

Getting a kidney transplant: What to know, plan & expect

Experts agree: getting a kidney transplant is the best treatment for end stage renal disease (ESRD) whenever possible. A successful kidney transplant is closest to natural kidney function and can help you live a longer, healthier life. If you're living with chronic kidney disease (CKD), the best time to start planning for a kidney transplant is now.



First things first

Discuss getting a kidney transplant with your doctor. Together, you and your doctor can determine whether you're a good candidate for kidney transplant surgery. If a transplant is a good option for you, you'll be ready to take the next steps.



We're with you

This guide will walk you through:

- How to get started in the kidney transplant process
- // What to expect at each step
- // How to get your questions answered along the way

Gathering information ahead of time can help you—and your loved ones—make a plan and get prepared.



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TIP

Get an overview of the transplant journey.

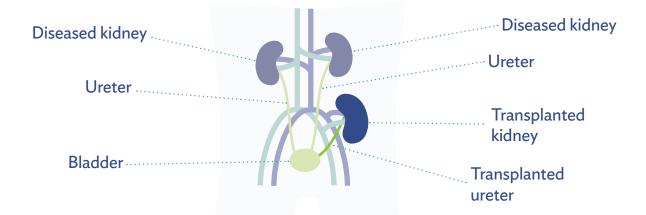
This list of steps gives an at-a-glance view of what's involved in preparing for a transplant. <u>See page 7</u>.

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Kidney transplant 101: The basics

What is a kidney transplant?

A kidney transplant is major surgery in which a person with kidney failure receives a new kidney from a living or deceased donor. The new donor kidney and attached ureter (urine tube) will be placed in your abdomen and the ureter will be attached to your bladder. If the transplant surgery is successful, your new kidney will take over the processes of filtering your blood and making urine.



What's the success rate of kidney transplant surgery?

According to the national Organ Procurement and Transplantation Network (OPTN), the success rate after a kidney transplant is high and varies slightly depending on the source of the kidney.

Source: Organ Procurement and Transplantation Network



DID YOU KNOW?

You only need 1 working kidney—so only 1 kidney is transplanted during surgery.
Typically, your 2 original kidneys will remain in place—your new kidney will be placed in another area of your abdomen.

Considerations for a successful kidney transplant

If you choose to pursue a kidney transplant, you should know that your best chance for a successful transplant relies on certain factors and conditions. In general, kidney transplant surgery requires:



1 Managing your health

To have a kidney transplant, you must be healthy enough for surgery. You'll have a complete medical exam and a series of tests to screen for any medical conditions that could affect your ability to have a successful kidney transplant.



2 A good kidney match

In order to be good match for you, your new kidney must be from a donor who has:

The same tissue type—aside from identical twins, no 2 people have the exact same tissue type. For transplant purposes, a match is considered the "same" if tissues match 12 certain protein markers.

A compatible blood type—certain blood types are compatible, meaning their antibodies won't attack each other. People with O blood type are the "universal donor" and are compatible with any blood type. People with AB blood type are the "universal recipient," and can receive a kidney from a donor with any blood type.

The ideal match is from a living donor with the same tissue and blood type whose genetic characteristics are most like your own. A blood relative is often the best match—though there are certainly unrelated donor matches that can be successful.



3 The right timing

The best time to get a kidney transplant is before you actually need dialysis. However, there are many factors that may affect the timing for kidney transplant surgery—including your health and the availability of a matching donor kidney.

If you're searching for a living donor

Finding a matching donor through family or friends can take some time. If you have a willing donor who turns out not to be a match, you can also explore a paired kidney exchange or donor matching program. These programs offer the opportunity to swap with other unmatched donors and recipients to find a match. (Learn more on pg. 13.)

If you're registering on a kidney transplant waitlist

Per the National Kidney Fund, the average wait time on the kidney transplant waiting list is approximately 3 to 5 years. Timing can vary, depending on the transplant center.

TIP

Understanding kidney waitlists

- The National Kidney Registry (NKR)—is the nationwide waitlist that lists all kidney donors and recipients who don't have a match. All organ matching across the country is managed by the Organ Procurement and Transplantation Network (OPTN).
- Your Center Registry—is the waiting list at your specific transplant center. When a kidney becomes available, OPTN tries to find a recipient at the center closest to the available kidney. Registering at more than one transplant center—called multiple listing—can make you eligible for a kidney in more than one area and increase your chances of getting a kidney faster.



Benefits and risks of a kidney transplant

There are big benefits to having a kidney transplant. A successful kidney transplant can help you live a longer life than you would on dialysis. You may also have fewer health issues—and a better quality of life.

