



YOUR GUIDE TO

Kidney Transplant

INTRODUCTION

The American Kidney Fund (AKF) believes that everyone in need of a kidney transplant should have equal access to this treatment option regardless of race, how much education you have or where you live.

Unfortunately, for many people, the process of getting a new kidney is often confusing, overwhelming and complicated. If you have felt this way in your journey toward a kidney transplant, AKF wants you to know you are not alone.

Many people find it hard to figure out where to go for answers or sometimes are not even sure what to ask. If you or someone close to you needs a kidney transplant, you may not be sure what questions to ask. You may have even gotten so many different answers to your questions, you do not know which answer is correct or who to believe.

This resource aims to give you the basics of a kidney transplant, while providing hope and resources to guide you through the transplant process.

Why is it important to learn about a transplant?

A transplant can be a life-changing surgery for you. However, conversations about this treatment often do not happen until after “crashing” into dialysis. At this point, you may feel overwhelmed about your new diagnosis and this big decision.

In addition, if you are a Black or Hispanic/Latino American, you may find added barriers throughout the transplant process, including¹:

- Being less likely to be evaluated for transplant
- Being less likely to have a living donor kidney transplant

By learning about the transplant option, you can be more informed about this treatment and feel more comfortable talking to your doctor about this at an earlier stage of kidney disease. You and your doctor can discuss if you are a good candidate and steps you can take to raise your chances of having a successful transplant.



“The option of transplant wasn’t discussed early on for me... but it’s important to share this information so people like me have options and considerations earlier.”

– Steven G., AKF Ambassador

Who is this for?

This resource is for anyone considering transplant, including:

- People on dialysis
- People who have not started dialysis yet
- Caregivers, support people and living donors who each play an important role during the transplant process

Who created this?

The best teachers are usually the people who have lived the experience. The American Kidney Fund believes this is true especially with something as life-changing as receiving the gift of life with a new kidney.

For this reason, AKF made sure a team of the most experienced people such as transplant surgeons, nurses, transplant center coordinators, kidney donors and people with a transplant all helped create this resource.

It can be frustrating to hear different information from different people. To avoid this, the AKF team has made sure all content follows the Organ Procurement and Transplantation Network (OPTN) policies and the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK) and the team will be updating this resource regularly.



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KIDNEY TRANSPLANT OVERVIEW

What is a kidney transplant?

A kidney transplant is a treatment option for you if your kidneys are not working well enough on their own. This is called kidney failure, also called end stage kidney disease or end stage renal disease. It is a surgery to give a person with kidney failure (the **recipient**) a healthy kidney from someone else (the **donor**).

Why should I consider getting a transplant?

If you have kidney failure, a kidney transplant can help you feel better and live longer compared to a lifetime on dialysis. It may be a good treatment option for you because it can:



Improve your quality of life:

While a kidney transplant is a major surgery and can seem scary, there can be many positive lifestyle changes. You may be able to return to the life you lived before kidney failure. You will no longer need dialysis and have fewer food and drink limits (restrictions), but it will still be important to keep a healthy weight and eat healthy foods.



Increase your chance of living longer:

Studies show that people who get a kidney transplant have a higher chance of living longer than people who stay on dialysis. On average²:

- People who are on dialysis have a 40% chance of living after 5 years with kidney failure.
- People who get a kidney transplant have a 80% chance of living after 5 years with kidney failure.



When is the right time to get a kidney transplant?

The right time for you to get a kidney transplant may be different from others. Your doctor will work with you to decide the right time for you to get a transplant. If possible, the best time to get a transplant is before you need dialysis, which is called a **preemptive transplant**. This is different from an **early transplant**, which is a transplant that occurs very soon after you start dialysis.

Doctors decide the best timing for a kidney transplant based on your eGFR and results of your transplant evaluation:

EGFR TEST:

Estimated glomerular filtration (eGFR) is a measure of how well your kidneys filter and remove waste products. Your doctor will use your results from the eGFR blood test to help decide when to refer you for evaluation for a transplant. A normal eGFR is 90 or more. You can be placed on the waitlist for a kidney transplant as soon as your eGFR is 20 or lower. But your doctor may refer you for evaluation before your eGFR is 20. Ask your doctor about a referral when your eGFR is 30 or less.

EVALUATION:

Before you get a transplant, you will meet with a transplant team and go through an evaluation process. The transplant team will do many screenings and tests to see if you would be a good candidate for a transplant. They will check blood and tissue types of you and your donor to be sure your donor's kidney is a good match for you (**compatible**).

What are my transplant options?

If you are considering getting a transplant, you have two options for where your donor kidney will come from: a living donor or a deceased donor.

LIVING DONOR TRANSPLANT:

A living donor kidney transplant is surgery where doctors give you a kidney from a person who is alive and chooses to donate one of their two healthy kidneys. A living donor transplant has different names based on how the donation happens:

- **Directed donation:** This is the most common type – the kidney is from a living donor who you know.
- **Non-directed donation:** The kidney is from someone who does not name a specific recipient but wants to donate to anyone – this is also called an “altruistic” donation.
- **Paired exchange donation (“kidney swap”):** This option may happen if you and your living donor are not blood or tissue type compatible with each other. You and your donor will be paired with another donor-recipient pair who better matches you and your donor. The other pair may be people you don't know, such as people from another area of the country.
- **Transplant voucher program:** This newer option allows your willing, yet incompatible donor, to donate to someone else at a time that's best for them. Their donation creates a voucher (credit) for you when you need a kidney in the future. Check if your transplant center offers this program and ask if this would work for you and your donor.

DECEASED DONOR TRANSPLANT:

A deceased donor kidney transplant is a surgery where doctors give you a kidney from an organ donor who has died. The average wait time is 3-5 years for a deceased donor's kidney and may be longer or shorter in some parts of the country.



Did you know? Going through a transplant can feel time-consuming, tiring and stressful. Yet some people have added barriers while going through this process. Black and Hispanic or Latino Americans are less likely to be added to the waitlist for a preemptive transplant, less likely to be referred for evaluation and less likely to receive a living donor kidney transplant. While many factors contribute to these added barriers, you can be your own champion. Start the conversation today with your doctor about these transplant options to learn if you may qualify.

What are the benefits and risks of getting a transplant?



WHY SHOULD I GET A TRANSPLANT?

- Most people live longer than those on dialysis.
- Most people have a better quality of life overall.
- They no longer need dialysis.
- People have higher energy levels.
- Working and traveling is easier.
- There are fewer limits on what you can eat and drink.
- Many people have an improved sex life and better chance of getting pregnant or getting someone pregnant.



WHAT ARE THE RISKS THAT COME WITH A TRANSPLANT?

As with any surgery, a kidney transplant has risks. Some of them include:

- Bleeding
- Infection
- Blocked blood vessels to the new kidney
- Leaking or blocked urine (pee) in the ureter (the tube that connects your kidney and bladder)
- Delay of the new kidney starting to work
- Rejection of the new kidney by your body
- Side effects from the medicine you must take during and after the transplant

What happens if my body rejects the new kidney?

Everyone wants everything to go as planned after having a kidney transplant. There is a lot of hope and excitement about the new life that comes with a new kidney. However, sometimes things do not go as planned. While the hope is that your body accepts your new kidney and that it will be with you for many years, it is unfortunately possible that your body may reject your new kidney³.

Rejection is the body's normal reaction to a foreign object, organ or tissue. You will take special medicines, called **immunosuppressants**, to trick your immune system into accepting the transplanted organ instead of rejecting, or attacking it.

Still, your body could reject the new kidney. This is because your body sees it as a threat, causing your immune system to attack it. This sometimes happens, even with the full screening and matching that happens before surgery.

If your body rejects your new kidney, try not to worry. This does not mean your new kidney will fail. It may mean that your doctor needs to adjust your medicines to stop your body from rejecting it.

It is normal to worry that this will happen to you! Many people have gone through this before and still have their new kidney. If you have worries, reach out to others who have gone through kidney rejection or kidney transplant support groups. You can also ask your doctor or kidney transplant team for resources to learn more about it.

Are there side effects from immunosuppressants?

Your health care team carefully plans your prescription medicines to lower the chance of kidney rejection. They also try to limit the side effects of each medicine.

However, immunosuppressant medicines can raise your chances of getting new diseases or health conditions. These may include:

- Diabetes
- High blood pressure
- High cholesterol
- Anemia (low level of red blood cells)
- Low level of white blood cells
- Bone loss
- Delayed wound healing

Can a person have more than one kidney transplant in their lifetime?

Yes. While the hope is that your new kidney will last, there is the possibility that it may stop working again.

If you are worried about this possibility or if this happens to you, there are options you can talk with your doctor about. It is likely you will need to go on dialysis. You can also be evaluated for a new kidney. If you are healthy enough for another transplant, your doctor may discuss this option.

There are many people who have had more than one successful transplant. If you feel unsure about this option, reach out to your kidney transplant team to connect with someone who has been through this before.

What's next?

This overview covered what a transplant is, benefits and risks and different transplant options. Hopefully you are finding out how a transplant can help you live a full life. Start talking with your doctor today to learn if and how a kidney transplant may be right for you.

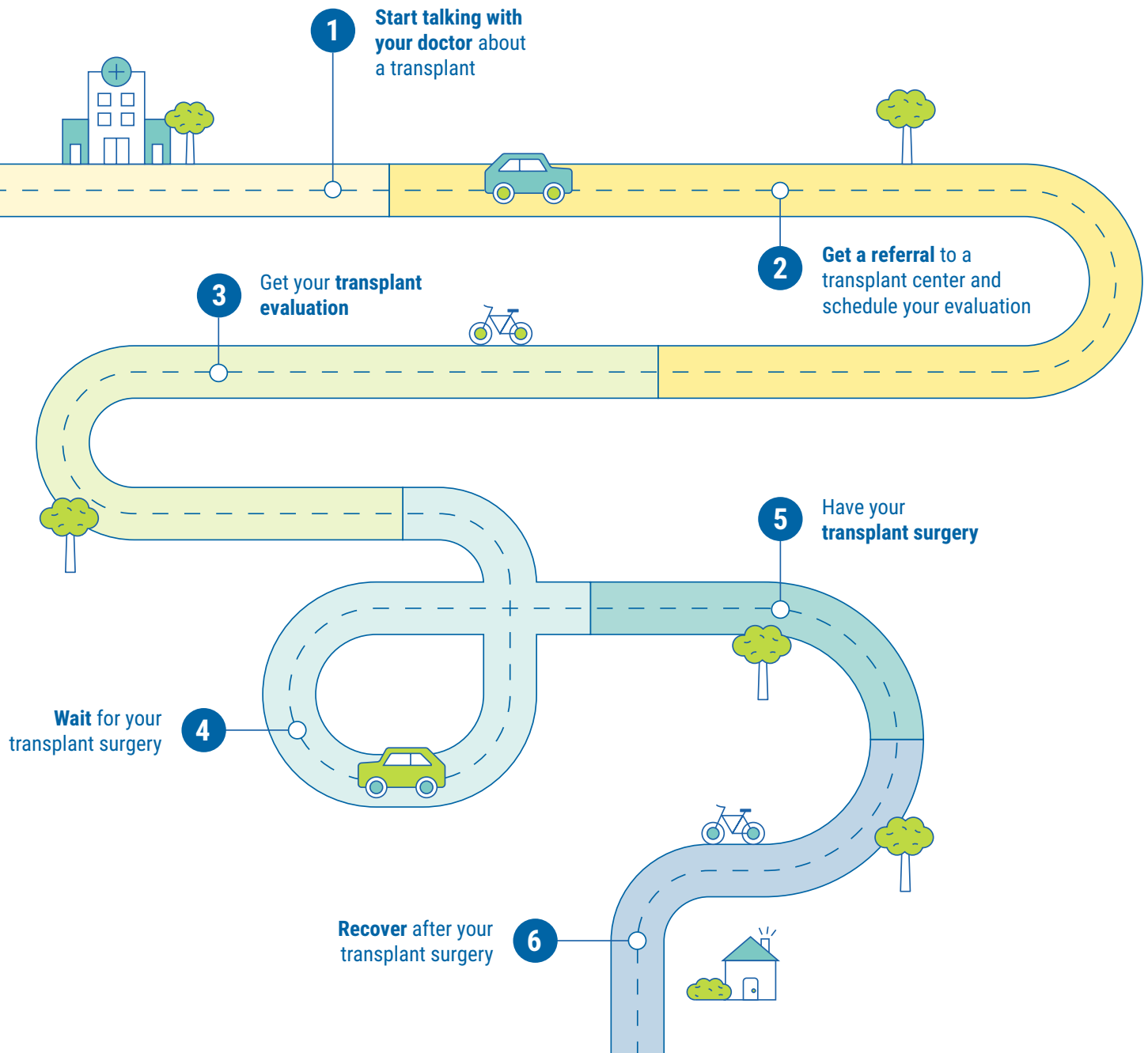


KIDNEY TRANSPLANT ROADMAP

As you consider a kidney transplant, it is important to know about the different steps along the way. You may find yourself overwhelmed by the many steps. You are not alone, and many have traveled this journey before with the support of some valuable resources.

