



# Your Journey to Kidney **Transplant**



“I’m so grateful, and I’m so humbled, and I feel amazing. It’s like I have a second chance at life.”



Travaughn

“The job that DaVita does, and the transplant team, is the reason that my kids still have a father, my wife still has a husband, my mother still has her son, and I thank them for that.”



Alex

“Getting a transplant and being able to have that freedom to go and get back to school and be more of myself, it’s something I will never regret.”



Marco

“I can be so much more independent. I can live my days the way I want to.”



Melissa

At DaVita, our goal is to help everyone pursue kidney transplantation. Our job is to keep you healthy on dialysis while you wait!



**Transplant** is the best treatment option for most people with kidney failure. But the journey to getting a transplant can be confusing. This booklet can be your personal guide. Use it. Write on it. Ask us questions! Make it yours!

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# The transplant journey

These are the key steps on your journey to transplant. Each section of this booklet is color-coded to match a step below.



## Learn about transplant

Learn as much as possible about transplant. Ask questions. Decide if transplant is something you want to pursue.

## Find a transplant center

Find a transplant center, and follow-up with your care team and insurance provider.

## Testing and evaluation

Go through testing to see if you are a candidate for transplant.



### A living donor...

The transplant center will test if your donor is a match. If they are not, your donor can still donate on your behalf!



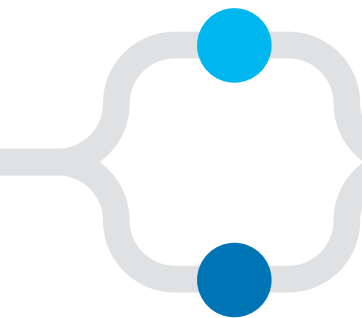
### Transplant surgery

Get your kidney!



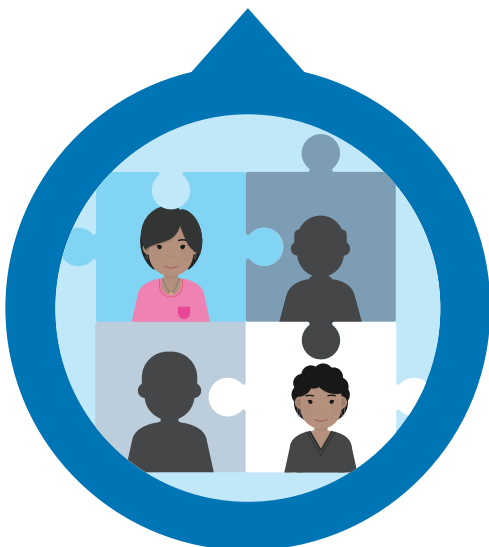
### Recovery

Learn to live a healthy life, free of dialysis!



### ...and join the waitlist for a deceased donor kidney

When you're pursuing a deceased donor kidney, stay healthy and active on the waitlist.



# What is kidney transplant?

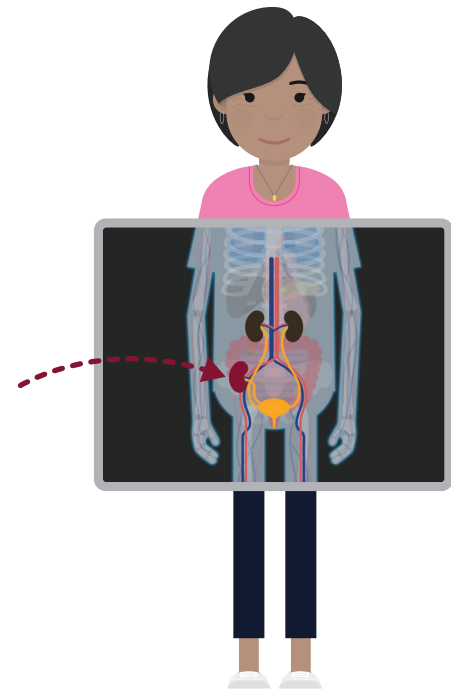
## What is transplant?

Transplant is when you take a body part from one person and put it in another person. Kidneys are the most common organ transplanted in the US.

In 2021 **24,670** kidneys were more than transplanted.<sup>1</sup>

The transplanted kidney takes over the work of your failed kidneys. It's amazing!

This means that after a successful kidney transplant you don't need dialysis. It's the best treatment for many people with kidney failure. It can help you feel as close as possible to life before dialysis.



**98%**

of kidney transplants are working 30 days after surgery.<sup>2</sup>

**98%**

of living donor kidney transplants are still working one year after surgery (94% of deceased donor transplants).<sup>3a</sup>

**90%**

of kidney transplants are working 3 years after surgery.<sup>2</sup>

Unfortunately, transplanted kidneys usually don't last forever. On average, kidney transplants from living donors last longer than a transplant from a deceased donor. Some people get multiple kidney transplants over their lifetime.

## Transplant is a treatment, not a cure.



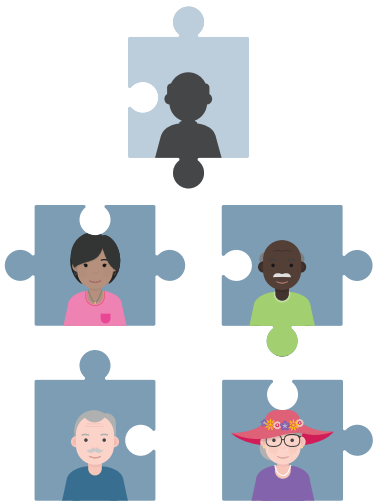
While kidney transplant is a cure for dialysis, it is not a permanent cure for kidney disease. You'll need to do your part to keep the new kidney healthy. This means taking medicines every day, seeing your doctor regularly, and more.

However, almost everyone that has a transplant agrees on one thing: it's all worth it. The surgery. The daily medicines afterwards. It's all worth having the freedom and energy that comes with a working kidney.

# Where do the kidneys for transplant come from?

Donated kidneys can come from people who are alive or recently died. Let's look at both:

## Deceased Donor Kidney:



A deceased donor kidney comes from a person who has recently died. This kind person has agreed to have their organs donated when they die. Even though a person's body has died, their kidneys can still function in someone else.

