

About Living Kidney Donation



NATIONAL KIDNEY
FOUNDATION®



The Sound of Change.

Change starts with you. A nationwide community of people affected by kidney disease is coming together to create change and you can help. Join Voices for Kidney Health, a community of patient and health professional advocates working with elected officials and public leaders to create big solutions to help everyone facing the challenges of kidney disease.

- ★ Protect living donors
- ★ Expand access to home dialysis
- ★ Advance healthcare equity
- ★ Spur investment in prevention and research

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About Living Donation

What is living kidney donation?

Living donation is when a living person donates an organ (or part of an organ) to another person. A healthy person who has two kidneys can donate one to someone in need. A living donor may donate to someone they know, like a family member, friend, or spouse, or a stranger who they've never met. A "potential donor" is someone who is thinking about donating. A "recipient" is someone with kidney failure who needs a kidney transplant.

Who can be a living kidney donor?

To donate a kidney, the person must be in good physical and mental health. Living donors must be at least 18 years old to donate at a transplant center in the United States. Some centers require a donor to be 21 or even a little older. There are some medical conditions that could prevent someone from being a living donor, including having uncontrolled high blood pressure or cancer.



Each transplant center is different, so always let the transplant center decide who would be a good donor. If someone is not approved as a living donor at one transplant center, they may be able to get evaluated at other centers. However, if a donor has someone in mind who they'd like to donate to, they have to get evaluated and approved at the same center where the recipient is waitlisted.

It's important to remember that anyone who is considering becoming a living kidney donor can change their mind and decide not to at any time.



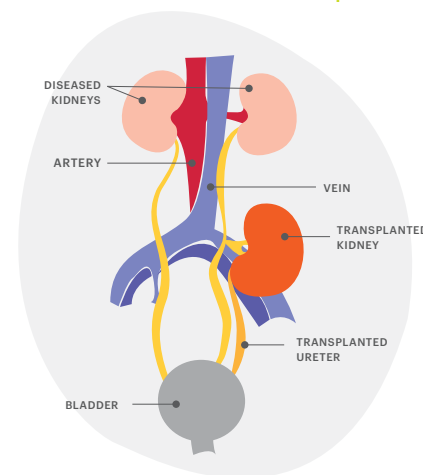
Are there different types of living donation?

THERE ARE TWO MAIN TYPES OF LIVING DONATION:

- **Directed Donation** is when the donor names a specific person who will receive the kidney. It is the most common type of living donation. Directed donations are often between blood relatives, like parents, siblings, or children. They can also happen between people with close personal relationships, such as a spouse, friend, or coworker.
- **Non-directed donation** is when a person does not have a specific person to donate to. In this case, the donor is paired with someone in need of a kidney on the transplant waitlist. Other names for a non-directed donor include "altruistic" or "good-Samaritan donor."

HOW LONG DOES A TRANSPLANTED LIVING DONOR KIDNEY LAST?

On average, a kidney from a living donor lasts about 15 to 20 years. Some will last longer; others might last for a shorter amount of time.



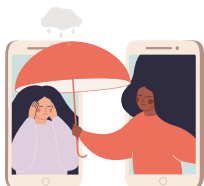


THE EVALUATION PROCESS

How to start the process

To be a directed donor to a specific person, the first step is to contact the transplant center where they are on the waitlist. At every center, the living donor needs to be evaluated at the same transplant center as the person they are donating to. For a non-directed donor whose kidney can go to anyone, they can go to any transplant center to begin the process.

Anyone who is thinking about donating a kidney should talk to family members or friends about the decision to donate. You can share information that will help them to understand what it's all about if they have any questions or concerns. Be sure to include people you trust in your decision-making process.



Many living donors find it helps to talk to someone who has already donated to learn about their experience.

855.NKF.PEERS
kidney.org/peers

What will happen after I contact a transplant center?

After a potential donor has contacted a transplant center, they will be asked to complete a Health History form, which includes questions about their medical and social history. Each center will have a different process or name for this form, but donors can expect some kind of paperwork before getting started. You can usually find these forms on the hospital's website. After the hospital gets your completed form, the living donor team will either call you to clarify any information on the form, or they will get in touch to schedule a time to come in for the living donor evaluation.

Before scheduling the evaluation and meeting with the living donor team, potential donors will be asked to give a blood and urine sample, either at the transplant center or at a lab near their home. This will help the team check for any major health issues that would prevent someone from donating before scheduling appointments.

What does a “full evaluation” involve?

Most transplant centers have a similar living donor evaluation. Most transplant centers have a two-day evaluation where every donor will meet with the living donor team, have more lab work (blood drawn), and complete imaging (such as CT scans and a chest X-ray.)



You can expect to see these team members during your evaluation:

- **Nurse Coordinator**

- » The nurse coordinator is the point person throughout the entire evaluation, surgery, and follow-up after surgery. They can help answer medical questions, review lab results, and keep the donor informed about the process.