Through this roadmap, AKF hopes to give you tools and resources to empower you to communicate openly with your doctors and transplant team throughout this process.

While this roadmap shows the best practices transplant centers use for the kidney transplant process, every transplant center is different. Your journey may not follow this exact path, but do not feel discouraged. When in doubt, reach out to your transplant coordinator. You can also ask them about peer support so you can talk to others like you who have navigated this process.



1

Start talking with your doctor about a transplant

Talk about transplant with your doctor when you feel comfortable and have questions. Talking about transplant early on gives you time to make lifestyle changes (for example, losing weight or being more active) that can help raise your chances of being a successful transplant candidate.

Once your eGFR is 25-35, start talking to your doctor about transplant as a treatment option.

2

Get a referral to a transplant center and schedule your evaluation

Is it time to be referred for an evaluation? Once your eGFR is 30 or less, ask your doctor about the option of referral. You can be placed on the waitlist as soon as your eGFR is 20 or less, yet your doctor may refer you earlier for an evaluation.

You are most likely going to be referred to a transplant center by your nephrologist (kidney doctor), dialysis unit social worker or you can call one yourself.

After you call the center, both the financial coordinator and the transplant coordinator may contact you for some basic information before you come to the center for your evaluation.

It may be a **few weeks** before you hear back from your transplant center. It may be a **few months** before you can get in for your evaluation appointment.



TIP: If no one from the transplant center has contacted you after you scheduled your evaluation appointment, **contact the transplant coordinator** to ask if they have the information they need about a week before your appointment. Don't hesitate to call them – they are there to help!

Get your transplant evaluation

Your first (initial) visit to the transplant center will include a transplant information session and your evaluation. This is a series of tests to find out if you will be a good candidate for a transplant.

Your evaluation visit may be long and involve a lot of tests, but you will have a transplant coordinator who will guide you through this process. Ask how you should prepare, such as:

- Wear comfortable clothes and shoes.
- Bring snacks, a book, or something to do while you wait.
- Use a walker or wheelchair to help you get around.

The evaluation process usually takes about **three months or less**.



TIP: Bring a notebook to write down your questions for the evaluation day.

THE EVALUATION PROCESS USUALLY INCLUDES THESE STEPS:

1. Every transplant center is different, so you may be at the center for a few hours or up to a full 8-hour day for your evaluation. In addition, you will likely have follow-up appointments for additional tests after your initial evaluation day.
2. You will likely hear from your transplant coordinator or their assistant often during the evaluation phase. They want to make sure your testing is completed and give you results and updates on your next steps.
3. Once the transplant center has all the information they need, members of the transplant team meet as a selection committee to decide if you are a good candidate for transplant.
4. If they decide you are a good candidate, they will mail a letter to your insurance so insurance can approve coverage for your transplant care. This typically happens four weeks after the committee meets. You will then receive notification from your insurance provider or transplant team.



NOTE:

- The transplant team tries their best to communicate with you throughout this process. However, some transplant coordinators may not be able to provide updates throughout the evaluation process. In this case, reach out to them with questions and allow them 2-3 business days to respond.
- Once you have completed all your appointments and tests, your evaluation can last up to two years. After this, you will need to be reevaluated. Some insurance providers may require you to get reevaluated after as short as six months. This process may feel long and tiring, but these policies are in place to make sure you are healthy and your body is ready for a new kidney when it's time.

Wait for your transplant surgery

Once you receive your letter letting you know whether you will be placed on the waitlist, you may not hear from the transplant center as often. This depends on if you have a living donor who is being evaluated and how much waiting time you have.

But you don't have to wait for the transplant center to call you. Feel free to reach out to them to check on your waitlist status, ask questions and get more resources on post-transplant care if you need them.

Waiting can be hard! You may be waiting for a long time. It's normal to feel a wide range of emotions while waiting for a transplant. During this time, it's extra important to try to stay positive, lower your stress and stay healthy.

Your transplant coordinator will probably check on you more often as you get closer to the top of the waitlist. It is important to give them all your current contact information. The last thing you want is to miss "the call" because you forgot to give them your new phone number. These calls do happen in the middle of the night – more than you might think.

If you have a healthy living donor who is up to date on their health screenings and you are active on the transplant waitlist, your process could be much quicker and could be as fast as 3-6 months.

Waiting for a transplant on the waitlist usually takes about **3-5 years**. The wait may be longer in some parts of the country.

Have your transplant surgery

It's transplant day! You either received the call that a kidney is available or you scheduled the surgery date with your living donor. Once you arrive at the hospital for your transplant, the entire team will be very involved in your care.

The transplant team will place the new kidney in your lower belly in the front side. They will leave your kidneys that are no longer working in place. You will likely spend between 3-5 days in the hospital after

surgery depending on the type of transplant. This is the time you will need to heal and make sure you are ready to return home. Donors often spend up to three days in the hospital.

Transplant surgery takes about **3-4 hours**.

Recover after your transplant surgery

It's time to recover! Recovery is different for everyone, but most people fully recover from their surgery after three months. You will likely go back to your normal activities after one month.

In the first six weeks after your transplant, you will meet often (usually every two weeks) with different members of your transplant team:

- Transplant doctor or nephrologist
- At some centers, with a dietitian and pharmacist
- A post-transplant coordinator who will give you more information on how to care for your new kidney long-term

Once you are stable, you will go back to your own nephrologist. The transplant center may call you sometimes to check on your health. Please keep your transplant center updated on your contact information even after your transplant.

You will meet with members of your transplant team for about the **first six weeks** after your transplant surgery.



TRANSPLANT CENTERS

What is a transplant center?

A transplant is a specialized surgery. To receive the best care for this surgery, you will visit a transplant center that is dedicated to one or more types of organ transplants. These transplant centers are places within medical centers and hospitals. Each center has a transplant team made up of many different members.

Whether the transplant center is in a big fancy building or a small office – the people inside are there to help you. So don't be afraid to ask them anything. All questions are good questions!



Did you know? Right now, there are over 250 kidney transplant centers in the United States. These transplant centers are certified and closely monitored by state and federal organizations. The organizations, also known as “regulatory agencies,” have very specific rules that all transplant centers must follow. This is to make sure that you and your loved ones are safe and get the highest quality of care.

How can I find a transplant center near me?

Some states have many transplant centers, while a few states don't have any at all. To learn about and find transplant centers near you, visit the [Organ Procurement and Transplantation Network \(OPTN\) website](https://optn.transplant.hrsa.gov/members/member-directory/) at <https://optn.transplant.hrsa.gov/members/member-directory/>. From this website:

1. Under “**Member Type**,” choose “**Transplant Centers by Organ**.” Press “**Go**.”
2. For “**Organ Type**” choose “**Kidney**.” Press “**Go**.”
3. For “**Member status**” choose “**Active**.” Press “**Go**.”
4. Choose your state or region. Press “**Go**.”

Ask your nephrologist and dialysis social worker for more information on local transplant centers. If you want to check if a kidney transplant is right for you, ask your doctor to refer you to a transplant center to meet the transplant team.

So, what exactly do transplant centers do?

Transplant centers have different roles before, during and after a transplant.

BEFORE TRANSPLANT:

- Your transplant team will share basic information on the kidney transplant process. Think of it as a kidney transplant 101 class.
- Your transplant team will start with a process called evaluation. You will meet with your transplant team and you will have many tests to see if you are a good candidate for transplant.
- Once all the testing is done, the center will tell you if you are a good candidate for transplant. If you are, you will be placed on the transplant waitlist.
- The transplant center may contact you for updates on your health while you are on the waitlist.

DURING AND AFTER TRANSPLANT:

- The transplant team will help you throughout the transplant surgery and recovery. As you go through this process, you will get information, training and support on how to take care of your new kidney.
- After the transplant, the transplant center will stay in touch with you or your nephrologist to get updates on your health. These “follow-ups” are required by the regulatory agencies and this information is then published on <https://srtr.org/> for each transplant center.



TIP: Don't be a stranger! Call your transplant coordinator and give them updates on how you are doing.



Did you know? Transplant centers follow the same rules and guidelines, and all perform the above tasks, but they can be very different from each other in **how** they do all these things. For example:

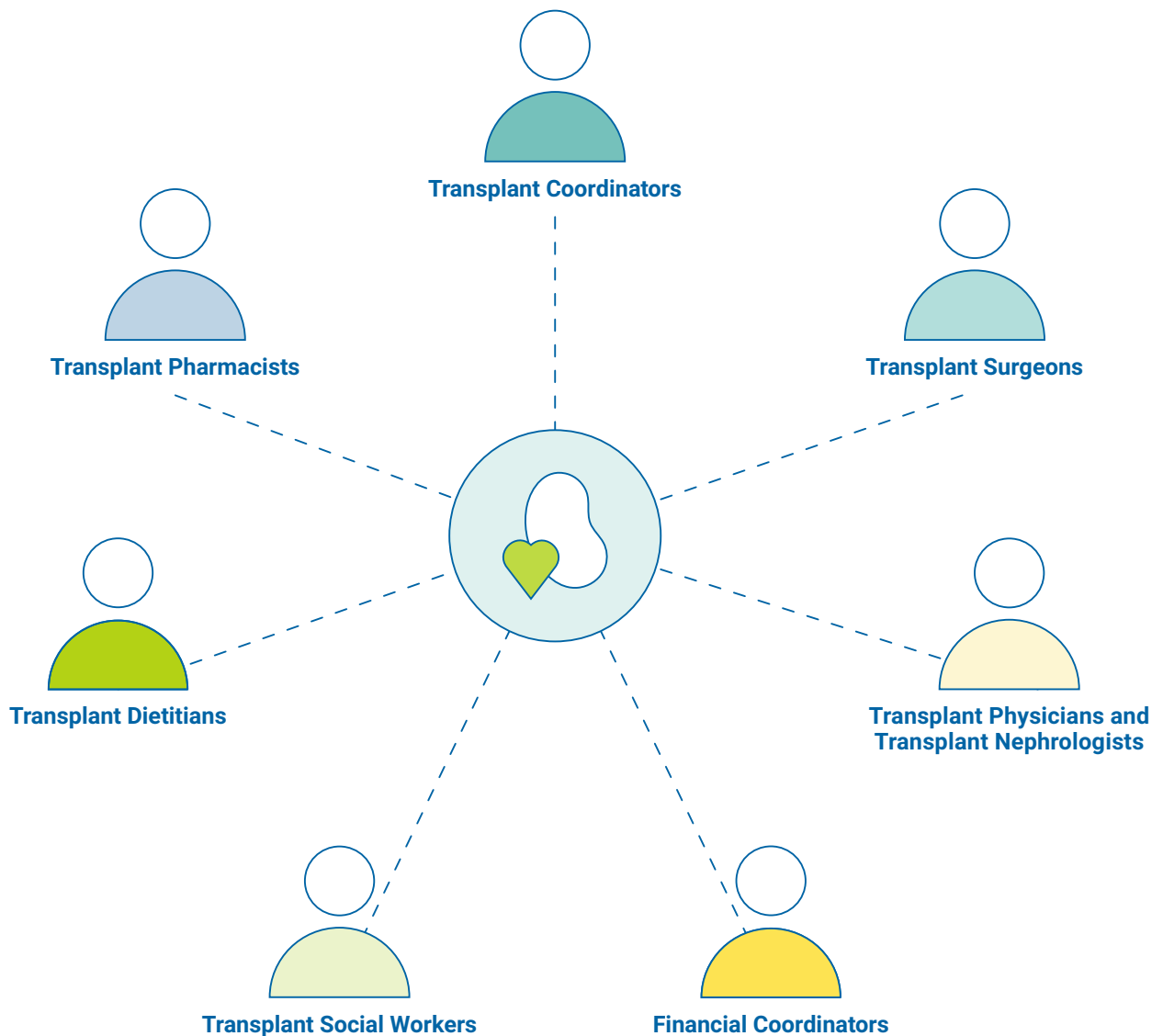
- Transplant centers choose their own selection or eligibility requirements by which patients can be accepted or not accepted as a transplant candidate.
- Their testing requirements can be different.
- The transplant evaluation is different at each center.
- Treatments and medicines may be different at different centers.
- How the center communicates with you can be quite different. For example, some may expect you to send an email to your coordinator rather than talk by phone.

The goal for all transplant centers is to make sure that you **understand the transplant process, options, risks and benefits** while helping you with each step. It is not easy and can be overwhelming. Ask your transplant team any questions you have about how your specific transplant center works.