The biggest benefits of getting a kidney transplant can include:

- Not needing dialysis
- Feeling more energetic
- 🖊 Achieving better overall health
- 🗲 Having fewer restrictions on what you eat and drink

DID YOU KNOW?

A transplanted kidney lasts an average of 12-15 years, though some will last longer and people may need multiple transplants in their lifetime.

Potential risks and side effects of a kidney transplant

As with any surgery, having a kidney transplant could potentially cause complications. It's important to understand and consider all possible outcomes. Your transplant care team and nephrologist will discuss these risks with you in more detail.

The potential **risks** of a kidney transplant may include:

- // Temporary lack of kidney function
- Ørgan rejection
- / Kidney failure
- 📕 Cancer
- 📕 Diabetes
- / Heart attack or stroke

The potential **side effects** of a kidney transplant may include:

- Narrowing of the artery leading to the kidney—also called renal artery stenosis
- / Blood clots
- Infection
- / Bleeding
- 🗸 Weight gain
- 📕 High blood pressure

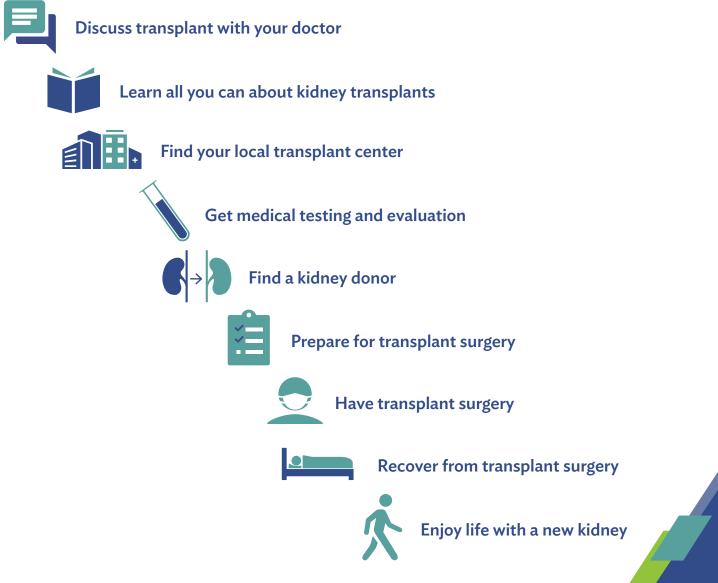


Planning for a transplant

The sooner you start planning, the earlier you may be able to get your kidney transplant. If you get a transplant before your kidneys fail, you may be able to avoid dialysis.

Your transplant journey

Ready to get started? Here's a list of what it usually takes to get a kidney transplant. Use this overview to help you understand what to expect.





Getting a kidney transplant is a very personal experience, so focus on making decisions and taking steps that are right for you and your health.

Who's on your kidney transplant care team

Your kidney transplant care team is the team of medical professionals who will care for you throughout the transplant process, once you're a transplant patient.



- **Transplant doctor**—A nephrologist with advanced training in kidney health who will oversee your care before and after your transplant.
- **Transplant surgeon**—The expert kidney surgeon who will participate in your transplant evaluation and perform your kidney transplant surgery.
- Transplant coordinator—Your main contact person at the transplant center and the first person you should call about any questions, health changes, or appointment scheduling.
- Transplant pharmacist—A dedicated transplant pharmacist who will fill your medications and educate you on how to take your medications.
- Transplant social worker—A social worker who specializes in providing emotional support and resources to transplant recipients, donors, and families.
- Transplant dietitian—The specially trained renal dietitian who will work with you to help you plan meals and stay healthy, based on your unique needs.
- Insurance coordinator—A dedicated expert to help with medical insurance, understanding costs, and questions about billing.

TIP

Make a transplant care team contact list. Write down the name, title, phone number, and email address for all of your care team members so you have them all in one place.

All about transplant centers

Organ transplants of all kinds are performed at specialty transplant centers. These centers are fully equipped for transplant surgery and staffed by expert care teams who are trained in helping both recipients and living donors through the transplant process. Most transplant centers are part of a hospital.

Should I register at more than 1 transplant center?

Yes. If there's more than 1 transplant center near you, it's recommended that you request referrals from your doctor and register at more than 1 center. This is called "multiple listing." Since the travel distance between donor and recipient is a key consideration, having multiple listings may give you a better chance of getting a nearby kidney.

NOTE: Be sure to talk to your insurance coordinator or insurance company to make sure you'll be covered for a transplant at any center you register with.

