donation, the donor chooses the recipient. A woman choosing to donate part of her liver to her uncle demonstrates directed donation.
2. **Nondirected donation** – In a nondirected donation, the recipient and the donor do not know each other. The donor chooses to donate a kidney or a portion of his or her liver to a person who needs it and is a “match.”
3. **Paired kidney donation** – Sometimes, a person who needs a kidney has someone who is willing and able to donate but is not a match. With paired kidney donation, two pairs of donors and recipients (let’s call them Pair A and Pair B) trade donations. Recipient A gets a kidney from Donor B, and Recipient B gets a kidney from Donor A.



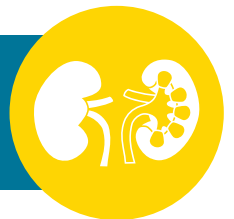
Potential living kidney or liver donors can take the first step toward finding out if they are eligible to donate with UMMC’s quick and easy online survey, available at ummclivingdonation.org.

WHO IS ELIGIBLE TO DONATE?

The requirements to be a living donor include:

- A prospective living kidney donor must be between 18 and 75 years old.
- A prospective living liver donor must be between 18 and 60 years old.
- The living donor must be in good health.
- The living donor must not have a history of kidney disease, liver disease, heart problems, diabetes, cancer, or other health problems that could cause difficulties in surgery.
- Living kidney and liver donors can’t abuse alcohol or illicit drugs.
- A prospective living kidney donor must have a body mass index (BMI) less than 35, and ideally 31 or less.
- A prospective living liver donor must have a BMI less than 35, and ideally 33 or less.
- The living donor must not have any financial motivation or be pressured or coerced into donating. The donation must be willingly given without expectation of compensation.

Living donor kidney transplants can last 15 to 20 years or longer.



OVERVIEW OF LIVING KIDNEY DONATION PROCESS

1. The donor and recipient both undergo an extensive evaluation process. This is done on each person’s schedule.
2. The living donor receives counseling and meets with a living donor advocate to ensure he or she is psychologically and emotionally ready to donate.
3. The surgery is scheduled for a convenient date and time for both donor and recipient.
4. Kidney donation surgery is generally done using minimally invasive techniques. The

surgeon makes several small incisions (less than one inch each) and uses special surgical instruments to remove one of the donor's kidneys.

5. The kidney is transplanted immediately into the recipient, ensuring the highest quality organ possible.
6. Although individual recovery time varies, living kidney donors typically spend one or two nights in the hospital before going home to continue recovery. They generally return to full activity within two to six weeks, depending on the nature of their work.

OVERVIEW OF LIVING LIVER DONATION PROCESS

1. The donor and recipient both undergo an extensive evaluation process. This is done on the donor's schedule.
2. The living donor receives counseling and meets with a living donor advocate to ensure he or she is psychologically and emotionally ready to donate.
3. The surgery is scheduled for a convenient date and time for both donor and recipient.
4. During the procedure, the surgeon removes a portion of the donor's liver (between one-quarter and two-thirds of the donor's liver).
5. The recipient's own diseased liver is removed, and the portion of the donor's liver is then transplanted into the recipient. The liver donation is transplanted immediately into the recipient, ensuring the highest quality organ possible.
6. The donor's liver grows back, typically within eight to 10 weeks.
7. Although individual recovery time varies, living liver donors typically spend four to seven nights in the hospital before going home to continue recovery. They generally return to full activity within 12 weeks, although they may be able to return to work within four to eight weeks depending on the nature of their work.
8. The portion of the liver the recipient received also regenerates, growing into a full liver in about eight to 10 weeks.



Getting Started as a Living Donor Champion

THE LIVING DONOR CHAMPION'S ROLE

Your goals as the living donor champion are to work to find a living donor for your loved one. This includes:

- Sharing your loved one's story
- Getting the word out to as many people as possible that your loved one needs a living donor
- Educating people about living donation
- Encouraging people to fill out an interest form and get evaluated
- Asking people to help find a living donor – by spreading the word and by getting evaluated as a potential donor
- Supporting your loved one throughout the process of finding a living donor
- Being steadfast in your dedication and motivation to continue the search until a suitable living donor is found
- Never giving up

MAKING THE ASK

When talking with a potential living donor, phrasing is important. Ask, "Will you help find a living donor?" rather than "Will you be the living donor?"



HOW TO SUCCEED AS A LIVING DONOR CHAMPION

Step 1: Learn about living donation

Start by educating yourself about living donation. In order to have conversations with prospective living donors, you'll need to be able to accurately answer some basic questions about how living donation works, including:

- Don't I need my kidneys/liver?
- How can I tell if I'm a match?
- How big of an operation is it? What's the recovery like?
- Can I live normally after donation, or will I have restrictions?
- Will I have to take medication for the rest of my life?

- How much does it cost to donate? Do I have to pay for my hospital bill?
- How long will I be in the hospital?