Who is on a transplant team?

Many different medical professionals at the transplant center will be on your transplant teams throughout the transplant process. They all help prepare you for the surgery and life after a transplant. Each member is a highly trained expert who plays a specific role in your care. They will communicate with each other to create and plan your transplant journey. They will be an invaluable resource as you go through this process. You will meet many of these team members in your first appointment at the transplant center.

MEET THE TEAM:





Transplant coordinators:

Transplant coordinators are also known as nurse coordinators because they are usually nurses. There may be a different nurse coordinator before, during, and after transplant. Coordinators are your connection to the transplant center and your best source of information throughout your journey. They will:

- Guide you through the evaluation, testing and teaching before, during and after a transplant
- Call you before your first visit and meet you in person when you come in
- Usually have transplant coordinator assistants to help you when you call the transplant center for any questions about your status, testing or updates. The assistants cannot give medical information, but they will get you to the right person who can.



Transplant surgeons

These are doctors who perform the transplant and living donor surgery. They may also give follow-up care. The surgeon will speak with you before the surgery about the surgery's risks and benefits and answer your questions. You may meet them at your first appointment, and will meet with them when your transplant surgery happens.



Transplant physicians and transplant nephrologists

These are doctors who manage medical care, tests and medicines for you and for the living donor if there is one. Before your transplant surgery, they usually:

- Meet you at your evaluation visit
- Take part in the living donor evaluation if you have a living donor
- Make sure you stay healthy and strong for transplant (see eligibility requirements section) while on the waitlist
- Communicate with your other doctors involved in the transplant process, such as your transplant surgeon

During transplant surgery, transplant physicians and nephrologists do not perform surgery, but they may:

- Meet you for the transplant surgery
- Often, will manage your hospital care after transplant surgery
- Manage the medicines that suppress your immune system after the transplant and any signs that your body is rejecting the new kidney
- Refer you back to your own nephrologist for follow-up care after you recover from the transplant surgery



Financial coordinators

These are people who have detailed knowledge of financial matters and insurance coverage. They will:

- Talk with you by phone before your first appointment and meet with you at your evaluation visit
- Help you understand and plan the financial aspects before, during and after transplant. It's important that you know early on what your share of the cost may be (if any) for your new post-transplant medicines.
- Share various resources to help you cover costs, including suggestions and tips around fundraising

Make sure to keep the financial coordinator updated on any changes with your insurance or financial situation.



Transplant social workers

You can call the transplant social worker any time during your journey. These are professionals who:

- Help you, your family and other support people in your life understand and cope with issues related to kidney disease and transplant
 - May also help you find resources in the community to help overcome any barriers to getting a transplant, such as mental health, housing and transportation
 - Meet with you at your evaluation visit and while you are recovering from surgery
-



Transplant dietitians

These are nutrition experts who will:

- Review your current eating plan (whether or not you are on dialysis)
 - Help you understand the best possible eating plan for you as you reach your goal of transplant
 - Stay connected with your dialysis unit dietitians as needed
 - Usually, meet with you at the time of your evaluation visit and during and after your transplant surgery
-



Transplant pharmacists

You may not meet a transplant pharmacist until you are in the hospital for your transplant surgery, but they are an important part of the transplant team. These pharmacists: Review your current eating plan (whether or not you are on dialysis)

- Monitor your lab results and medicines before, during and after the transplant surgery
- Review your medicines, health history and allergies, and communicate regularly with the rest of the transplant team



Did you know? Potential living donors also have their own “team” that is separate from your team. You can read more about their team on page 47. Potential living donors get their own nurse coordinator and advocate. It’s important that patients and living donors contact their own nurse coordinator with any questions or concerns.

That way, both you and your potential living donor enjoys privacy and the full attention you both deserve.

Communication is key!

Many questions may come up as you go through your transplant journey. Your transplant team will be a valuable resource for these questions. Anytime you want to learn more about your transplant status, you should call the phone number (or email) that the transplant center gives you. They will refer you to the right person even if you do not remember with whom you need to speak.



NOTE: It is your duty to always update the transplant center with your current contact information.



TIP: Transplant team members are responsible for hundreds, if not thousands, of people just like you. How often you will hear from your transplant team members depends on where you are in your journey.

- Be patient if you have to leave a message, but also be persistent! If you don’t get a return call or email within 3-5 days, politely call to leave another message.
- It is okay to ask if someone else can answer your question.



NOTE: Changes happen! It is important for you to keep the transplant team updated on any changes to your contact information. They will not have a way to reach out to you otherwise.

ELIGIBILITY REQUIREMENTS

Now that you've decided to explore the option of a kidney transplant, you may wonder if you are eligible to get one. Every transplant center has a list of eligibility requirements (also called criteria) that their team uses to find out if a person will be a good candidate for transplant.



Did you know? Transplant centers use other names for "eligibility requirements," including:

- Selection criteria
- Acceptance criteria
- Absolute and relative contraindications
- Exclusion criteria

What are eligibility requirements?

Eligibility requirements are factors about you (the kidney patient) such as medical conditions, mental well-being or financial situations that determine if you qualify to be on the waitlist and get a transplant.

You will share a lot of information about yourself, which can feel stressful. Transplant centers use these thorough eligibility requirements to make sure you will be healthy and supported enough to have a successful transplant.

There are two types of eligibility requirements for a kidney transplant:

- 1. Organ Procurement Transplant Network (OPTN):**
You must have kidney failure that is irreversible (cannot get better).
- 2. Transplant center requirements:**
Each transplant center must create their own eligibility requirements (usually called selection criteria) for choosing transplant candidates. These are based on their experience, success rate, and willingness to take high-risk patients (such as, patients with infectious diseases like HIV and Hepatitis C). Transplant centers get "report cards" on how they are doing, so it's common for transplant centers to change their eligibility requirements from time to time.



NOTE: The Center for Medicare & Medicaid Services (CMS) **requires** that every transplant center have a list of their eligibility requirements. The transplant centers must give a copy of that list to you and the dialysis unit social worker if asked.

Why are there eligibility requirements?

These requirements are all about safety— for you, the living donor (if you have one) and the kidney itself. Currently, there are not enough kidneys available to meet the number of people needing one. Therefore, transplant teams use these requirements to carefully select recipients who will have the highest chance of a successful transplant. You must meet the eligibility requirements to get added to the waitlist, as well as while you are on the waitlist.



NOTE: If you are (or plan to be) on the waitlist at more than one transplant center, you need to meet the requirements for **each** center

OPTN KIDNEY WAITLIST ELIGIBILITY REQUIREMENTS

The OPTN requirements are very straightforward:

- You must have irreversible kidney failure. This means either:
 - Your estimated glomerular filtration rate (eGFR) must be at 20 or below, or
 - You are on chronic (long-term) dialysis

If you have a living donor and are not yet on dialysis, you may be placed on the waiting list with an eGFR above 20, but you will not start to build wait time until it is at 20 or less.⁴ If you're not sure what your kidney function or eGFR is, call your doctor to ask.

- You must be evaluated and listed at an approved transplant program that is located in a hospital (here in the U.S.) that:
 - Has a Medicare provider agreement, and
 - Is contracted with the Organ Procurement and Transplant Network (OPTN)

TRANSPLANT CENTER SELECTION CRITERIA

Transplant centers have many different names for their eligibility requirements. The most common term is “selection criteria,” which is what will be used here.

Most centers present their selection criteria as absolute or relative contraindications. These are factors that can make a transplant risky and will often be a reason the team will not recommend you for a transplant:

- **Absolute contraindications:** These are things about a patient (including a medical, social or other condition) that a transplant center will absolutely **not** accept for waitlisting or transplant. Common examples are current cancer or drug abuse.
- **Relative contraindications:** These are things about a patient that the transplant center **may** consider on a case-by-case basis to decide if they are safe for a transplant. Examples include a patient with a heart problem that can be fixed or a patient who is overweight but loses the weight to become eligible.

What are the most common reasons someone may not be eligible?

If a transplant center decides you are not a good candidate for a transplant, don't give up. You can talk with the transplant center to see if there is anything you can do to improve your chances.

There are sometimes things you can change to help you become eligible, such as meeting a weight goal or getting certain medical treatments. Talk with your doctor about how you can work on these things to try again.



HAVING CANCER

Having a current or recent case of cancer is one of the most common factors that can prevent you from being a good candidate for transplant. The medicines you must take after a transplant (to prevent rejection of your new kidney) can cause complications if you have cancer, as they:

- Are meant to lower your immune system's (your body's defense against infection) response, making you "immunocompromised."
- Can allow cancer to grow faster.

Even if you are finished with all your cancer treatment, a transplant center may require you to wait for a certain amount of time just to make sure there's no chance of your cancer coming back.

The transplant center will evaluate your situation and let you know if you qualify. They will look at your type of cancer, treatment, how long you've had it and what your cancer team expects to happen.

If you are **already on the waitlist** when you are diagnosed with cancer, your transplant team will discuss the plan with you once they get medical records about your cancer. They may put you on hold or remove you from the waitlist. If one transplant center tells you that you do not qualify based on having cancer, you can always ask for a second opinion from another transplant center.

Even if you haven't been diagnosed with cancer:

- Ask your family members if there's a history of cancer in your family.
- Ask your doctor to schedule you for routine cancer screenings as recommended, since it's better to find cancer early and get it treated.

- Tell your transplant team if you have ever had cancer, even a small skin cancer. This allows them to request your medical records and let you know if it affects your ability to get a transplant.



HAVING A CURRENT INFECTION

As with cancer, the immune suppressing medicines after a transplant can help a current infection spread quickly throughout your body. Having a current infection, including an open sore, is a common factor that could prevent you from moving forward in the transplant process. Even something as small as a dental cavity can advance into a life-threatening infection because of the transplant medicines.

Infections such as colds, open sores or catheter infections may cause the transplant center to place you on hold until your infection is gone.

Many centers will not consider you for a transplant if you have a chronic infection such as HIV or Hepatitis C, yet some may. It depends on how well treated or controlled your infection is. Some transplant centers do not have the specialty programs or resources to transplant patients with these types of infections, but you can ask to be referred to a center that does.

Talk to your transplant team if you have questions about any infections you may have.

When the transplant center calls you in for the kidney transplant surgery, they will ask you if you have **any** type of current infection.

Infections happen, but you can help **prevent** them:

- Make sure you get your teeth checked every 6 months by a dentist. If you are worried about the cost, ask your doctor or transplant team for local dental resources that cost less.
- Get vaccines as recommended by your doctor and transplant team.
- Take medicine as prescribed for treating chronic infections such as HIV or Hepatitis C.



HAVING A SEVERE PROBLEM WITH YOUR HEART, LUNGS OR BLOOD FLOW

You may see this on the selection criteria as “severe unrepairable or irreversible cardiac, pulmonary or vascular issues.” Other than having a successful kidney transplant, the most important thing is for you to survive and thrive. For this reason, it is vitally important to ensure your heart, lungs and circulation (blood flow) are healthy. Severe damage to these organs is a common reason for being turned down for transplant.

Heart problems: Also called “cardiac problems.” Heart disease is a common reason to not qualify for transplant, but you may be able to prevent, fix or improve your heart health. You may still qualify for a transplant, even if you know you have heart problems or had procedures on your heart. Get help from your care teams:

- Your transplant team will make sure you get all the testing and treatment needed to see if you qualify for a transplant.
- You can ask your dialysis or transplant dietitian for ways to keep your heart healthy.
- If you already have a heart doctor, make sure to go to your visits and get testing as they recommend.

Lung problems: Also called “pulmonary problems.” If you have severe lung disease, especially if you depend on oxygen, you may not qualify for transplant. This is due to the high risk for recovery from surgery and higher risk of infection. Get help from your care teams:

- Your transplant team will run tests to find out if you can have a transplant.
- If you already have a lung doctor, make sure to go to your visits and have scheduled tests.
- It’s also important to continue to take any medicines or inhalers as prescribed, even if you feel fine.
- If you still smoke, **stop** right away. If you are having trouble quitting, ask for help! Many transplant centers will not consider anybody who smokes because smoking damages the lungs, lowers blood flow to other organs and puts you at a risk for a more difficult recovery after the surgery.

Circulation problems: Also called “peripheral vascular disease (PVD).” This affects the blood vessels leading from your heart, down through to your legs, especially in the lower belly and upper leg region. There can be two issues:

- The blood flow (circulation) is slower due to narrowing of the vessels (like a tunnel that gets smaller and smaller).
- Your vessels become very hard (calcified). This is sometimes called “hardening of the arteries,” which can make it very difficult for your kidney to be connected by the surgeon. People with diabetes are especially likely to have poor circulation and hardening of the arteries.