Unfortunately, there is a waiting list to get a deceased donor kidney. There are a lot more people waiting for a kidney than there are people donating kidneys. The average wait time to get a deceased donor kidney is 3 to 5 years in the US. In some areas, it can be as long as 8 years.

The waitlist is discussed more starting on page 25.

**Did you know?** Your time on dialysis counts toward the deceased donor waitlist. For example, let's say you have been on dialysis for 3 years and join the list. You would wait 3 years less for a kidney than a patient just starting dialysis.

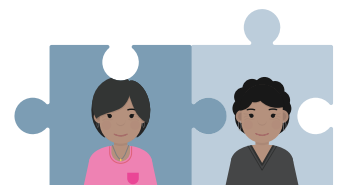
## Living Donor Kidney:

Living donor kidneys come from a living person who is willing to donate one of their kidneys. People with healthy kidneys can live with just one. Some living donors are family, friends, or community members. Other living donors can be complete strangers who choose to donate and help someone in need.

The person donating the kidney and the person getting the kidney need to complete a medical evaluation. This evaluation checks to see if both people are healthy enough for the surgery. It also checks to make sure they are a match.

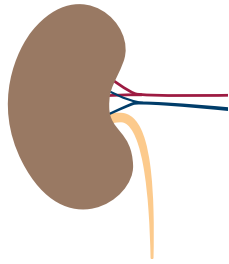
If the person you are donating to is not a match, you can do a paired donation. This is where your donor will donate to another kidney recipient and their donor will donate to you.

Living donor kidneys tend to function better and last longer than deceased donor kidneys.



# Benefits of transplant

## Benefits:



Dialysis is not needed while the transplanted kidney is working. The new kidney filters blood all day so toxins don't build up like they do between dialysis treatments. This usually means more energy and less fatigue.



Transplant can give you more time and freedom to enjoy life. It may be easier to take part in social activities and hobbies. Travel is easier.



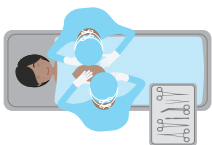
Fluid and diet are less restricted than on dialysis.



On average, people with a transplant live longer than those on dialysis.<sup>4</sup>

## Considerations:

While transplant is a great treatment option, there are important considerations:



A kidney transplant is a serious procedure. It requires surgery and multiple days in the hospital.



You'll have to take medications to help your body accept the new kidney as its own. It is important to take your medications daily as directed by the transplant team.



Transplanted kidneys usually don't last forever. Transplant is considered a treatment, not a cure.



# Who can get a transplant?

You don't need to be perfect to get a transplant. You don't need to be a celebrity or fitness model. People of different shapes, sizes, ages, races, and health get them every day, but there are some guidelines.

Every person has the right to be referred to a transplant center!

## What are the rules for who can get a transplant?

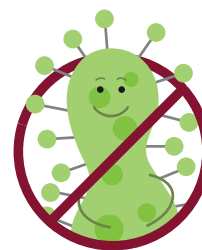
Each transplant center has their own guidelines. Here are some common rules:



Not too overweight



No active substance abuse or dependence



No active cancer or infection



Strong enough to undergo surgery



Overall decent health

Remember, every transplant center has their own rules on who can get a transplant. The transplant center will run tests to see if you meet their rules. We describe this process on pages 14-16 of this booklet. If one center doesn't accept you, another one might.

**Did you know?** You can get on the waitlist for a transplant before you start dialysis. Talk to your care team to learn more about preemptive transplants.

# Your DaVita Team

DaVita and your doctors are here to support you every step of the way to transplant.

You're not alone. You have a whole team behind you! This includes:



## **Nephrologist/Kidney Doctor: Your leader**

- Your trusted voice and leader throughout the journey
- Helps you solve problems and stay healthy for transplant
- Refers you to a transplant center



## **Registered Nurse: Your Coordinator**

- Helps you understand the surgical process
- Helps you stay healthy for your transplant
- Performs labs and tests to keep you active on transplant list



## **Social worker: Your main helper**

- Helps you find a transplant center
- Can help you get a referral to a transplant center
- Guides you through the process and answers your questions
- May be able to help with insurance questions



## **Insurance counselor: Your insurance guide**

- Helps you find a transplant center that takes your insurance
- Helps you understand what your insurance covers for transplant evaluation, surgery, and medications
- Helps you explore insurance options that might offer more coverage or more transplant center choices



## **The rest of DaVita team: Your supporters**

- Take your monthly blood draws
- Help with your diet, maintain healthy weight and good labs
- Keep you as healthy as possible on dialysis

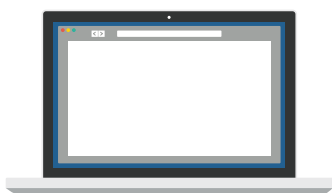
# What is a transplant center?



Transplant centers are where organ transplant surgeries take place. But they are much more than that! Each transplant center has a full team that specializes in helping transplant patients through every step of the process.

Transplant centers are normally located in a hospital. However, not every hospital has a transplant center. And some transplant centers might not do kidney transplants. Your dialysis social worker and care team can help you find the closest centers to you.

## How to find a transplant center:



A great place to start your search for a center is the Organ Procurement and Transplantation Network (OPTN) website. OPTN has a search tool to find kidney transplant centers near you. The website is:  
<https://optn.transplant.hrsa.gov/members/member-directory/>



Talk with your dialysis social worker or care team. They can give you a list of nearby transplant centers.



Talk with your insurance company. They may be able to help you find a center that takes your insurance.

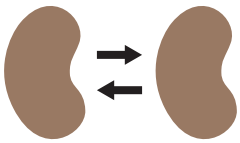
## Can I compare transplant centers?

You have the ability and the right to compare transplant centers. We recommend starting with the Scientific Registry of Transplant Recipients at <https://www.srtr.org>. There are reports on every transplant center. You can see:

- The number and type of transplants the center performs each year
- The transplant center's kidney transplant survival rates
- Living and deceased donor information
- And much more

### Comparing transplant centers (continued):

You can also call the transplant center with questions. Here are some things to find out:



Find out if the center offers paired donation or donation chain programs. These programs might increase your chances of receiving a living donor kidney.