- **Nephrologist**

- » The transplant nephrologist, or kidney doctor, talks to potential donors about how well their kidneys are working and if they are healthy enough to donate one.

- **Social Worker**

- » Everyone meets with a social worker during the evaluation process. Some topics the social worker will talk about include support for taking time off work, caregivers during the hospital stay and after surgery, recovery, and emotional well-being. They'll also check to see if donors qualify for any financial help with non-medical costs like gas, hotels, meals, or care for children during the process of donation.

- **Surgeon**

- » The surgeon will ask about past surgeries and explain how the living donor surgery will take place. The surgery is usually done through small incisions in the belly area. The surgeon will also talk about pain management medicine for a short period after surgery. If the donation goes ahead, the surgeon will visit the donor a few times in the hospital after surgery.

- **Dietitian**

- » The dietitian will review daily eating habits and talk about life after donation. Even though living donors don't have to change their diet after donating, the dietitian will review what a healthy, well-balanced diet looks like, to help donors take proper care of their body before and after donating.

- **Independent Living Donor Advocate**

- » An Independent Living Donor Advocate (also known as an ILDA) is a care team member who is totally separate from the living donor team. Every living donor meets with an ILDA during the evaluation to talk about their reasons for wanting to donate. The ILDA is there to support the donor, to make sure that no one is pressuring them in any way, and to provide support at any step of the process.





At minimum, potential donors will need lab work and imaging done during the evaluation to check on their health and their kidneys:

- **Lab work**

- » After the first blood work before coming in for the evaluation, the team will do another blood draw and urine sample at evaluation to check on the potential donor's health. The blood work will also tell the team about whether the donor is a good match with the person they are planning to donate to.

- **Imaging**

- » During the evaluation, imaging tests will help the team see the size of your kidneys and how well blood is moving through them. These tests usually include a chest X-ray and a CT scan. These images also help them to decide which kidney is the best one to donate so the donor keeps the healthier kidney.



Extra Costs during Evaluation

The living donor team is there to make sure every potential donor is in their very best health. This includes both the special testing for kidney donation and any normal healthcare tests that healthy people get. This is considered “routine” healthcare and is not covered by the recipient's insurance. Potential donors are responsible for covering routine care with their own health insurance, including dental, OBGYN, colonoscopies (for those over 65 years old), etc. Potential donors who don't have health insurance can talk to the social worker to find low-cost or free clinics for these services.



When a donor is not a match

Directed donors may not always be a good match for the person they want to donate to. It is hard to predict who will be a good match. Even if the donor and recipient are related, they may not be the best match. If that is the case, some transplant centers offer “paired exchange” programs. A paired exchange involves two pairs of living donors and their recipients. The two recipients “swap” donors so that each receives a kidney from a compatible (well-matched) donor. Directed donors should ask the transplant center if paired exchange is an option. If so, the transplant team will take care of the entire process, including finding the matching pair.

How long does the evaluation process take?

The length of time it takes to complete the evaluation process is different for each person. It will depend on the donor’s schedule for the in-person evaluation, the numbers of tests, the results of those tests, and the transplant center’s schedule. If the recipient’s transplant center is far away, potential donors may be able to complete some tests at a hospital or lab closer to home. Talk to the transplant center for more information.

What happens after the evaluation is complete?

The living donor team will meet to take a careful look at all the evaluation and test results and decide if the potential donor is healthy enough for surgery and for life with one kidney. The team will call the donor to let them know if they've been approved. If the donor still wants to move forward, they'll schedule a date for surgery that works for both the donor and the recipient.



SURGERY AND RECOVERY

What does the operation involve?

The living donor is put to sleep with general anesthesia, like any other surgery. Most transplant centers also give donors “pain blocks” before going into surgery, which means the belly area will be numb for 12-24 hours after. Doing this helps to lessen the amount of pain medication needed after the surgery and reduces the amount of pain, overall.

Living donor surgery takes about two to three hours. Most transplant centers perform laparoscopic surgery, which means using a tool that makes two to three tiny incisions (cuts) to remove the kidney.



Most donors are up walking the same day of surgery and stay in the hospital for about one to two nights. Pain medicine is only needed for a short amount of time after surgery.

What are the risks of surgery? Just like having any other surgery, there are some risks to be aware of with transplant surgery. Some of the most common risks are:

- bleeding or getting an infection in the surgical area
- developing a hernia if the donor lifts anything too heavy right after surgery
- getting a UTI, or Urinary Tract Infection. This can be caused from having a urinary catheter placed during surgery to allow the body to urinate (pee) while in surgery and under anesthesia
- Death rate is extremely low, at 0.03% (3 in every 10,000 people who donate)

How long will I need to recover?

Most donors stay in the hospital one to two nights after surgery. Most donors are fully recovered after four to six weeks. Some donors return to work two weeks after surgery if they don't have a very physical job. If a donor has a physical job and needs to return to work soon after donating, some employers will offer an option to do non-physical work like working at a desk. Talk to the transplant team about returning to work and other physical activities, like playing sports.