If the transplant team feels you are at high risk for these problems, they will order tests to check both the blood flow and the vessels in your lower abdomen (belly) and legs. They may repeat these tests while you are on the waitlist.

Ways to lower your risk of PVD:

- Stop smoking.
- Manage your high cholesterol, high blood pressure and diabetes as best you can. Ask your doctor for ways to help with this.
- See your doctor regularly so they can see early signs of these problems and treat them right away.



WEIGHT LIMITS

Some transplant centers will have specific weight limits listed as selection criteria for transplant. Each transplant center has their own, so you may need to look into what these limits are.

Discussing your weight with your transplant team may cause anxiety, but remember they are trying to make sure you are healthy enough for surgery and a new kidney. You can work with them to get to that healthy weight!

Overweight: If a transplant center does have a specified weight limit, they will use the Body Mass Index or BMI. For some transplant centers, the BMI limit is 40, but each center differs.



You can find your own BMI at https://www.cdc.gov/healthyweight/assessing/bmi/adult_bmi/english_bmi_calculator/bmi_calculator.html.

The reason there are weight limits is because being overweight can make the surgery and recovery more challenging, as well as the high risk of health problems after a transplant and the stress it puts on the kidney. It is never easy to lose weight, but it is something that you and your health team can work on together. Losing weight will put less stress on your heart and new kidney, allowing a transplant to be possible.

Underweight: It is rare to have patients who cannot get a transplant because of severe malnutrition. However, it will depend on the cause and if it can be treated. It is not just based on being underweight, but on your lab tests and if they show that you are truly malnourished and unable to tolerate a transplant. Being malnourished can put you at a higher risk to heal slowly after transplant and you may be more likely to get an infection.



TIPS:

- If the transplant center decides to deny you because you are underweight or overweight, ask that they clarify how many pounds you would need to gain or lose to be eligible.
- Speak with your dialysis dietitian or ask your doctor for a referral to a dietitian, so they can give you tips on safe and healthy weight loss.
- If you are on the waitlist but have been placed on hold until you lose or gain a certain amount of weight, ask for a meeting with the transplant dietitian. They can work with you on an eating plan to reach your goal weight.



AGE LIMITS

Some transplant centers also have an upper age limit listed as selection criteria for transplant surgery. The reason that some places will not accept patients who are older is due to the risk of other health problems during and after surgery. Some centers do not mention age limits because they would prefer to meet you, look at your overall health, and assess health risks and whether you will be able to take care of your health after a transplant surgery.

You can't change your age. But you can always call your local transplant centers to explain your situation (for example, if you are in your 70's, but have a living donor) and see if they will have you come in for an evaluation.



LACK OF SOCIAL SUPPORT

You can't do this alone. You may be a very independent person, but you will still need the help of others during your transplant journey. People who get support from family, friends or caregivers are often successful before and after transplant. This happens for many reasons, including:

- After the transplant, you need someone to drive you to the transplant center for follow-up and lab work visits.
 - You won't be allowed to drive for many weeks because of all the new medicines and their side effects and some pain at the surgery site.
 - Since you will be immunosuppressed (at high risk for infection), your transplant team may ask you not to take public transportation while you recover. If you were taking medical transportation while going to dialysis, they often do not pay for that same transportation after the transplant.

Social support is usually a required selection criteria because:

- Most transplant centers require that you can take care of the kidney after transplant, which requires the support of others while you recover from surgery.
- They need to be able to reach you. The transplant center will ask for the names and numbers of all your support people. This is to make sure they can reach your family or friends if they can't reach you when a kidney is finally available.
Can you imagine getting a call for a transplant and no one can find you? It happens more than you think.

It is important to give updated names and numbers to your transplant center if anything changes. Don't worry if you are not sure you have enough help. This is a selection criteria item that can usually be fixed. You and your health care team can work together to identify people in your life who will be willing to help you before and after the transplant.



TIP: If you do not have reliable transportation, reach out to your transplant coordinator and ask about national and local resources.



NOTE: Your transplant team will reach out to you often throughout this process and they will need a dependable way to contact you. Having a phone and stable housing (meaning you don't move from place-to-place a lot) is important for this communication. You can reach out to your dialysis or transplant social worker to help you with resources for housing, getting a reliable phone, a mailing address and more.



TIPS:

- If it's too much for one person to help, ask if 2-3 people are willing to share in driving you to and from the center. Write down names and phone numbers because the transplant center will most likely want to have their information on file.
- Check in with your contacts every once a while to make sure they are still willing and able to help out when needed before or after transplant. It is a good idea to get a couple of backup people in your life in case the main person is unable to help.



LACK OF FINANCIAL SUPPORT

Having enough insurance is a required selection criteria to qualify for a transplant. Transplants are expensive, so you need to make sure you have enough insurance to cover the transplant surgery, medical visits, lab tests and the medicines afterward.

This can feel daunting, but your transplant financial coordinator will go over all of this with you. They will share resources to help fundraise and help you fix any issues that may come up.



TIPS:

- It is important that you keep up with any insurance premiums or paperwork your insurance requires so your insurance is not suddenly cut off. This is especially true while you are active on the waitlist.
- If your insurance is cut off, suspended or changed, you must contact your doctors, transplant team and the transplant financial coordinator right away. They can help you get reinstated or get coverage through new insurance for a transplant. If you are already on the waitlist, you may be put on hold until you take care of any financial problems that come up.



MENTAL HEALTH CONDITIONS THAT PREVENT YOU FROM UNDERSTANDING TREATMENT OPTIONS

Many patients with mental health conditions, such as those with depression and anxiety, are transplanted successfully every day. However, there are mental health conditions transplant teams need to carefully consider when evaluating you for a transplant.

This selection criteria is about patients with severe mental health disorders such as unstable schizophrenia, severe mental disabilities or other brain disorders. They may not be eligible for a transplant.

If you have any conditions that affect your thinking or memory (such as dementia), you may not qualify for a transplant because you may not understand or remember how to care for the kidney. Other reasons why you may not qualify if you have thinking or memory issues include:

- Not being able to understand enough information given to you about the transplant to be able to consent to having it.
- Being at a higher risk for infections and healing poorly after transplant if you are a patient in a nursing home, memory care or other care facility.
- Being at a higher risk for a failed transplant and more psychiatric symptoms because there are certain psychiatric and transplant medicines you cannot take at the same time.
- Being unable to guarantee, as a caregiver or guardian, that a patient will take their medicines or be closely supervised.

Having a history of a severe mental health disorder limits your chances of being eligible for transplant, but every case is different. The transplant center may ask for records before deciding if you or your loved one can come in for an evaluation.



TIPS:

- If you have a legal guardian or caregiver, make copies of any legal paperwork and give them to the transplant center if they ask for it.
- Make sure you have all the necessary paperwork and contact information for the nursing home or other facility where you live and give copies to the transplant center if they ask for it.



NOTE: If you are taking any medicines to treat mental health conditions, they may not mix well with the transplant medicines. That's why it is important to bring your list of medicines and contact information of the doctor prescribing the medicines for your mental health. Your doctors may need to adjust the medicines so you and the kidney are okay after transplant.



CURRENT SUBSTANCE USE DISORDER

Almost every transplant center will not consider you for transplant if you have a drug or alcohol dependency.

Drug and alcohol use disorder is a barrier to transplant because if you are dependent on drugs or alcohol:

- You may have trouble taking medicines regularly or following through with treatments before and after the transplant.
- You may have a higher risk of your body rejecting the kidney.

If you used to have a substance use problem and quit, you may be eligible for a transplant, depending on the transplant center. They may recommend routine drug testing and proof of attendance at a rehab program.

If you really want a transplant but need help quitting drugs or alcohol, reach out for help through your doctor or dialysis unit social worker.



NONCOMPLIANCE

No one wants to hear that word, but it means "not following your doctor's recommendations." For example, noncompliance might be not taking medicines as ordered or skipping tests or treatments.

Being compliant is a required selection criteria for most transplant centers. If you are skipping dialysis treatments and are admitted to the hospital often for fluid overload, the transplant center may believe you are unable to take good care of a new kidney.

You may have valid reasons or barriers for why you are not able to do everything the dialysis or transplant center asks you to do. Be honest and talk to your dialysis unit or transplant social worker about what's going on and get help with any barrier that is keeping you from taking better care of yourself. They are there to help!

So, what can you do if you are having problems with noncompliance?

- Ask your doctor, dialysis social worker or transplant social worker for help. They can help you reach your goals by creating a plan and giving resources.
- Ask for support from your family, friends, house of worship or faith-based institution or mentors to encourage you in your goal to take better care of yourself. Explain that this goal will help you become eligible for a kidney transplant. Pair up with someone going through similar issues so you both can support each other, and accept help offered to you.



OTHER CRITERIA

There are other conditions under which a transplant may not be possible at a certain transplant center. Here are a few:

- **Multi-organ transplant:** If you need more than a kidney, such as a pancreas or heart transplant too, some centers may not be able to accept you simply because they do not do multi-organ transplants. In this case, you will be referred to a multi-specialty transplant center. You can research some of this on your own or ask your specialist for a referral.
- **History of multiple abdominal (belly) surgeries:** Depending on what type of surgeries you have had, it may be impossible to place the kidney in you. This includes many previous transplants, previous trauma or bowel obstructions (blocked bowels). Sometimes the transplant center will run tests to see if a kidney transplant is possible.
- **Recurrent kidney disease or multiple transplants:** If you have a recurring kidney disease, such as focal segmental glomerulosclerosis (FSGS), or have had many transplants before, the transplant team may decide against surgery because of the high risk of loss, or difficulty placing the kidney in your body. If this happens, you can always seek a second opinion from another center.
- **Lack of communication:** While this is rare, there are times when you will be placed on a waitlist hold because the transplant center cannot reach you or any of your contacts. It is important to stay in touch with the transplant team and give them updated contact information. Never assume the transplant center has your new phone number that you gave to your doctor or dialysis unit. It is more common than you think for patients to miss out on a transplant because the transplant center could not contact them.

This is a lot of information about selection criteria. Just remember that **most** people who apply for a transplant get approved to be on the waitlist.

If you have been told you are too high risk for a transplant, do not give up! Every center has different criteria, so it is possible one center may say you are not eligible while another center may accept you on their waitlist.

If at any time you do not understand why you were turned down for a transplant, call and speak with your transplant coordinator and ask them to explain it to you. If you don't feel like you have anyone to talk to, ask your doctor for counseling resources.

Remember that you always have the option of seeking a second opinion from another transplant center. If you decide to do this, the new transplant center will get all the records from the previous transplant center. While they may still order some more testing, it will speed things up.



SUMMARY OF SELECTION CRITERIA

This process can feel overwhelming. Transplant centers do not expect you to be in perfect health. Hopefully this section can help you better prepare for your transplant journey by understanding the ins and outs of eligibility criteria. Remember that most people do qualify, and you can fix or improve some issues you may have.



NOTE: Always ask your kidney or transplant team about your specific eligibility. Every transplant center is different, just as every patient is different.



Evaluation day

Once you have been referred to a transplant center, a member of the team will reach out to you to schedule an evaluation day. Your evaluation day may be long and may even be more than one day. To help you through the long day, you may want to wear comfortable clothes, bring snacks, a book or even a friend or family member to keep you company.

WHAT WILL HAPPEN ON MY EVALUATION DAY?

The visit will:

- Give you and your support person a chance to meet the members of the transplant team and learn about the process at their center.
- Include many tests to determine if you are an eligible transplant candidate. You may have:
 - Blood tests and tests to check your heart and other organs.
 - Tests to evaluate your mental and emotional health.
- Include conversations about your finances, health insurance coverage and support system to make sure you are prepared with the best care.

If you are on dialysis, it is important to share all the details about your dialysis treatment with the transplant center.

If you have a living donor, they will also need to be tested to make sure they are healthy enough to donate a kidney:

- During the mental health test, you and your living donor will meet with your separate transplant social workers. Your social workers will make sure that you are both mentally ready to have a transplant and able to follow all the directions about caring for yourselves and your new kidney.
- Your transplant team may also ask questions about your finances, health insurance policy and support system to prepare the best care for you.

Your team will give you and your support person or people important information about preparing for a transplant, what to expect during recovery and what medicines you will need to take.

WHAT MEDICAL TESTS WILL I GET?

Medical tests include:

- **Chest x-ray** to check your lungs
- **EKG test** to check your heart
- **CT scan** to check your kidneys
- **Blood and urine tests** to check your kidney function, rule out infection and make sure there are no other medical conditions that would disqualify you as a transplant candidate.
- **Blood type testing:** This to see if your blood type is compatible with the donor (living or deceased).
- **Tissue typing:** Also called human leukocyte antigen (HLA) typing, this testing checks to see how many antigens you and your donor have in common. This is a way to raise the chance your body will not reject the kidney as a foreign object.