Understand the medical costs that may be billed before, during and after your transplant. Costs may include tests, organ procurement, surgery, hospital stays, and transportation to and from the center for the procedure and follow-up appointments.



Find out if the transplant center offers additional services or support. This might include support groups, travel arrangements, help with local housing for your recovery period, and referrals to other resources.



Ask about the technology and techniques they use. You can search online or ask your doctor to see if these are helpful.

## Checking your insurance coverage

Most insurance plans cover parts of kidney transplant. Medicare and Private Insurance are the two most common types of coverage. Let's look at both:

### Private Insurance

- Many private insurance plans offer coverage for kidney transplant.
- Plans may cover a high percentage of transplant-related costs.
- Plans usually offer some coverage for immunosuppressant medications after surgery.

### Medicare

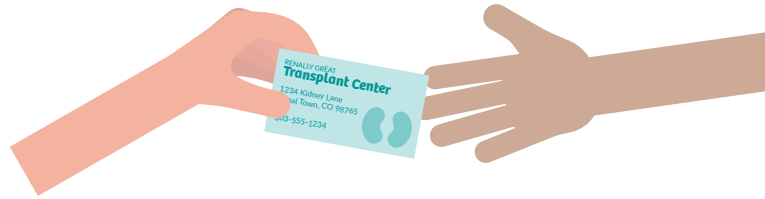
- Medicare Parts A & B usually cover about 80% of transplant related costs.
- Medicare participants may look at adding Medicare Supplement insurance to help with the 20% gap.
- Medicare will cover lifetime anti-rejection medication starting Jan. 1 2023.



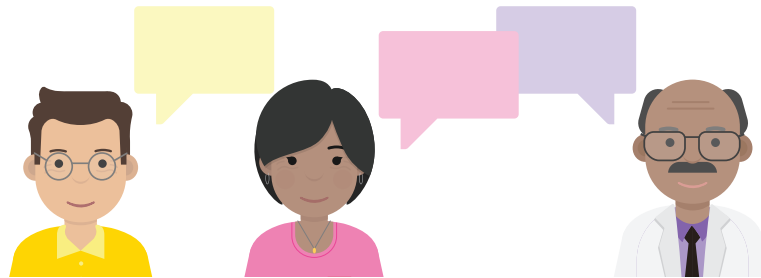
With all insurance, it is important to go to a transplant center that is "in network". Talk to your care team for help. You can also talk to your insurance company for help on finding an "in-network" center.

# The referral process

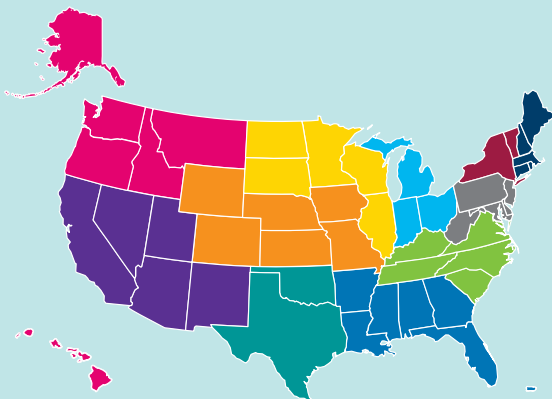
## Getting a referral:



Once you've found a center, it's time to get a referral for kidney transplant. What is a referral? Consider it your "ticket" to begin talking to the transplant center. The first step is to talk to your kidney doctor or care team. They can both help answer questions and give you guidance. Most importantly, they can give you a referral to the transplant center.



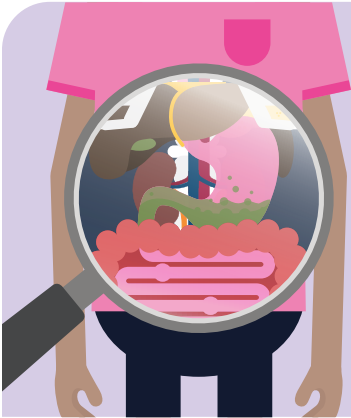
Your physician may or may not be supportive of you going for transplant. If they do not support you, they may not give a referral. Know this: you still have the right to pursue a transplant. Ask your social worker or care team for a referral. Ultimately, it is the transplant center that is responsible for approving or denying you for transplant.



### Insider Tip:

You have the ability to join the waitlist at multiple transplant centers. This may give you a better chance of getting a kidney and sooner. Talk to your doctor, social worker, or care team about getting multiple referrals, if interested. See page 26 for more information on transplant waitlists.

# What is transplant evaluation?

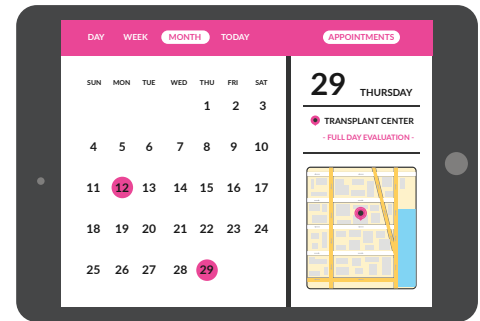


The evaluation is one of the biggest steps along the transplant journey. Transplant evaluation is a set of medical tests. The tests check to see if kidney transplant would be a safe and helpful option for you. Most of the time, the evaluation takes place at the transplant center. Some transplant centers do all of the evaluation tests in one day. Other centers do it over several appointments. Each transplant center does the evaluation a little differently.

## Scheduling your evaluation appointment(s):

The transplant center will usually contact you within 30–60 days of receiving your referral. If you don't hear from them, you can always give them a call. They will schedule you for one or more evaluation appointments.

Make sure you let them know which days you are at dialysis. We don't want you to accidentally miss a dialysis appointment.



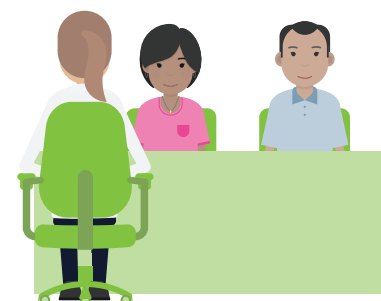
If you need help with transportation, ask your social worker or care team.