When should I be referred to a transplant center?

Discuss getting a kidney transplant as early as possible with your doctor. Referrals to a transplant center are typically made in stage 4 or stage 5 of chronic kidney disease (CKD). Getting accepted as a patient at the transplant center means you'll be ready as soon as you find a kidney donor.

How do I find a transplant center near me?

Ask your doctor for a referral to the nearest transplant center. To search for all available kidney transplant centers in your region, visit the Organ Procurement and Transplantation Network (OPTN) at <u>OPTN.Transplant.HRSA.gov/Members/</u> <u>Member-Directory</u> and start by selecting "Transplant Centers by Organ."

TIP

When choosing a transplant center, consider these factors:

- Coverage and cost under your insurance
- Icolation and ease of travel to and from
- Whether the center performs living donations
- If the center participates in a paired kidney exchange program

What do I need to know about insurance and the cost of a kidney transplant?

<u>Insurance coverage</u> for a kidney transplant varies by insurer and plan. It's important to find out about all associated costs ahead of time, so you know what to expect.

For a kidney transplant, costs may include:

- 📕 Your hospital stay
- / The actual kidney transplant surgery
- Medications you'll take on a regular basis afterward
- Follow-up appointments
- Transportation to and from the center
- Any professional caregiving you need after surgery

Insurance typically covers about 80% of initial surgery and medication costs; however, out-ofpocket costs are dependent on secondary insurance, deductibles, and out-of-pocket limits. Review your coverage and talk to your transplant insurance coordinator to find out what your insurance covers.

What are other ways to help manage transplant costs?

There are many online resources and tools available that may help you manage the cost of an organ transplant. You can also create a personal fundraising page to share your transplant story and ask for support.

HELPFUL RESOURCES

- HelpHopeLive.org/Get-Started/Transplant-Campaigns
- LivingDonorAssistance.org/Resources/Additional-Resources
 - TransplantLiving.org/Financing-a-Transplant/Financial-Resources-Directory

GOOD NEWS!



You don't have to figure this out alone. Your care team can help you understand your transplant insurance coverage and answer your questions.

Getting your transplant evaluation



What is a transplant evaluation?

A transplant evaluation is an exam of your health and wellbeing to make sure that you're physically and emotionally fit for transplant surgery. Because your transplant care team wants to make sure your kidney transplant can be successful, the evaluation takes time—sometimes as long as several months. The evaluation process and timing can also vary from center to center.

What should I expect from the transplant evaluation process?

- An initial phone call—a coordinator from the center will gather your personal and insurance information. He or she will also schedule your visit to the transplant center.
- Your first appointment—you'll visit the center to discuss having a kidney transplant, as well as any physical or financial needs you may have. Bring a family member or friend with you and plan for a long day.
- A full health examination—your overall health and wellbeing will be examined in detail.

My doctor has already cleared me for a transplant. Do I need more tests?

Each transplant center has its own set of requirements for transplant patients. To get accepted at a center, you'll need to complete that center's evaluation and be assessed by the transplant care team.



4 things to expect during your health evaluation



- A review of your medical history—to fully inform your transplant care team
- A complete physical exam—to identify any health issues that may prevent a successful surgery
- A psychosocial assessment—to make sure you're emotionally prepared to cope with surgery and recovery
- A series of medical tests—to assess your compatibility with your living donor or a deceased donor off the transplant list

TIP

Preparing for your evaluation visit

- Your center coordinator will tell you what information to bring with you and give you any pre-visit instructions to follow.
- / Try to be as well-rested as possible for your evaluation. The process can take time.
- Bring a list of any questions you have about insurance coverage, costs, or the transplant itself to your initial visit.

NOTE: If you're already on dialysis, be sure to talk to your insurance coordinator and social worker before making any changes to your insurance. It's important to understand your options while you're waiting on a transplant and still on dialysis treatment.



Facts on kidney donor options and matching

Once your transplant care team has accepted you as a candidate for a kidney transplant, you'll need a kidney from a matching kidney donor. Here's what you need to know.

There are 2 sources for a donated kidney

<u>A deceased donor</u>—a recently deceased person with a healthy kidney for donation.

<u>A living donor</u>—a family member, friend, acquaintance, or stranger who's willing to donate a healthy kidney.

3 necessary factors for a donor match

📕 The same tissue type

Aside from identical twins, no 2 people have the exact same tissue type, though a match is considered the "same" if tissues match 12 certain protein markers.

🖊 Compatible blood type

Certain blood types are compatible, meaning their antibodies won't attack each other.