NOTE: If you are considered a highly sensitized candidate (98-100 panel reactive antibody, or PRA), you may have a longer wait time to find a kidney that your body won't reject. However, if you have a PRA of 80 or higher, you will be given a higher priority when there is a kidney that could be a match for you. Reasons for higher sensitization include having a previous transplant, blood transfusion, pregnancies or a viral or bacterial infection. Talk to your doctor if you are not sure about your options.



Did you know? Transplants are now possible between donors and recipients with incompatible blood and tissue type, known as **incompatible kidney transplants**. If you are interested in learning more, ask your transplant team for the options.

Other tests typically scheduled after the evaluation day:

- **Crossmatching:** This testing takes your blood sample and mixes it with your potential donor to see if their antibodies react with yours. If your antibodies attack the donor's, you are "sensitized," which means your body may reject their kidney.
- **Dental exam**
- **PAP test and mammogram** for women
- **Colonoscopy** if you are over the age of 50
- **Other tests**, depending on your age and medical history

If you meet the eligibility criteria, you will be placed on a national waitlist for a kidney (for deceased donation). Depending on your transplant center policies, you will have regular blood tests while you wait for a kidney match to become available.

- If you have a living donor, you can schedule the transplant surgery in advance. You may have your transplant as soon as both you and your donor meet the eligibility criteria.
- Remember: If your transplant team decides you are not ready for a kidney transplant, do not be discouraged! You can be evaluated again. Talk with your transplant team and discuss what you can do to become ready for transplant.

CAREGIVER ROLE

Who can be a caregiver?

A caregiver is someone who gives support throughout the transplant journey and can be anyone you choose, such as a spouse, life partner, adult child, sibling, other family member, friend, neighbor, co-worker, fellow parishioner or congregant, among others.

Why do you need a caregiver?

The transplant process involves many steps, including talking to many team members and managing various parts of your health. Having extra support from a caregiver can make this process much easier for you. Your caregiver, along with other family members, are welcomed (and may be required) to attend transplant center appointments and educational sessions with you. The transplant team will give you more information on how they can support you.

As emotions rise and fall throughout the transplant process, your caregiver can:

- Give emotional support to you.
- Learn what to expect during the transplant recovery process and how to deal with delayed graft function (a transplanted kidney that does not work right away) and potential kidney rejection.
- Learn how to advocate and support you in asking for a living kidney donor, if appropriate.

How can I prepare for others helping me through this process?

As mentioned earlier, you can't do this alone. You will need the support of the people in your life to help you through this. You can:

- Give your caregivers and other support people important phone numbers, such as the names and phone numbers of your transplant center and coordinator.
- It is extremely helpful if the caregiver or support person attends transplant center visits so they can get a better idea of what they are expected to do, and when.
- As the person going through the transplant journey, it is your responsibility to tell the transplant center if there is a change in who your caregiver is or if their contact information changes.

- Complete a will, trust, planning guardianship (if you are a single parent) and advance directive (a living will). You should consider naming a trusted person as your medical power of attorney or health care proxy. This person can make decisions for you in case you are unable to do so. While the hope is you will not have complications, unexpected events happen and it's important to plan for them.
- Assign someone to handle your finances temporarily. If you and your caregiver do not share a joint checking or credit account, talk with your bank to find out how to give your assigned person temporary access to your accounts.
- Talk with a financial or family law attorney if your financial or legal matters are complex (such as financial or property division or custody or guardianships). Contact your local bar association for a referral.
- Give written permission for another adult to take your children for medical care (emergency or routine) if they are under 18 and will be away from both parents while you are in the hospital and recovering. You can ask your children's doctors to give you a medical release form.

What should I expect as a caregiver during the transplant process?

As a caregiver, you will be a needed source of support for your loved one during what can be an overwhelming process. During this time, you can help them communicate with others, stay organized and be an important person for them to lean on. Some ways you can help before and after the surgery are below.

BEFORE SURGERY

You can help your loved one manage medical information and appointments:

- Attend appointments with your loved one so you can listen to the transplant team share information about their care.
- Take notes and write down your questions ahead of time in a notebook so that you can be prepared to discuss any concerns during the visits.
- Ask important questions or encourage your loved one to ask questions to prepare for transplant. It can be important to learn about eating plans to follow or exercises to do as your loved one prepares for transplant surgery. Staying strong throughout that wait time can help your loved one stay on the waitlist and have a faster and easier recovery period.



TIPS:

- You are an important contact person for the transplant center as updates come up. Make sure the transplant center has your updated contact information to avoid miscommunications.
- Use a notebook with folders, so that you can bring copies of your loved one's medical history and test results in the folders. You can also have a copy of the list of names and phone numbers of contacts from the transplant center in these folders.

DURING SURGERY

- Organize a phone tree or email group to update family and friends on the progress of the surgery. You can designate a lead person who will instruct others on the list to pass on information. This will allow you to focus on the immediate needs of your loved one, instead of contacting everyone on the list.
- Talking to your loved one to understand their goals, concerns, and questions. Ask them if they would like you to document the transplant experience through pictures or videos.
- Help them pack loose-fitting comfortable clothing so their surgery site will not be irritated. Footwear should be comfortable, easy to put on and non-slip.
- Remind them to pack a small, firm pillow for that they can use as a “splint” pillow for the hospital and later in the car on the drive home. They can hold the pillow to their belly for support when they are getting up, sneezing or coughing.



TIP: You need to take care of yourself as well! Bring comfortable and warm clothes and shoes in case the hospital room is cold.

HELP PREPARE FINANCIALLY AND LEGALLY

You can:

- Look into insurance coverage and the costs they will need to cover.
- Discuss with the financial coordinator the costs of medicines your loved one will need to take after surgery.
- Learn about how to keep their health insurance and other benefits active.
- Research available financial resources available for your loved one.
- Encourage your loved one to complete their estate plan which includes legal documents that protect family, finances, medical care directives and property if needed.
- Understand the Family Medical Leave Act (FMLA) and the process for signing up for both you and your loved one.



Did you know? FMLA is a federal law which grants you unpaid, job-protected leave for specific family and medical reasons while your health insurance coverage continues under the same terms and conditions as if you have not taken leave.

If your employer is covered under FMLA, you are entitled to 12 work weeks of leave within a 12-month period to care for your spouse, child or parent with a serious health condition. For caregivers of military service members, you are entitled to 26 work weeks of leave during a 12-month period.



TIPS:

- Ask the social worker or financial coordinator about national or local resources to help with these costs.
- If you do not live with your loved one, talk to them ahead of time about their household bills so you can help manage these payments.

AFTER SURGERY

Once your loved one is out of surgery, you have an important role to make sure they can focus on resting well. Transplant is a major surgery and rest time is important to aid in their recovery.

Support your loved one while in the hospital

- Help manage visitors to make sure that they can get the rest they need. They will likely be in pain and tired after the surgery, so limiting visitors may be important.
- Listen to the transplant team and take notes on their instructions on eating, drinking and walking around in the days after surgery. You can take in information that the transplant recipient may not remember.
- You get them out of bed and help them walk the halls, if the medical team recommended it.
- Help them take the right medicine at the right time and change dressings, if needed.

Support your loved one at home

- Help prepare meals so there are healthy meals ready to eat when they are recovering at home.
- Cook food safely and help follow guidance about what is safe to eat.
- Help with post-transplant care at home. You may need to stay with them for a few days after surgery to help with activities such as driving, cooking, cleaning, running errands and childcare.
- Drive them to the hospital or clinic for appointments or emergencies. This may be on short notice and urgent.
- Help keep their home clean to prevent infections.
- Help take care of children and pets.
- Provide encouragement and emotional support. Remind them that they are improving daily and that recovery takes time. Caregivers are cheerleaders and positive advocates during recovery.

Emotional journey of a caregiver

Being a caregiver can be a rewarding experience, but it can also be stressful seeing your loved one go through a difficult time while trying to manage your own life and feelings. It is common to feel worried during this process. Take time to acknowledge and process your feelings. Your feelings are normal and there are resources to help you cope with them.

HOW CAN I CARE FOR MYSELF AS A CAREGIVER?

It is important to take time to care for yourself, but it can be easy to forget about your own needs. Here are a few ways to help you rest and recharge:

- Ask for help when you need it.
- Accept help when it's offered.
- Be realistic about what you can and cannot do.
- Talk to your manager or employer about your new caregiver role so they understand these changes and can help you manage your workload. Find out if your employer offers paid leave.
- Look for caregiver resources in your area, whether it is meal delivery service, transportation or state-offered respite care.
- Stay on top of your own health. Keep routine doctor's visits. Eat healthy and be active most days.
- Try to take 5-10 minutes every morning and, or evening for yourself. This can be time to read, be quiet, breathe, meditate or pray.
- If you are spending a lot of time by your loved one's side, make sure you take time for breaks by simply getting up to walk down the hall or go outside.



TIP: Consider having family members rotate with caregiving responsibilities to allow for breaks. You can also find someone who might be your backup in case you are unable to care for your loved one at the last minute.

QUESTIONS TO HELP PREPARE YOU FOR TAKING CARE OF A LOVED ONE THROUGH TRANSPLANT

Questions to ask the social worker or financial coordinator:

- Is there financial assistance to help my loved one with the costs of the surgery and medicines?
- What are the benefits of Family Medical Leave Act? How do I start that process?

Questions to ask your employer:

- Does [employer] offer paid medical leave? How do I start that process?

Questions to ask the transplant team:

- What is your success rate of your transplant program?

Questions to ask your loved one:

- What are your goals?
- How can I support you through this process?
- Which visitors would you prefer having the first few days after surgery? How many would you like to see?



FINDING A LIVING DONOR

Whether you are on a transplant waitlist or going through transplant evaluation, your transplant team will likely talk with you about living donation.

What is living donation?

Living donation is when you receive a transplanted kidney from a living person, which could be someone you know or do not know. If someone wants to donate a kidney to you, you may have many questions. This section will answer some of these questions and guide you through what to expect from this process.



Did you know? You do not have to be on dialysis to have a living donor transplant. If your eGFR is 20 or more AND you have a potential living donor, you may be referred to the transplant center where you both will be evaluated.

What are my living donation options?

When you are diagnosed with kidney failure, you may hear about different transplant options. Once you are referred to a transplant center, your transplant team will explain your living donation options in detail.

A living donor transplant has different names based on how the donation happens:

- **Directed donation:** This is the most common type – the kidney is from a living donor who you know.
- **Non-directed donation:** The kidney is from someone who does not name a specific recipient but wants to donate to anyone – this is also called an “altruistic” donation.
- **Paired exchange donation (“kidney swap”):** This option may happen if you and your living donor are not blood or tissue type compatible with each other. You and your donor will be paired with another donor-recipient pair who better matches you and your donor. The other pair may be people you don’t know, such as people from another area of the country.
- **Transplant voucher program:** This newer option allows your willing yet incompatible donor to donate to someone else at a time that’s best for them. Their donation creates a voucher (credit) for you when you need a kidney in the future. Check if your transplant center offers this program and ask if this would work for you and your donor.



Did you know? You and your potential living donor can say **No at any time** and decide not to go through with the transplant. It is okay to say No.

Due to HIPAA (privacy laws that protect personal medical information), the transplant center will not tell you why a donor has decided to say No. If you know your donor, this can put a strain on your relationship. It's important you both support each other and clearly communicate your decisions.

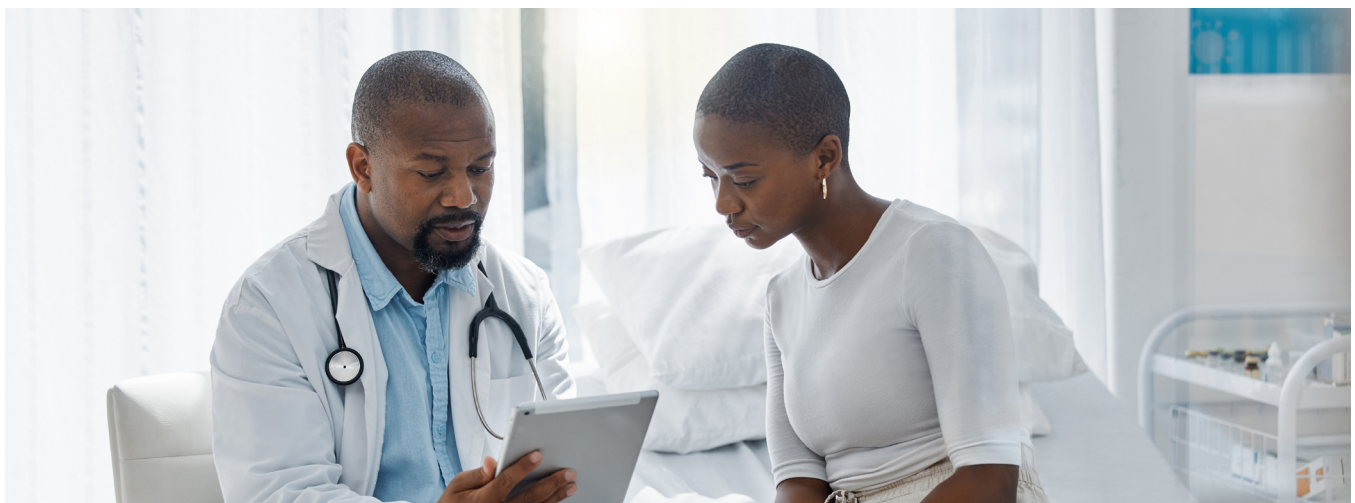
What are the benefits of living donation?