## Preparing for evaluation:



The transplant center may ask you to collect some information before your appointment. This may include past medical history, a list of medications you take, X-rays, and more. If you're having trouble collecting the information, ask your care team. They may be able to help!

It's a good idea to bring a family member or friend with you to the evaluation appointment. They can help take notes, ask questions, and keep you company over the day.

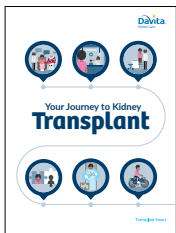


As you get close to your appointment, make sure to follow the transplant center's instructions. They may have you prepare for the evaluation the day before by fasting or eating a limited diet.

## Checklist for evaluation day:



Get a folder ready with everything they have asked you to bring to the appointment. This might be medical records, forms, or documents.



Bring this booklet with you. Be sure to reference page 17 for questions to ask during your appointment.



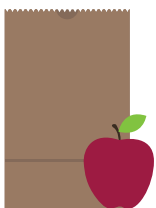
Wear comfortable shoes and clothing. Bring a jacket in case the hospital is cold.



Don't forget your glasses or hearing aids.



Bring a pen or pencil and paper to take notes. You will meet a number of different people and you will receive a lot of information. It can be helpful to bring a loved one to help take notes for you. You can also share these notes with your care team or family members.



You might want to pack a few kidney-healthy snacks or even a lunch. It might be a long day!



Plan to arrive at the center 15 minutes before your appointment.

# Your evaluation appointment

The big day is here! The transplant evaluation goes a bit differently at every transplant center. Some centers will do your evaluation all in one long day. Other centers will do evaluation over multiple days. Either way, they usually have similar steps. Let's look at what's usually included.

**?** Your transplant evaluation appointment(s) is a great time to ask questions. Ask as many questions as you can! See page 17 for a list of possible questions to ask.

## 1. Meet your transplant team

You'll get the opportunity to meet all, or most, of your team. This usually includes:



### Transplant doctor

Reviews your labs and overall health during the transplant evaluation and during your time on the waitlist. They do not replace your regular nephrologist.



### Transplant surgeon

A doctor trained in surgery who specializes in transplants. They will be part of decisions along the way too.



### Living donor transplant coordinator

The main point of contact for your potential donor. They arrange your donor's appointment, answer questions, and can help solve any problems.



### Transplant social worker

Helps you find support programs, social services, and more.



### Transplant dietitian

Helps you eat well and get good lab results before and after transplant.



### Financial counselor

Helps you with insurance questions and issues and can help you find financial support programs.



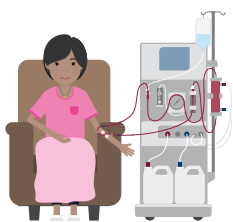
### Transplant pharmacist

Ensures you have the right prescriptions before and after transplant.

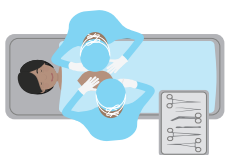


## Your two care teams:

You probably noticed that the transplant team looks a lot like your care team. Each has a dietitian, social worker, and counselors. So, how are they different?



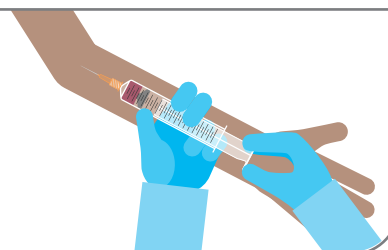
Your care team, including your nephrologist, lead your care. Dialysis is needed to keep you healthy on the way to transplant. They also see you often and can answer questions you have about transplant, insurance, and more. They'll point you to the transplant center team when they can't help.



Your transplant team leads the transplant process. They are responsible for making sure you get all of the tests, counseling, and everything else needed to make sure you're ready when a kidney is available. They also do the transplant surgery and help you afterwards.

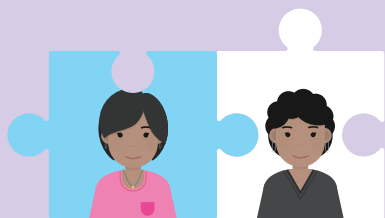
## 2. Blood tests

You'll need to have blood tests to find a donor kidney that's a good match for your body (see below for more). Blood tests also look for general health and disease.



## Kidney Matching

Your immune system's job is to fight off anything foreign that might hurt you. Usually, this is great! It protects you from bacteria and viruses that can make you sick. But when someone else's kidney is put into your body, your immune system could think it's an invader to fight off. To prevent this from happening, your doctors will do blood tests on you and your donor (living or deceased) to look for certain similarities. This is known as matching. A good match makes it more likely the kidney will work in your body.



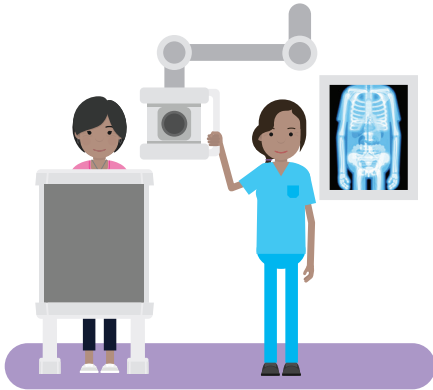
What does it mean to be a match? Each person has different special proteins in their blood called antigens. Antigens are like labels that tell your immune system what belongs in your body and what doesn't.

Your blood type is based on which antigens you do or do not have. Because of these antigens, you can receive blood (or a kidney) from only certain other blood types. So, the first test your doctors will do is blood typing (also called ABO compatibility).

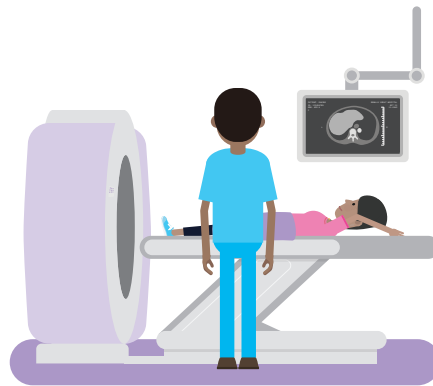
The next blood test, called tissue typing, looks at the number of antigens you and a donor have in common. Once you have a donor, you'll have a cross-matching test to see if your body will react to the donor's kidney.