AFTER DONATION

What are the long-term risks of donation?

Research has shown that living donors can live a normal, healthy life with one kidney. In fact, when one kidney is removed, the other kidney will grow to take over the work the donated kidney was doing. This is called “compensatory growth”. Studies show that after donation, a donor’s total kidney function (how well the kidney works) returns to roughly 70% within 10 to 11 days, and about 70 to 80% at long-term follow-up.

Donors will have a slightly higher than average risk of developing high blood pressure in the long term. It’s important to eat a healthy diet and get back to regular physical activity after recovery to stay healthy. This is especially important for female donors who may want to become pregnant after donation.

There is also a slightly higher risk of developing kidney failure after donation compared to the average person. Research so far has shown this occurs in less than 1% of people who donate. Less than 1% of people who have donated end up needing dialysis or a transplant, themselves, which is only slightly higher than the average risk of someone who hasn’t donated. The small number of donors who have problems with their kidney later in life are able to get a higher place on the waitlist because they have donated a kidney.

What can I expect after donation?

Living donors generally rate their experience as positive. Studies show that between 80–90% of donors say that after they’ve donated, they would still make the decision to donate. Some donors have reported feeling anxious or depressed after donation. The process of getting through the evaluation and surgery while hoping to give someone a kidney can bring a lot of different emotions. Feelings of depression among living donors for a short time after donation are not uncommon, even when both donor and recipient are doing well.

Donors should talk to the transplant team to let them know how they are feeling both physically and emotionally during follow-up visits because emotional health is important, too. For donors that are struggling with mixed emotions at any time during the process or after donation, NKF recommends:

- Talking to the living donor social worker or Independent Living Donor Advocate (ILDA) for support and guidance.
- Talk with and hear from other living donors who have had similar experiences. You can call 855.653.2273 or visit **kidney.org/peers** to learn more.

MAKING AN INFORMED DECISION

Donating a kidney is a very personal decision. Any donor who has any concerns during the decision-making process is encouraged to talk with the ILDA, the transplant team, family members, or other trusted people like a faith leader for more guidance. All conversations between the donor and the transplant team will be kept confidential. The potential donor can change their mind at any time, for any reason, and the reason will be kept private.

Many donors find it helpful to talk to someone who has already donated. The National Kidney Foundation's Peer mentoring program connects potential living donors with people who have already donated to ask questions and share their experiences. You can call 855.653-2273 or visit **kidney.org/peers** to learn more.

What if I decide not to donate?

The decision to donate a kidney is completely up to the donor. Potential donors should never feel any kind of pressure, including from the person they are donating to. Donors have the right to decide that donating a kidney is not right for them. Potential donors can delay or end the donation process at any time, including up until the day of surgery. The reasons for the donor's decision will be kept private and confidential by the transplant team.

If you are thinking about donating a kidney

1

DECIDE TO DONATE

CONTACT A TRANSPLANT CENTER

- To donate to someone you know, reach out to *their* transplant center.
- For non-directed donations, contact *any* transplant center.
- You can change your mind at any time for any reason!

2

EVALUATION

ENSURE YOU'RE HEALTHY ENOUGH

- Lab work (blood and urine samples) to check your health and compatibility.
- Meet with the transplant care team to discuss your physical and emotional health.
- Imaging (x-rays or CT scans) to examine your kidneys' health.

3

SURGERY

IN THE HOSPITAL

- Living donor surgery is usually laparoscopic, with small belly incisions
- Most donors stay in the hospital for 1-2 nights.

4

RECOVERY & FOLLOW UP

APPROXIMATELY 4 – 6 WEEKS

- You will have follow up appointments to check your health
- After 2 years, most donors return to their primary care doctor

MORE INFORMATION

Where can I find more information?

NKF Cares is a toll-free patient help line for people affected by kidney disease and for people looking for more information on transplant and living donation. Patients, families, and caregivers can speak with a trained specialist who will help answer questions and listen to concerns.

855.653.2273

NKFCares@kidney.org

You can also find free educational material and other resources by calling, emailing, or visiting the website.

Setting a Standard for Care

The National Kidney Foundation, through its *Kidney Disease Outcomes Quality Initiative* (KDOQI®), defines stages of kidney disease and offers guidelines that help your doctor and healthcare team make important decisions about your medical treatment.

The information in this booklet is based on those recommended guidelines.



The information contained in this publication is based on current data and expert guidance available at the time of publication. The information is intended to help patients become aware of their disease and its management. This publication is not intended to set out a preferred standard of care and should not be construed as one. Neither should the information be interpreted as prescribing an exclusive course of management. Patients should always consult with their healthcare providers regarding decisions about their individual plan of care.



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The National Kidney Foundation is revolutionizing the fight to save lives by eliminating preventable kidney disease, accelerating innovation for the dignity of the patient experience, and dismantling structural inequities in kidney care, dialysis, and transplantation.

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