There are several benefits of living donation over deceased donation, such as:

1. You may be on dialysis for a shorter time. This can lower your chance of medical problems from dialysis.
2. You may be on the waitlist for a shorter time.
3. You can get back sooner to the things you did before kidney failure, such as work or caregiving, because the process is usually shorter.
4. The kidney usually lasts longer. Many studies have shown that on average:
 - Living donor kidneys can last 15-20 years
 - Deceased donor kidneys can last 10-15 years



Did you know? Finding a living donor can be difficult. In particular, Black and Hispanic or Latino Americans receive fewer living donor kidney transplants than white Americans. Don't be discouraged! It is possible to increase your opportunities of finding a living donor by talking early on with your friends and family. They can help spread the word to others who could also be a match. If you don't feel comfortable having these conversations, ask your transplant coordinator for some tips and resources to make them easier.



What is the living donation process?

This process may be different depending on your transplant center. Here is how it typically goes after you have been referred to a transplant center:

1. You will start your evaluation to see if you are a good candidate for a kidney transplant.
2. While you are going through evaluation, potential donors can call your transplant center to let them know they are interested in donating a kidney to you. The transplant office will refer them to a separate team called the living donor team.
 - Since it is their choice, the potential donors must be the ones to make this call. Not you or anyone else!
3. The living donor team will evaluate your potential donor to see if they are healthy enough to have surgery and if their kidney is a match. Their team will work with them through the whole process.
4. If both of you are approved and cleared for surgery, then the operations will take place on the same day:
 - First, your living donor will go into surgery so doctors can take their kidney out.
 - Next, you will go into surgery so doctors can put the kidney into you.
5. Your donor may go home a few days after surgery. You may stay for longer to recover from the transplant and learn how to take care of your new kidney.
6. After a transplant, you will return to the transplant center for checkups. These checkups will continue for the life of your kidney.

Privacy and communication during the living donor process

You and your donor will have separate teams during this process. Each of you must only talk with your own nurse coordinator or team. This is for privacy reasons protected by laws:

- The Center for Medicare & Medicaid Services (CMS) requires this for all transplant centers
- The federal Health Insurance Portability and Accountability Act (HIPAA) protects you and your potential donor's confidentiality (privacy) and medical information. HIPAA laws must be followed, even if your donor is your spouse, child, sibling or friend.

Most transplant centers will have you and your living donor sign an agreement that you understand this policy.

Can you and your living donor talk about everything? Of course! You can share anything with each other throughout the process. In fact, both of your nurse coordinators will encourage open communication.

How can I find a living donor?

Some living donors volunteer on their own, but not always. It helps if you let people know that you need a kidney transplant. However, it is not always easy to ask someone to donate and you may be hesitant to reach out. This may seem uncomfortable or even impossible, but many people find a living donor through sharing their story.

Here are some tips on how to let people know you need a transplant:

1. **Learn about the living donor process.**

This way, you can explain the process when you tell people you need a transplant. Your transplant team may have brochures or booklets you can hand out to people.

2. **Ask your family and friends** to help spread the word.

3. **Share your story online** through reputable social media platforms. Ask others to share your posts. Your transplant center may also have resources to help you write a social media post.

- Be careful about widely sharing your story through social media outside of your social circles or support groups. Some scammers may contact you pretending to want to donate. There are a lot of scammers who never plan on donating, fake their medical history, or even ask you for money – which is illegal.

4. **Ask indirectly.** If you are hesitant to ask others directly, ask others to do the asking for you. Consider having your pastor, coworkers, neighbors or others ask for you.

5. **Use brochures.** You can leave brochures about living donation around your home, family gatherings, workplace, church or other places. Add your name and transplant center contact number on the brochure.

6. **Connect people to a coordinator.** Someone may be interested in donating, but feel afraid or hesitant. You can encourage them to call your transplant center and speak with a living donor coordinator. Connecting them to a coordinator can help lower their fears.

Be careful: You may find a website promising they can find you a living donor. Most of these sites are not real.

Call your transplant coordinator and ask them to check it out. It is their job to protect you!



If you are unsure how to start, [American Kidney Fund has resources on how to write your story for an online platform.](#)

If you're looking for more ideas, call and speak with your transplant coordinator or transplant social worker. They usually have some great ideas for finding a living donor.

What are my next steps if I have a potential donor?

If you have a potential donor, that's great! Here are the next steps for you both:

1. Talk to your transplant coordinator about:
 - Your living donor options
 - When your potential donor can call the center
2. The living donor team will talk with your potential donor about the entire process. They will make sure your potential donor understands everything, and wants to continue, before moving to the next step.
3. The living donor team will evaluate your potential donor. To see if they will be a good match for you, the team will check their:
 - Overall health
 - Social habits
 - Blood type
 - And more
4. Talk with your transplant financial coordinator if you have financial concerns for you or your potential donor. They can answer your questions.
 - Generally, your insurance pays for your donor's expenses such as testing, surgery and follow up appointments.
 - Your living donor can talk with their financial coordinator about financial support for housing, medical leave and other expenses they are concerned about.

What if I have more than one potential donor? Good news! All of them can call your center and start this process. Most transplant centers will test more than one donor to see if they are a match with you and are healthy enough for the surgery.



How do I deal with the emotional challenges of living donation?

The transplant process can be a stressful time for you and your living donor. It's normal to worry about your living donor's experience while they worry about yours.

Here are some tips to help you:

1. Take care of yourself and stay as healthy as you can. This can help lower your stress while keeping you healthy for the transplant.
2. Communicate openly with your living donor. It helps when you both understand each other's feeling of stress and anxiety. It may help you grow closer.
3. Get support from your loved ones. Sharing your feelings often helps lower your stress. You can also ask your transplant team about peer-to-peer counseling or support groups.
4. It can be devastating to find out that your potential living donor is not eligible to donate a kidney. It's common to feel sad, angry or even confused as to why your donor could not donate.
5. Reach out to your transplant team if you feel depressed or anxious anxiety before or after a transplant, including feeling sad, worried or hopeless that lasts more than a few weeks. They can help you and refer you to counseling if needed.

The transplant center can't tell you why your potential donor was not eligible due to HIPPA laws. Know that they made that decision for your and your donor's safety. The potential donor can share the reason with you if they want to.

Summary

It is a life-changing gift to receive a kidney from a living donor. There are many benefits to a living donor kidney. However, asking someone to donate to you can be one of the hardest things you do. By spreading the word, you'll find that many people can ask on your behalf. This experience can be a very stressful and emotional time for both you and your living donor. Do not be afraid to ask for help and support to lower your stress levels.

Remember that you are not alone! Your transplant team will help answer any questions you have.

BECOMING A LIVING DONOR

A kidney transplant can be life-changing for someone with kidney failure. However, there are not enough available kidneys for everyone who needs one. There are over 90,000 people in the U.S. that need a kidney transplant.⁵ By volunteering to donate your kidney, you can:

- Make a difference in someone's life
- Reduce this kidney shortage
- Shorten the transplant wait time from years to months for someone who needs a kidney

Donating your kidney is not an easy decision. You have the chance to change someone's life, but there are possible risks as well. Remember that you can change your mind at any time throughout the process.

What is a living donor kidney transplant?

A living donor kidney transplant is a surgery in which doctors take a kidney from a living person and put in a person who needs a kidney. There are different types of living donor transplants:

- **Directed donation:** This is the most common type – the kidney is from a living donor to a person they know.
- **Non-directed donation:** The kidney is from someone who does not name a specific recipient but wants to donate to anyone – this is also called an “altruistic” donation.
- **Paired exchange donation (“kidney swap”):** This option may happen if a recipient and their living donor are not blood or tissue type compatible with each other. The recipient and their living donor will be paired with another donor-recipient pair who better matches them. The other pair may be people they don't know, such as people from another area of the country.
- **Transplant voucher program:** This newer option allows a willing yet incompatible donor to donate to someone else at a time that's best for them. Their donation creates a voucher (credit) for the recipient when they need a kidney in the future.



What are the benefits of living donation for the recipient?

For the person receiving the kidney, there are several benefits of a living donation over a deceased donation, such as:

1. They may be on dialysis for a shorter time. This can lower their chance of medical problems from dialysis (such as fatigue, pruritus or itchy skin, and infections).
2. They may be on the waitlist for a shorter time.
3. They can get back sooner to the things they did before kidney failure, such as work or caregiving, because the process is usually shorter.
4. The kidney usually lasts longer. Many studies have shown that on average:
 - Deceased donor transplants can last 10-15 years
 - Living donor transplants can last 15-20 years

Can I donate a kidney?

You can donate a kidney if you meet certain requirements, such as:

- You are age 18 or older
- Your kidneys work well
- You do not have certain medical conditions, such as:
 - Uncontrolled high blood pressure
 - Diabetes
 - Cancer
 - HIV
 - Hepatitis
 - Acute infections

If you meet these requirements and are interested in donating, contact your recipient's transplant center to start the donor process. If you do not have a recipient but are interested in donating, contact the nearest transplant center to you.

The transplant team may look at other factors to decide if you are a good candidate for donation. These can vary from center to center.

Do I have to be a match to donate my kidney?

No, even if you are not a match to the person you would like to donate to, you can still donate your kidney. You may still be able to help them through a paired exchange program or transplant voucher program.

Are their risks of being a living donor?

Many living donors go on to live healthy and active lives. While the hope is you will likely be able to return to your normal activities after donating, it is important to share the risks involved in being a living donor. These risks include:

- **Lower kidney function:** On average, donors have 25-35% less kidney function after donation.
- **Higher chance of high blood pressure:** Kidneys help your body keep a normal blood pressure. With only one kidney, you may be more likely to have high blood pressure in the long-term.
- **High risk pregnancy:** Donation may lead to certain pregnancy risks, such as a higher chance of:
 - Gestational diabetes
 - High blood pressure
 - Pre-eclampsia
 - Loss of the baby
- **Financial challenges:** Being a living donor may cause some financial issues. This can include:
 - The costs of the transplant surgery
 - Not being able to work while recovering
 - Issues getting disability and life insurance

However, there are many national and local resources that can help you with finances related to donation.

You may feel anxious thinking about these risks – that is perfectly normal. As you consider living donation, feel free to reach out to your transplant team to review these concerns. They can help you through these.



What are the steps to become a donor?

1. CONTACT A TRANSPLANT CENTER

The first step is to contact a transplant center:

- If you would like to donate to a specific person, contact their transplant center.
- If you would like to be a non-directed donor, you can contact any transplant center.
- If you would like to be either a direct or non-direct donor, [you can also visit the National Kidney Registry's website to complete a questionnaire to see if you would be an eligible donor and pick a transplant center closest to you.](#)

2. SCREENING PROCESS

You will then go through a screening and evaluation process. Transplant centers do these to decide if you are healthy enough for surgery and are a good donation candidate. During the screening process, you will:

- Talk on the phone to a member of the transplant team. During this phone call, you will:
 - Learn more about the donation process
 - Learn about the risks of donation
 - Talk about your medical history
- **Get lab tests.** These tests check your blood type and kidney function.

After the screening, the transplant team will decide if you can continue to the evaluation process.

3. EVALUATION PROCESS

For the evaluation process, you will go to the transplant center for a whole day of tests. This process can be overwhelming, as you will be meeting with many members of your transplant team. The evaluation process is similar to the process transplant recipients go through. Tests may include:

- **Blood and urine (pee) tests:** These will check your kidney function, rule out infection, and make sure there are no other medical conditions that would make you ineligible to be a donor.
- **Blood type testing:** This will test if your blood type is compatible with your potential recipient.
- **Tissue typing:** This will test if your kidney is compatible with your potential recipient. If your kidney is compatible, it is more likely that your kidney will not be rejected by their body. (Also called human leukocyte antigen (HLA) typing.)
- **Crossmatching:** This test mixes a sample of your blood with a sample of your potential recipient's blood. If the recipient's cells attack and kill your blood cells, the recipient has antibodies "against" your cells. This means the recipient's body could potentially reject your kidney.
- **CT scan:** To make sure both of your kidneys are normal and healthy.
- **Chest x-ray:** To make sure your lungs and heart look healthy.
- **EKG test:** To test your heart and make sure it is healthy.
- You may need more tests depending on your age and medical history.