## 3. Medical exams

Next up, your transplant team will make sure your body is healthy enough to have a kidney transplant. You and donor will have several medical screenings, such as:



A chest X-ray to check your lungs and airways



A CT scan to see your liver, gallbladder, and kidneys



An EKG to evaluate the activity of your heart



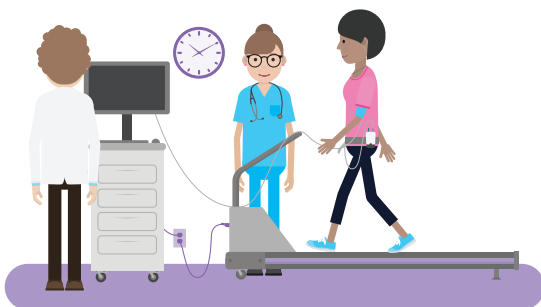
An echocardiogram to see the structure of your heart



A colonoscopy, pap smear, or mammogram



A dental exam to check your teeth



### Stress test

They'll also test to see how strong your heart is.

If you are healthy enough for exercise, they may have you ride an exercise bike or walk on a treadmill. During this exercise, they'll monitor to see how your heart is working.

If you cannot exercise safely and without pain, they may take a different approach. They can give you an injection that will speed up your heart rate, almost like you are exercising. They can then test to see how your heart is working.



That's usually it! It can be a little long and tiring, but transplant evaluation can feel like a big accomplishment. It's a big step on the transplant journey.

# Questions to ask your transplant team

You will have a great opportunity to ask questions during your transplant evaluation. Here are some good ones to ask:

How will I know when I am definitely on the waiting list? \_\_\_\_\_

\_\_\_\_\_

How long is the waiting list at this transplant center? \_\_\_\_\_

\_\_\_\_\_

What is required to stay active on the waitlist? \_\_\_\_\_

\_\_\_\_\_

Which surgeons will be available whenever an organ is offered to me? \_\_\_\_\_

\_\_\_\_\_

How many living donor and deceased donor transplants are performed at the center each year? \_\_\_\_\_

\_\_\_\_\_

Does the Transplant center offer paired donation? \_\_\_\_\_

\_\_\_\_\_

How often will I need to come in for appointments and testing while on the waiting list?

\_\_\_\_\_

\_\_\_\_\_

What are the potential risks and benefits of the surgery? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

What is the expected recovery time after the transplant? \_\_\_\_\_

\_\_\_\_\_

Can you help with transportation and parking? \_\_\_\_\_

\_\_\_\_\_

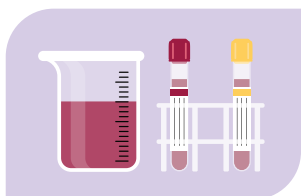
How much time would I have to get to the transplant center if a kidney became available?

\_\_\_\_\_

\_\_\_\_\_

# What's next?

## Candidate review:



What happens after your evaluation? The transplant center team will get together to discuss your evaluation results. They'll look at your labs, test results, medical images, and more. Then, they'll make a decision on if a kidney transplant is safe for you. If it is safe, they will add you to the deceased donor waitlist!

What's next depends on if you have a living donor or need to join the waiting list for a deceased donor kidney. If you have a living donor, learn more about the living donation process starting on the next page.

## Joining the waitlist:

If you're hoping to be added to the waiting list for a deceased donor kidney, the transplant center will usually come back with one of three possible results.

- ✓

**1. Yes!** Congratulations, you've made it onto the official transplant list. You're in line to get a deceased donor transplant. Being on the transplant list comes with excitement, but it also comes with great responsibility. You'll need to do your part to stay on the list. See pages 27–30 for more information.
- ?

**2. Maybe.** You might be a candidate for kidney transplant but the transplant center isn't ready to add you to the list just yet. They may need more tests. They may need you to lose weight. They might need to wait until a medical condition clears up. It could be many reasons. Work closely with your transplant center to understand what you need to do to get on the list.
- ✗

**3. No.** Being told you are not a candidate is hard. But that doesn't mean your hopes of a transplant are over. You may have options like:

  - Explore the reasons you were not a candidate, and find other transplant centers in your area. They may have different rules. Talk to your kidney doctor or care team for referral to a new center.
  - If you were not accepted as a candidate for a reason like obesity, you may be able to take action. You could work with your dialysis center dietitian on a weight loss goal.
  - Ask your transplant center if you might be a candidate for living donation. Some centers have different rules for living versus deceased donations.

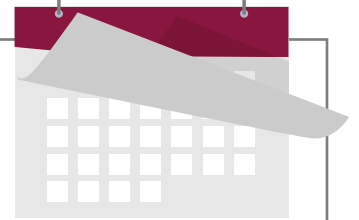
Whatever the news, we're here for you! Please keep your care team up-to-date on your transplant status. We'll help you figure out what's next.

# Finding a living donor

Living kidney donation is when a living person donates one of their kidneys. The person who donates can continue to live normally with just one kidney.

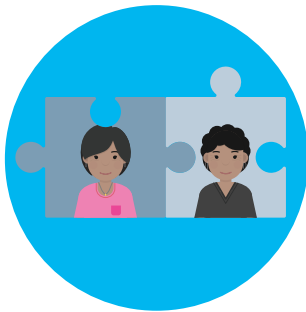
## Benefits of a living donor:

A living kidney donation is usually the fastest way to get a transplant. While the deceased donor waiting list is 3 to 5 years on average, a living kidney transplant can happen in just months.

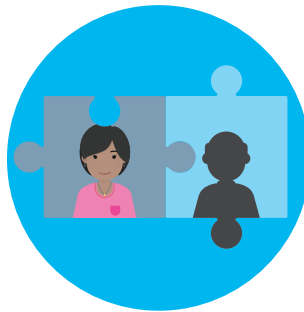


Also, living kidneys generally last longer than deceased kidneys. Living kidneys last 12 to 20 years on average<sup>3</sup>. Deceased kidneys last 8 to 12 years on average<sup>3</sup>.