Negative serum crossmatch tests

This series of blood tests looks at the reaction between a kidney donor's and a transplant recipient's blood or organs. Negative test results mean there are no antibodies from the recipient's blood that would affect the donor's.

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WHAT'S NEXT?

If you have a living kidney donor match who has already been evaluated and confirmed: Your transplant coordinator will work with both of you to move forward with the kidney transplant process.

If you still need a living kidney donor match: It's time to start your search.

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What to expect on the national kidney transplant waiting list



If you don't have a living kidney donor—or if your donor arrangements aren't finalized—registering on the transplant waitlist for a kidney is an important step. Here's what to know.

How long will I be on the kidney transplant waitlist?

Once you register to be on the kidney transplant waitlist, there may be a fairly long wait. According to the National Kidney Fund, there are approximately 95,000 people on the waitlist and the average wait time for a deceased kidney is 3 to 5 years.

Can I do anything to get a kidney sooner?

Because of organ transport times, the physical distance between a donor and the transplant center is a factor in kidney matching. If you live in an area with access to more than one transplant center, it's recommended that you get screened and accepted at as many transplant centers as possible to have a greater chance of finding a kidney donor sooner.

How will I know my transplant list status?

Your doctor will be notified when you are officially placed on the waitlist and you may receive a letter or a phone call from your transplant team.

What should I do while I'm waiting?

You'll need to take care of your health, keep your information up to date, tell your transplant coordinator about any changes in your health, and attend appointments and dialysis treatment sessions, as prescribed. It's also important to keep your insurance coverage to meet your current needs and avoid making any unnecessary insurance changes while you are waiting on a kidney. If you have questions about your coverage, talk to your insurance coordinator.

How early can I join the waitlist?

You can get on the waitlist for a kidney transplant when your GFR is 20 or below before kidney failure. The sooner you can get on the list, the better. Remember, you'll need to complete your transplant evaluation at your transplant center before you can get a referral from your transplant doctor.

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Staying healthy while you wait for a kidney transplant

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It's important to stay your healthiest while you wait to get a transplant. Going into surgery as healthy as possible can help with your recovery.

Some things you can do to stay healthy

- Keep all your scheduled doctor appointments. Your transplant team will monitor your health while you're waiting.
- Complete dialysis treatment as prescribed by your doctor. Some people may get a transplant before needing dialysis, though many people will need dialysis while they wait.
- **Take all medications as prescribed.** Talk to your transplant coordinator about your current medications and any changes to your prescriptions.
- **// Keep up with vaccines.** Follow your doctor's direction on what you need.
- Follow a healthy, kidney-friendly diet and manage your fluids. Your dietitian or nurse can provide kidney-friendly recipes and help you manage your fluid intake to avoid fluid overload.

NOTE: Managing fluid can help you avoid a higher risk of high blood pressure or hospitalization—which could affect your eligibility for a transplant.

- Keep active and engaged. Follow your doctor's guidelines for exercise and keep up with hobbies and activities.
- Adopt healthy habits. Consider losing weight and quitting unhealthy habits, like smoking. If you make a change, tell your care team!
- Stay in touch. Check in with your transplant team—and make sure they can reach you with updates on your waitlist status.
- Get support. Reach out to family and friends and share what you're going through. Your social worker can also help with support resources.

Helpful online resources



General transplant information:

- Kidney.org/AtoZ/AtoZTopic_Transplantation
- TransplantLiving.org/Kidney
- AmericanTransplantFoundation.org

National listing of transplant centers:

OPTN.Transplant.HRSA.gov/Members/Member-Directory

Information on dialysis:

- Kidney.org
- FreseniusKidneycare.com/Treatments

Information for kidney donors:

- LivingDonorAssistance.org
- // Kidney.org/Transplantation

Help with managing transplant costs:

- SSA.gov/Benefits/Medicare/PrescriptionHelp
- MedicineAssistanceTool.org
- <u>RXassist.org/Patients</u>

Post-transplant care:

- Kidney.org/AtoZ/AtoZTopic_Transplantation
- <u>TransplantLiving.org/After-The-Transplant</u>

JOIN OUR ONLINE COMMUNITY



Find support, ask questions, and connect with people sharing similar experiences. Sign up today at <u>FreseniusKidneyCare.com/Community</u>

DID YOU KNOW?



The Fresenius Medical Care Foundation has partnered with Donate Life America (DLA)—the nation's leading transplant organization—to make it easier for living donors to be matched with people in need of a transplant. Together, we're developing home testing kits for potential living donors and a groundbreaking national, universal living kidney donor registry.