After this evaluation, your transplant team will meet to discuss:

- If you are a good match for the recipient and can continue with surgery
- If you are not a good match, what other ways you might be able to donate

4. SURGERY

If you are a good match, you will schedule a surgery with your recipient. Living donation is an elective surgery, this means you can schedule the surgery at any time.

If you want to do a non-directed donation, you can donate:

- To the transplant center's waitlist
- To other registries such as the National Kidney Registry, UNOS or Alliance for Paired Kidney Donation (APKD)
- Through the National Kidney Registry's voucher program
- Through other paired exchange registries

5. RECOVERY PROCESS

During the recovery process, you may only be in the hospital for a few days after surgery. This can vary depending on your health. Many donors go back to work after 4 weeks and return to their pre-donation activities after 12 weeks.

You will need to return to the transplant center for several follow-up visits. The timing of visits can vary. Usually, you will have a visit 2 weeks, 6 months, 1 year and 2 years after your surgery.

Who is on a living donor care team?

Independent living donor advocate (ILDA):

An ILDA is separate from the transplant team but works with them to advocate for you. They are also not involved with the recipient's care. They are usually someone with a nursing or social work background.

They will:

- Support you throughout the process
- Listen to your thoughts and opinions
- Make sure your needs are shared with the transplant team

Living donor coordinator: This care team member usually has a nursing background with transplant or critical care experience. This role is more medical. They are involved in the screening, evaluation, surgery, recovery and follow-up process.

Transplant nephrologist: A doctor who specializes in kidney disease. They will test the function of your kidney and the safety of your donation. They will work with the transplant team to decide if you are healthy enough to donate your kidney.

Transplant surgeon: A doctor who performs the surgery. They will meet with you and talk about:

- If you can and should donate a kidney
- How donating a kidney can affect your health
- Risks of the surgery
- Possible problems after your donation

Social worker: A professional who will meet with you to do a psychosocial evaluation (how you feel mentally and how your relationships are). This helps them learn how well you might cope with the stress of donation. They will help you find people in your life who can support you throughout the donation process.

Registered dietitian: An expert in food and nutrition. They will do a nutritional assessment to see if you need more nutrients in your diet. During the assessment they will ask you about your eating habits and what you eat. They can also help you learn more about nutrition.

Psychiatrist/psychologist: These clinicians may do an in-depth evaluation of your psychosocial history and your relationship with your potential recipient prior to the surgery.

You may need to see other doctors for evaluations and tests. For example, some people need to see a pulmonologist (lung doctor), hematologist (blood doctor) or a cardiologist (heart doctor) to check if they have other medical conditions.

What are the costs involved with donation?

Your potential recipients' insurance will usually cover your medical expenses. This includes the costs of:

- Testing
- Surgery
- Follow-up appointments

However, you may need to pay for other costs, such as:

- Travel
- Food
- Wages lost while you are in surgery and recovering

If you need help with these costs, you can:

- Talk to your financial coordinator who can connect you to local resources or [Donor Shield](#).
- Apply for help through the [National Living Donor Assistance Center](#).

Donating a kidney is giving someone the gift of life. You have the potential to bring hope and joy to many around you. However, this decision can take time to consider. Your transplant team can answer any questions you have and are there to help.

Conclusion

You now know more about the process of getting a kidney transplant, a promising and life-changing treatment for kidney failure. You may feel stressed as you go through the transplant process – this is normal. You can use this resource as a source of hope and a guide you can refer to during this process.

After reading about the basics of a transplant, you may have specific questions about what's best for you. Your doctor or transplant team are there to answer any medical questions you have. Remember – you are your best advocate!

MYTHS AND FACTS ABOUT KIDNEY TRANSPLANTS

Myths and facts about receiving a kidney transplant

<p>Myth #1: A transplant is a cure for kidney failure.</p>	<p>Fact #1: A transplant is not a cure for kidney disease. A transplant is a treatment option, just like dialysis. You may need more than one transplant in your lifetime. You will also have to take medicine for as long as you have the new kidney.</p>
<p>Myth #2: I can only get a transplant after I start dialysis.</p>	<p>Fact #2: The best time is actually before you start dialysis (called a preemptive transplant). The time to get a transplant is different for each person.</p>
<p>Myth #3: All transplant centers are pretty much the same.</p>	<p>Fact #3: While all follow the same federal and state regulations, transplant centers have different ways of doing things.</p> <p>Different transplant centers can:</p> <ul style="list-style-type: none"> • Have different eligibility requirements • Transplant only certain organs • Accept different types of insurance • And more
<p>Myth #4: Transplant centers can be at any hospital</p>	<p>Fact #4: Transplant centers are only at hospitals or medical centers that are Medicare-certified.</p>
<p>Myth #5: I can only go to one transplant center.</p>	<p>Fact #5: You can go to any transplant center. However, which center you go to may depend on:</p> <ul style="list-style-type: none"> • Your insurance • Where you live • If you can travel to it • Their eligibility requirements
<p>Myth #6: It's very hard to qualify for a kidney transplant.</p>	<p>Fact #6: Actually, most people who apply for a kidney transplant are accepted onto the waitlist.</p>
<p>Myth #7: Once I am on the transplant waitlist, I don't have to worry about the eligibility requirements anymore.</p>	<p>Fact #7: You must continue to meet the eligibility requirements while you are on the waitlist and until the transplant surgery. If you no longer meet the requirements, the transplant center may place you on hold or take you off the waitlist.</p> <p>For example, if you gain weight and your BMI becomes over the transplant center's limit, they may place you on hold until you lose weight.</p>

Myths and facts about receiving a kidney transplant

<p>Myth #8: I can take care of myself before and after the transplant!</p>	<p>Fact #8: Every transplant center requires that you have a support system to help you through the process. After your transplant, they will want your support system to:</p> <ul style="list-style-type: none"> • Drive you to and from the center • Help you with cleaning and cooking • Help you go to the pharmacy • Help you organize your medicines
<p>Myth #9: My support person needs to be a family member or a member of my household.</p>	<p>Fact #9: Your support person or people can be anyone you choose. They must be available after your surgery for a few weeks. They will need to:</p> <ul style="list-style-type: none"> • Drive you to and from your doctor’s appointments • Help with housekeeping and personal needs • Help with your medicine and medical care • Be there to help if you get sick
<p>Myth #10: All transplant centers have the same eligibility requirements.</p>	<p>Fact #10: Most transplant centers have some of the same eligibility requirements. However, they may have some different requirements. Because of this, you could be turned down at one center but approved at another.</p> <p>If you do not meet the requirements of one transplant program, contact another transplant center to learn about their requirements.</p>
<p>Myth #11: If my living donor is not a match, there’s nothing we can do.</p>	<p>Fact #11: Actually, there are options such as a paired exchange. This happens when your donor donates to a compatible recipient and that recipient’s donor donates to you. Your transplant team will discuss these options if needed.</p>
<p>Myth #12: My donor will have to cover all the costs of their evaluation, surgery and follow-up appointments.</p>	<p>Fact #12: As the recipient, your insurance covers the costs of the donor’s evaluation, surgery and follow-up appointments.</p> <p>Your donor can talk to their coordinator about help for other costs, such as travel and housing.</p>
<p>Myth #13: My donor and I have to be the same race and ethnicity for us to be a match.</p>	<p>Fact #13: No, not at all. Race and ethnicity are not considered when reviewing potential donors. Instead, the transplant team tests if your blood and tissue are compatible.</p>
<p>Myth #14: I have to take care of my new kidney for the life of the kidney.</p>	<p>Fact #14: Yes, you’re expected to take care of any kidney for life. Also, once the kidney is donated to you, it is your kidney.</p>

Myths and facts about becoming a donor or caregiver

<p>Myth #1: You cannot donate your kidney to your loved one if you are not a match for them.</p>	<p>Fact #1: You can still donate your kidney if you are not a match to your loved one through a paired exchange or transplant voucher program.</p>
<p>Myth #2: After you donate a kidney, you will only have half (50%) of your kidney function.</p>	<p>Fact #2: You will have about 70-75% of your kidney function in the long term. The kidney you have left will compensate for your missing kidney. You can live a completely normal life.</p>
<p>Myth #3: You must be related to your donor.</p>	<p>Fact #3: Many people donate to people outside of their families, including friends, acquaintances or people they do not know.</p>
<p>Myth #4: A donor must not participate in sports after donating their kidney.</p>	<p>Fact #4: Donors should be able to return to normal activities, including sports and other physical activities, 8-12 weeks after surgery.</p>
<p>Myth #5: Female donors cannot get pregnant after donation.</p>	<p>Fact #5: Donors can try to get pregnant 3-6 months after donating. They can talk with their transplant team with any specific questions.</p>
<p>Myth #6: Only family members can be the primary caregivers for a kidney transplant recipient.</p>	<p>Fact #6: Your caregiver can be anyone you choose.</p>
<p>Myth #7: As a caregiver, I must always be available and near the recipient.</p>	<p>Fact #7: Caregivers do not need to always be available and nearby. It is important that you find time for yourself when caring for your loved one.</p>
<p>Myth #8: There can only be one caregiver for the transplant recipient.</p>	<p>Fact #8: It is a good idea to have others who can be a backup in case you are unable to care for your loved one.</p>

QUESTIONS TO ASK YOUR TRANSPLANT TEAM

When it comes to your health, it is important to make informed choices. You can do this by asking questions, by speaking up for yourself if you feel you've been misheard or ignored and by asking others to help you ask questions and express your options.

These questions can help guide conversations between you and your transplant team. You do not have to use all of them. Just pick the questions that are best for you.

1. Am I a good candidate for a kidney transplant?
2. What are this center's eligibility requirements for a transplant?
3. How do I get on and stay on the waitlist?
4. How will I know I'm on the waitlist? Will I get updates and if so, who will give me these updates?
5. How long is the waitlist at this center?
6. What exactly do you consider enough social support?
7. Does this transplant center participate in paired exchange or transplant voucher donation?
8. Do you know of local resources to help pay for transportation to and parking at the transplant center?
9. How much time do I have to get to the transplant center when a kidney becomes available?
10. How long is the recovery time after transplant surgery?
11. What are the restrictions after transplant surgery? Can I exercise? Do I need to follow a different eating plan?
12. How often do I need to return to the transplant center after the transplant?
13. Do you have my updated names and numbers for my backup contacts?

CHECK YOUR UNDERSTANDING

Take this quiz to check your understanding about the kidney transplant process.

1. The kidneys do all the following **except**:
 - a. Help control blood pressure
 - b. Tell your body to make more red blood cells
 - c. Tell the heart to pump blood throughout the body
 - d. Filter waste, fluid and minerals from the blood through urine
2. True or false? A kidney transplant is the only cure for people whose kidneys are not working properly.
 - a. True
 - b. False
3. True or false? After the transplant, you will need to take immunosuppressants for three months to make sure the kidney is not rejected.
 - a. True
 - b. False
4. What are the three types of kidney transplants?
 - a. Matched, unmatched and spontaneous transplant
 - b. Liver, lung and kidney transplants
 - c. Non-surgical, surgical and procedural transplants
 - d. Living donor, deceased donor and paired exchange
5. Who is not a part of the transplant care team?
 - a. Transplant surgeon
 - b. Nurse coordinator
 - c. Dialysis social worker
 - d. Financial coordinator

6. True or false? Instead of calling the transplant center with a question or updating your contact information, just wait until they call you. They can get updated information from your nephrologist (kidney doctor).
- a. True
 - b. False
7. Which is an important function of the transplant center?
- a. Explaining the transplant process to you in detail
 - b. Ordering and reviewing your test results to make sure you qualify for a transplant
 - c. Preparing you to take care of your new kidney
 - d. All the above
8. Who would you contact at the transplant center for help with your medicine insurance coverage following your kidney transplant?
- a. Transplant nurse coordinator
 - b. Pharmacist
 - c. Financial coordinator
 - d. Nephrologist
9. True or false? All transplant centers have the same eligibility requirements.
- a. True
 - b. False
10. True or false? Transplant centers must give you a copy of their eligibility requirements if you ask for it.
- a. True
 - b. False
11. Name three common reasons you may **not** qualify for a transplant:
- a. _____
 - b. _____
 - c. _____