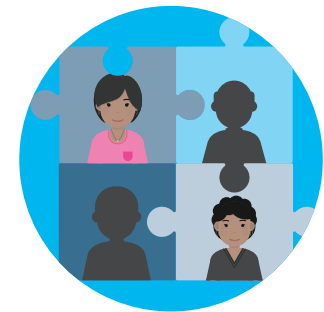
## There are three types of living donor processes:



**A directed donation** is a living donor who gives a kidney directly to you.

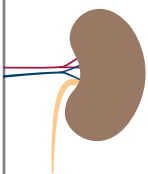


**A non-directed donation** is a living donor who donates to any kidney recipient waiting on the transplant list.

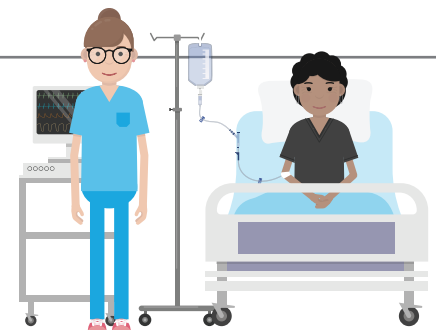


**A paired donation** is when your intended living donor is not a match, so they give to another recipient and their donor gives to you.

## Living with one kidney:



People are able to live totally normal lives with just one working kidney. This is why living kidney transplant is possible. When a healthy person gives a kidney away, the remaining kidney takes over. It does the work of two kidneys. It may even grow a bit larger!



Transplant surgery is generally safe for donors. Complications are rare. However, the donor will need to plan for 2–3 days in the hospital and 4–6 weeks of recovery after surgery. Once they've recovered, they won't notice any difference between having one working kidney or two. They'll feel just the same as before. They don't even need to change their lifestyle, activities, or anything else. They just go on with life as normal.

## Finding a living donor:

Finding a living donor can feel like a hard and even scary task. After all, it's not easy to just walk up to someone and ask for one of their kidneys. Thankfully, there are tips and tricks that people have used which can make this easier.



It all comes down to one thing: give people the opportunity to volunteer. It is surprising how many people volunteer to donate without being asked. The donor hears a family member, friend, or even stranger tell the story of their struggle to find a kidney. Without being asked, they volunteer to help. It's so inspirational when a person does something as selfless as giving a kidney. So, how do you share your story?

## Share your story.

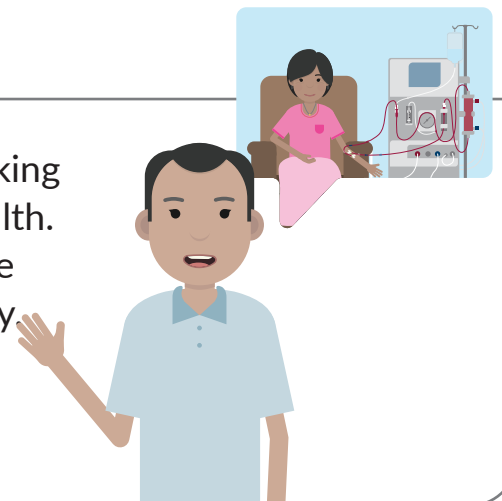


People can only volunteer if they know you need a kidney. That's why it's so important to share your story with everyone possible. Here are some topics to think about:

- How long you have had kidney failure
- What kidney failure means for your health and life
- How kidney disease can be a burden on you and your family
- How dialysis makes you feel, and how it makes life harder
- Educate people on how transplant can give a better and healthier life than dialysis
- Educate people on living donation and how most donors live healthy lives with one kidney

## Finding an advocate:

Many of us have a hard time talking about ourselves and asking for anything. It's especially hard to tell stories about our health. That's where an advocate comes in. An advocate is someone who speaks on your behalf. They tell other people your story. They spread the word. It's amazing how many people find a donor through their advocate. Think about asking a family member or friend to be your advocate.

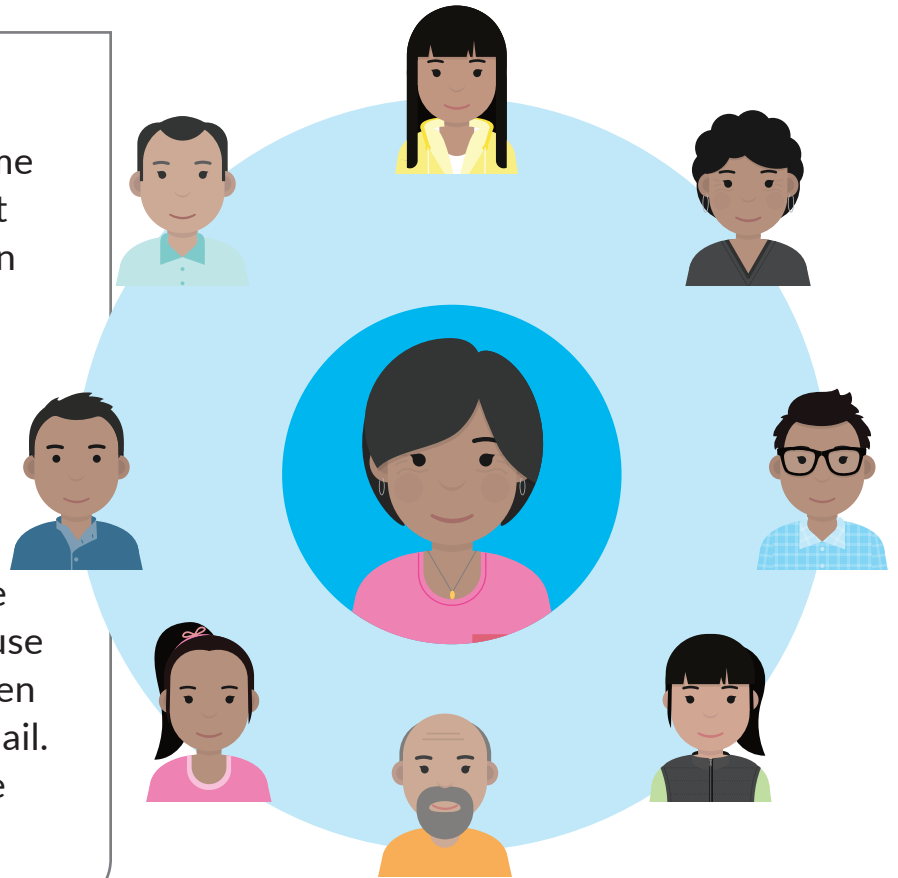


**Tell your story to everyone.** Friends. Family. Co-workers. Your faith community. The people at your local coffee house. Anyone that you can talk to. The more you tell your story, the better your chances. You never know who might step up and offer to donate.