Step 2: Prepare to share the story

Collect the information to share your loved one's story. This may include:

- Pictures of your loved one in good health
- Details about your loved one - what's important to him or her, what he or she loves to do
- An overview of his or her health situation - why he or she needs a kidney or liver donor
- Information and facts about living donation

Step 3: Start with close ties, then work outward

Most living donors are people within the recipient's network, and the closer the person is to the recipient, the more likely the person is to consider being evaluated. Get contact information from the recipient, and start contacting the recipient's family and close friends.

Share the recipient's situation and explain that living donation is the recipient's best option for a full recovery. Ask the individual for help finding a living donor. The best way to help is to get evaluated as a potential living donor, but the individual may also help by spreading the word to his or her network.

Step 4: Broaden your reach

Get your loved one's story in front of as many people as possible.

Remember, not everyone who is evaluated as a potential living donor will be eligible, so getting as many people evaluated as possible is key.

Here are some ideas:

1. **Start a Facebook group** - Facebook is a great way to connect with people who care about the recipient and may be willing to be evaluated as a potential donor. Here is a step-by-step guide on setting up a Facebook group: facebook.com/help/167970719931213. Once you set up your Facebook group, you can:
 - Post an appeal for help
 - Post updates about the search and your loved one's condition
 - Post milestones in your loved one's life, like birthdays and anniversaries, to keep your loved one front of mind for the group
 - Share photos, videos, and inspiring or motivating content to keep hope alive

- Post a celebratory message when a donor has been found, and share updates after surgery and through recovery

2. **Consider posting on CaringBridge or similar websites** - CaringBridge (caringbridge.org) is also a place to share your loved one's story and need for a living donor. Run by a nonprofit organization, CaringBridge focuses on sharing the stories and journeys of people with medical conditions.
3. **Share with other groups in your community** - From people in your church to people at your gym, you and your loved one are parts of many groups within your community. Share the story wherever you can, and ask people to help.
4. **Do not forget about snail mail** - Use nondigital methods, like letters, postcards, articles in a local community newsletter or church bulletin, or other methods to spread the word.
5. **Connect with people one on one** - Posting online is great, but in some cases it's better to talk with people one on one, whether in person or by phone. Explain your loved one's condition, and ask for their help in finding a living donor. Be ready to answer questions about the process, and do not expect anyone to make a decision during the conversation. Ask people to take some time to consider before deciding.



TIPS TO HELP YOU TALK WITH A POTENTIAL DONOR

When it comes to discussing something as important as living kidney or liver donation, it is natural to be unsure about what to say or how to say it. There's no denying this is a big, life-changing request. But keep in mind that for your loved one, it could be the request that saves his or her life. That's why you, as the living donor champion, are stepping up.

Here is a general outline you can use to guide your conversation with a potential living donor:

- Start by letting the person know that you want to talk with him or her about something important.
- Talk about the recipient and the recipient's medical condition.
- Explain that the recipient's doctors say a transplant is the best option, and explain that you're looking for a living donor for the recipient.
- Be prepared to answer questions about the living donation process, including why seeking a living donor is the recipient's best hope.
- Ask the person to think about whether he or she might be able to help, and confirm that there is no pressure to decide right now.
- Make sure the person you are speaking with has several ways to get in contact with you once he or she has had time to think it over.

Note on what not to say: Do not ask people for their organs outright. Instead, ask them for their help. If they are willing to help, they can fill out an evaluation form to see if they might be eligible. If they do not want to go that far, they can show support by spreading the word within their own friends and family networks.



ABOUT UMMC'S LIVING DONOR TRANSPLANT PROGRAM

For more than 50 years, the University of Maryland Transplant Center has provided patients with world-class surgical and medical expertise. Transplant patients receive compassionate care and become lifelong health partners.

The University of Maryland Medical Center (UMMC) is home to the region's largest kidney transplant program. UMMC's transplant team has performed more than 6,000 kidney transplants since 1988.

Learn more about the living kidney and liver donor programs at the University of Maryland Transplant Center at umms.org/ummc/health-services/transplant/process/living-donor

CONCLUSION: YOUR ROLE IS IMPORTANT

Throughout the journey toward a kidney or liver transplant, the living donor champion walks alongside the recipient, offering a mix of compassionate support and dedicated action that combined, give the recipient the best chance of making a full recovery.

If you have any questions about becoming a living donor champion, or if you are a living donor champion who needs support, contact UMMC's transplant team at livingdonorchampion@umm.edu.

Thank you for being part of the recipient's team. Together, we keep hope alive.



Potential living kidney or liver donors can take the first step toward finding out if they are eligible to donate with UMMC's quick and easy online survey, available at ummclivingdonation.org.

¹ Donate Life America. Kidney Donation. Retrieved from www.donatelife.net/types-of-donation/kidney-donation. Accessed November 7, 2022.

² Donate Life America. Liver Donation. Retrieved from www.donatelife.net/types-of-donation/liver-donation. Accessed November 7, 2022.

³ Scientific Registry of Transplant Recipients (SRTR). The OPTN/SRTR Annual Data Report. Retrieved from: www.srtr.org/reports/optnsrtr-annual-data-report. Accessed March 1, 2023.