- 12.** Which of the following can you do if you are turned down for a transplant?
- a.** Call the transplant center and ask for more details and what your options are.
 - b.** Ask your nephrologist (kidney doctor) or dialysis unit social worker to refer you to another center for a second opinion
 - c.** Ask for resources to help improve your ability to get a transplant. For example, you can try to lose weight, stop smoking or exercise.
 - d.** All the above
- 13.** True or false? Once you are accepted on the transplant waitlist, you don't have to worry about the eligibility requirements anymore.
- a.** True
 - b.** False
- 14.** True or false? Kidneys from living donors last about as long as kidneys from deceased donors.
- a.** True
 - b.** False
- 15.** Tina's potential donor is her daughter. How can Tina find out more about how her daughter's evaluation is going?
- a.** She can ask her transplant coordinator
 - b.** She can ask her daughter's living donor coordinator
 - c.** She can talk to her daughter, the potential donor
 - d.** None of the above
- 16.** Which of the following can help you find a donor?
- a.** Have your friends and family share with others that you need a kidney
 - b.** Share your story on social media
 - c.** Leave brochures about living donation at your next family gathering
 - d.** All the above

17. A living donor transplant can be very stressful for you and the potential donor. List some ways you can lower your stress:

a. _____

b. _____

18. Who can be a caregiver?

a. Only a family member

b. Only a family member or friend

c. Anyone the transplant candidate chooses

19. What are some important duties of a caregiver?

a. Go to appointments with the transplant patient

b. Help them with care after surgery, such as moving around (if approved) and taking medicine

c. Learn about care after surgery

d. All of the above

20. True or false? As a caregiver, it is a good idea to find others who can be a backup in case you can't care for your loved one.

a. True

b. False

21. True or false? As a caregiver, you must be by your loved one's bedside at all times.

a. True

b. False

Answers

1. c
2. False - A transplant is a treatment option, not a cure for kidney disease.
3. False - Transplant recipients need to take immunosuppressants for as long as they have the new kidney in their body.
4. d
5. c
6. False – It is your responsibility to update your transplant center when your information has changed.
7. d
8. c
9. False – While all transplant centers require that you have irreversible (cannot get better) kidney failure, each transplant center must create their own eligibility requirements.
10. True – If you request eligibility requirements from your transplant center, they must provide a copy to you.
12. d
13. False – Once you are on the transplant waitlist, you and your doctor will continue to monitor these eligibility requirements. This is important so that you stay healthy enough for your transplant surgery and new kidney.
14. False – Living donor kidney transplant can last 15-20 years and deceased donor transplants last 10-15 years on average.
15. c (Note: Tina *can* ask her transplant coordinator, but they cannot share any donor information with her.)
16. d
18. c
19. d
20. True – It's important to identify somebody else who can be your backup in case you're unable to care for your loved one at the last moment.
21. False - It's important to find time for yourself while you are caring for your loved one. Take a walk, read or have some quiet time to yourself.

RESOURCES

OVERVIEW OF TRANSPLANTS	
Donate Life America – Types of Donation	Describes the types of donations available.
UNOS (Transplant Living) – Before the transplant	Describes the steps of a transplant including the evaluation process, waitlist, transplant and aftercare.
National Kidney Registry	<p>The National Kidney Registry works to increase the number of living donations. They protect and support living donors throughout the process.</p> <p>Their website has information for potential donors and recipients.</p>
American Kidney Fund - Preparing for transplant	Information on what to expect when you are looking for a match, and the benefits and risks of a kidney transplant.
FIND A TRANSPLANT CENTER	
OPTN - Search membership	You can search for transplant centers near you on this page.
HELP WITH ELIGIBILITY REQUIREMENTS	
Substance Abuse & Mental Health Services Administration (SAMHSA)	Helpful links for a helpline to help you quit drugs, alcohol and tobacco. It also has local mental health resources.
UNOS - FAQs about Kidney Transplant Evaluation and Listing	Answers frequently asked questions about kidney transplant evaluations and the waitlist.
RESOURCES FOR CAREGIVERS	
Today's Caregiver	A website with information, support, and guidance for families and professional caregivers.
National Alliance for Caregiving	The National Alliance for Caregiving works to make life better for family caregivers. Their website has guidebooks and resources for family caregivers.

Gift of Life Howie's House - Caregiver Lifeline Program	A program that provides services to help transplant patients, their families and caregivers.
Healthcare Hospitality Network	The Healthcare Hospitality Network (HHN) provides lodging and support services to people and their families who have to travel to get a transplant. You can search for a HHN House near your transplant center.
National Kidney Foundation - Online Communities	Lists online communities where patients and caregivers can share experiences, ask questions and get answers about the transplant process.
Kidney Transplant Recipient Patient Checklist	A checklist to help transplant recipients and their caregivers create and review their care plan. It reviews things to do before, during and after the transplant.
National Institute on Aging - Advanced Care Planning	Resources on how to prepare for making medical decisions when your loved one is too ill to communicate their wishes.
RESOURCES FOR POTENTIAL LIVING DONORS	
National Living Donor Assistance Center	The National Living Donor Assistance Center gives financial help for travel, lost wages, lodging and dependent care that is not covered by your insurance.
ESRD Risk Tool for Kidney Donor Candidates	A tool to help people thinking about donating their kidney learn their estimated risk of kidney failure. This tool only gives an estimated risk before donating a kidney, not after.
Donor Shield	Donor Shield is a program to help living donors. It can give financial help for lost wages, travel and dependent care. It also provides other services.
RESOURCES FOR POTENTIAL RECIPIENTS	
UNOS Transplant Living - Support groups	Describes the benefits of joining a support group and lists national and local support groups by state.
AKF - How to ask for a kidney donation	Describes ways to ask for a kidney donation. It also has social media and email templates.

<p>UNOS - How to Find a Living Donor: Make your Transplant Happen</p>	<p>A booklet that has:</p> <ul style="list-style-type: none"> • Detailed information about donor transplants • What to expect during the process • A “to do” list to help you find a living organ donor • Questions to ask your transplant center and potential living organ donor
<p>Find a Kidney</p>	<p>With this website you can create your own page to help you find a living kidney donor. You can share your page with others to spread the word that you need a kidney transplant.</p>
<p>OTHER RESOURCES</p>	
<p>Department of Health and Human Services (HHS) - Programs & Services</p>	<p>Information about HIPAA and your health rights, health insurance, social services, providers and their facilities and more.</p>
<p>State health departments</p>	<p>You can search and be redirected to your state health department’s website. There you can find more information about services such as:</p> <ul style="list-style-type: none"> • How to find your vital records (such as your birth certificate) • COVID-19 facts • More health information
<p>HHS - FAQs about Medicare and Medicaid</p>	<p>Answers to commonly asked questions about Medicare and Medicaid.</p>
<p>WIC How to Apply</p>	<p>Explains how to apply for WIC. WIC is the federal Special Supplemental Nutrition Program for Women, Infants, and Children. It gives supplemental food, healthcare referrals and education about nutrition to eligible women and children.</p>
<p>OPTN - Educational Guidance on Patient Referral to Kidney Transplantation</p>	<p>An FAQ section about being referred for a kidney transplant.</p>
<p>How much does a Kidney Transplant cost?</p>	<p>Describes the estimated cost of a kidney transplant. It details what each part of the process costs, such as the screenings, donor match, surgery, after care and medicines.</p>
<p>AKF - Blood test: eGFR (estimated glomerular filtration rate)</p>	<p>Describes the eGFR blood test and what your results mean.</p>

GLOSSARY

Absolute contraindications	Any condition (medical, social or other) that a transplant center will absolutely not accept for listing or transplant. Common examples are active cancer or drug abuse.
Advance directive (or living will)	A legal document that provides instructions for medical care if a person becomes unable to communicate their own wishes.
Centers for Medicare and Medicaid Services (CMS)	The Centers for Medicare & Medicaid Services (CMS) is a part of the Department of Health and Human Services (HHS). It provides health coverage through Medicare, Medicaid and the Children’s Health Insurance Program.
Criteria	A set of clinical or biological standards or conditions a person must met.
Deceased donor	Someone who has recently died, and while living, agreed to donate their organs and tissues after they passed.
Delayed graft function	When a transplanted kidney does not work right away. This is also called a “sleepy” or “slow to wake up” kidney.
Department of Health and Human Services (HHS)	The U.S. Department of Health (HHS) provides public health and social services to support the health of people in the U.S.
Directed donation	When an organ is donated to a specific recipient. This is usually a family member or friend donating to their loved one who needs a transplant.
Donor compatibility	A series of tests the transplant team does to find out if the recipient’s body will accept the donor’s organ.
Early transplant	A transplant that happens very soon after dialysis is started
Eligibility requirements	Certain things about the potential recipient, such as medical conditions, mental well-being or financial situations, that determine if they qualify to be on the waitlist and get a transplant. This is also called selection or acceptance criteria.
Enable	To give someone or something the authority or means to do something.
Estimated glomerular filtration rate (eGFR)	A measure of how well the kidneys are working. The eGFR shows the kidney’s ability to filter and remove waste products.
Health care proxy	A person who is appointed to make health care decisions for a person when they are unable to make decisions for themselves.

Immunosuppressants	Medicines that lower the body's ability to reject a transplanted organ. They are also called anti-rejection drugs.
Incompatible kidney transplant	A transplant in which the donor and recipient have different (incompatible) blood types. Doctors will do this type of transplant when there is not a compatible donor available. Due to the different blood types, the recipient will need more treatments to lower the chance of their body rejecting the kidney.
Independent living donor advocate (ILDA)	A person or team who works with a living donor and advocates for them. They are separate from the recipient's care team. They make sure the donor's rights are protected, respected and maintained.
Kidney failure	When a person's kidneys do not work well enough on their own to keep them alive.
Living donor	A living person who donates an organ to another person for a transplant, such as the kidney, lung, liver, pancreas or intestine. Living donors may be family, friends or strangers.
Non-directed donation	Someone who donates a kidney to anyone in need of a kidney transplant. The recipient does not know the non-directed donor.
Organ Procurement and Transplant Network (OPTN)	The OPTN is a partnership of transplant professionals in the U.S. The goal of the OPTN is to improve the U.S. transplant system so that more organs are available for transplant.
Organ rejection	When the recipient's immune system sees the donor organ as a foreign object and attacks it.
Paired kidney exchange (or paired exchange donation)	An option when a recipient and their living donor are not compatible. They are paired with another donor-recipient pair who are better matches. In paired kidney exchanges, two living donor transplants happen in the same day. Also called a "kidney swap."
Preemptive transplant	A transplant that happens before a person starts dialysis.
Recipient	A person who receives a transplant
Regulatory agencies	An organization recognized by the government that is responsible for: the registration, licensure and policies of transplant centers. The main agencies responsible for the oversight of transplant centers include the United Network for Organ Sharing (UNOS), Organ Procurement and Transplant Network (OPTN), Centers for Medicare and Medicaid Services (CMS) and the Department of Health and Human Services (DHHS).
Relative contraindications	Any condition that a transplant center may consider on an individual basis. Examples include patients with heart conditions that can be fixed or a patient who is overweight but loses the weight to be eligible for a transplant.

Self-care	Doing things to promote your own well-being and happiness during periods of stress. This can include eating healthy, exercising and doing activities you enjoy.
Support person	Someone who gives their loved one practical or emotional support. Support can include cooking meals and driving them to an appointment.
Transplant voucher program	An option for incompatible donor-recipient pairs. A living donor can donate their kidney when they want. Their donation creates a voucher (credit) for the recipient to use when they need a kidney.
Trust	A legal arrangement in which you (a trustor) give another person (a trustee) the right to hold your property or assets for your beneficiaries. Beneficiaries are the people you want to give your property or assets to.
United Network for Organ Sharing (UNOS)	UNOS is an organization that manages the U.S. organ transplantation system. UNOS manages the national transplant waitlist, matches donors to recipients and provides education on organ donation and transplant processes.
Will	A legal document that states a person's wishes as to how their property should be managed and distributed after they die.

Citations

¹ <https://www.kidneyfund.org/kidney-health-for-all/kidney-transplants>

² <https://usrds-adr.niddk.nih.gov/2023/end-stage-renal-disease/6-mortality>

³ <https://www.kidneyfund.org/kidney-donation-and-transplant/life-after-transplant-rejection-prevention-and-healthy-tips/kidney-rejection-after-transplant>

⁴ https://optn.transplant.hrsa.gov/media/eavh5bf3/optn_policies.pdf

⁵ <https://donatelifenet.com/donation/organs/kidney-donation/>

NOTES

Know Your Numbers:

HEIGHT: _____

WEIGHT: _____

BLOOD PRESSURE: _____

BLOOD GLUCOSE _____

TOTAL CHOLESTEROL: _____

ESTIMATED GLOMERULAR
FILTRATION RATE (EGFR): _____

URINE ALBUMIN-
CREATININE RATIO (UACR): _____

Important questions:

Important phone numbers:



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