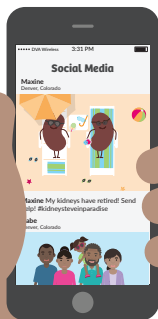
## Asking family for help:

Many people also find living donors by asking for help. This can take some courage and some people prefer not to ask. If you are willing to ask, it can be effective.

Most people start by asking their closest family members such as children, brothers, sisters, parents, aunt, uncles, etc. Close family members are the most likely to have kidneys that match your need because you're related. Some people ask when talking in person. Some ask over email. Some ask on social media. There are many possibilities.



## Using social media:

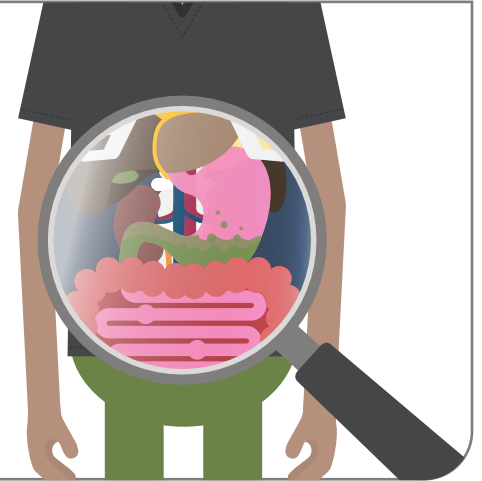


It's surprising how many people are finding kidney donors on the internet. It usually goes back to telling your story. This time, it's online. You might tell your story on Facebook or Instagram. When you do, all kinds of people can see it. Some will share your story with their friends and family. You never know who will see your story and volunteer to donate a kidney.

# Living donation process

## Is your donor a candidate?

Once you've found a kidney donor, the next step is for them to be tested. The testing process is much like the patient's transplant evaluation process. The goal is for the transplant center to determine if the person is healthy enough to donate a kidney. They consider the person's age, physical health, mental health, and future risk of kidney disease. The goal is to make sure this person can live a full, healthy life after giving away a kidney.

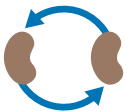


## Is your donor a match?

If the person is healthy enough to donate, the transplant center will also determine if the person is a match for you. They'll look at blood type and other genetic factors. See page 15 for more info.



If they are a match for you, great! Transplant surgery can be scheduled.



If the person is healthy but not a match, they may be able to still donate in a paired donation. Learn more on page 23.



Let your transplant center know about anyone who is willing to donate a kidney to you. Even if you know in advance they may not match you, they still might let you become part of a paired or chain donation.

## Donor surgery and recovery:

Your living kidney donor will go through surgery the same day you do. They will be given general anesthesia so they sleep through the procedure. The surgeon will make small incisions and remove the kidney. They'll sew them back up, and that's it! The surgery team will then quickly get to work on transplanting the kidney.

The recipient's surgery process is described on page 33 of this booklet.





# Paired donation process

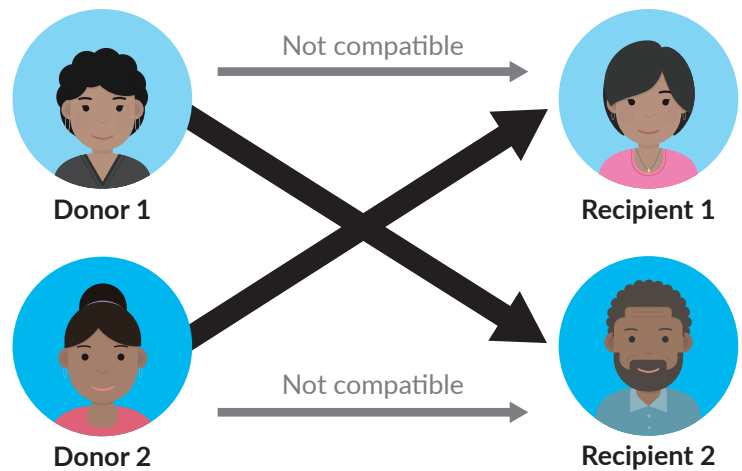
You might find a donor who is not a match for you. Luckily, they may still be able to donate and help get you a kidney! Some transplant centers help incompatible pairs of recipients and donors through the process of paired donation.



## How paired donations work:

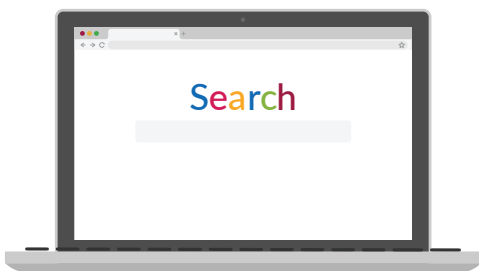
There are situations when someone else's donor may be a match for you, and you swap. Their donor gives you a kidney and your donor gives them a kidney. That way, donors who aren't a match for their recipient are still able to donate. And, two recipients receive a new kidney. Usually surgery is done for both pairs on or around the same day.

This swapping can happen between more than two pairs. There have been chains with as many as 50 people who exchanged donors, allowing everyone to receive a matching kidney.



## Finding a paired donation program:

It's a good idea to check if your transplant center offers a paired donation or exchange program. If they don't, here are some other organizations that might be helpful:



- Alliance for Paired Donation: [paireddonation.org](http://paireddonation.org)
- National Kidney Registry: [kidneyregistry.org](http://kidneyregistry.org)
- Organ Procurement and Transplantation Network (OPTN) and United Network for Organ Sharing (UNOS) Kidney Paired Donation Program: [unos.org/transplant/kidney-paired-donation](http://unos.org/transplant/kidney-paired-donation)

To learn more about the paired donation process, talk to your care team.

# Living donor FAQ

Many potential kidney donors have the same questions. We've answered some of the most common ones here. This may help you address concerns when talking to others.

**Question: Are there long-term health issues for donors living with one kidney?**

Answer: Studies show no long-term health affects.

**Question: What happens if a donor needs a kidney later in life?**

Answer: Being a kidney donor gives you priority status on the transplant list, if you need a kidney in the future. This does not put you immediately at the top of the list, but improves your position. Ask your center if they have a kidney donor protection program.

**Question: Do donors need to take anti-rejection medications after surgery?**

Answer: No. The person receiving the kidney transplant is the one that will take the anti-rejection medications.

**Question: Do I get paid time off for recovery after kidney donation?**

Answer: There is no national policy, but some transplant centers may participate in a program that provides lost wage reimbursement to living donors. Your employer may or may not offer paid time-off for organ donation recovery. Donors are covered under the Family Medical Leave Act (FMLA), so you do not need to worry about losing your job. Talk to your boss or human resources department for more information.

**Question: Does health insurance cover the cost of donation surgery?**

Answer: Generally, the health insurance of the person you are donating to will cover costs related to the donation, including surgery. Work with the transplant center for more details.

**Question: Will donors be able to drink alcohol with one kidney?**

Answer: Your liver is the organ that is primarily responsible for handling alcohol. If you were able to consume alcohol responsibly before surgery, you will likely be able to afterwards. Talk to your doctor for specific guidance.

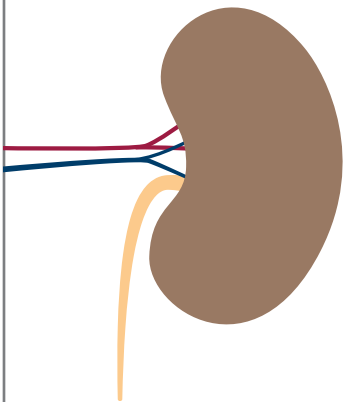
**Question: Is the kidney donation surgery risky?**

Answer: Kidney donation is a major but routine surgery. It is fairly similar in risk to having another organ removed, like the appendix. Serious complications are very rare. Talk to your transplant center for more information.

# Journey of a deceased donor kidney

Deceased donor kidneys (kidneys from organ donors that have recently died) are the most common type of kidney used for transplant. The journey each kidney takes from donor to recipient is amazing. Let's look at how it all comes together.

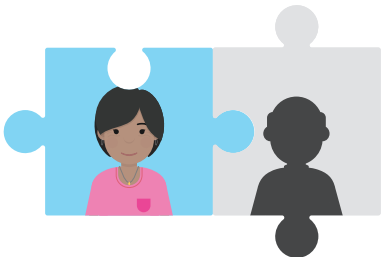
## Organ donor:



The amazing journey of a deceased donor kidney starts when someone dies and donates their organs. The hospital draws blood from their body to check blood type and other factors.

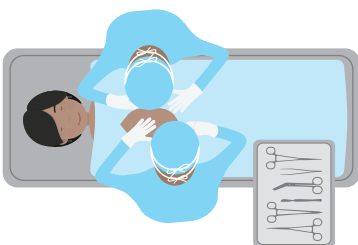
The hospital then contacts UNOS, the group that runs the transplant list. UNOS stands for United Network of Organ sharing and is a non-profit organization that tracks and allocates all organs for transplant. The hospital lets UNOS know they have new organs ready for transplant.

## Finding a match:



UNOS uses the waitlist to find a match for the donor kidneys. UNOS first looks in the local region. The goal is to limit how long the kidney has to travel. Shorter is better for the health of the kidney. If there isn't a match locally near the top of the transplant list, UNOS will look at nationally.

## Surgery:



Once a transplant recipient is found, the hospital moves quickly. They will get the kidney ready to transport. The kidney is then sent to the hospital where the transplant recipient will have surgery. When the kidney arrives at the center, it is prepped for surgery. The kidney is then surgically put into the patient's body.

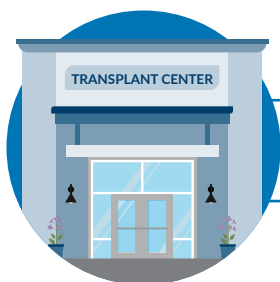
# What is the transplant waitlist?

The transplant waitlist matches patients needing a kidney with deceased donor kidneys. It does not apply to living donors. Here is how the waitlist works.

## Waitlist:

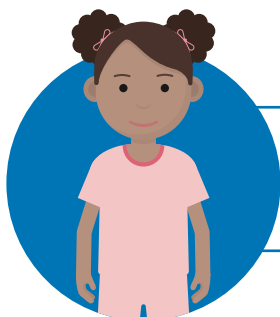
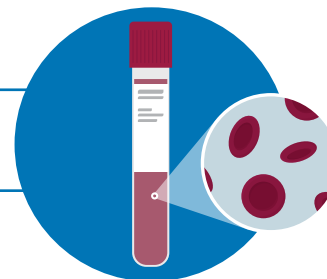
The transplant waitlist is run by UNOS (United Network of Organ Sharing). UNOS starts giving out kidneys within a 250 mile distance from the kidney donor's hospital. When a kidney becomes available, UNOS finds a recipient based on multiple factors including:

Time on dialysis or waitlist time prior to start of dialysis.



Closeness of the donor hospital to the recipient's transplant center.

Your blood type and antibodies.



Other priorities such as being a previous living donor or a pediatric patient.

**Quick reminder:** Your waitlist time starts from your first day of dialysis, not your referral date to the transplant center. So, it's never too early or too late to ask about transplant!



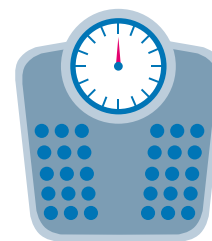
When a deceased donor kidney becomes available the donor's antigen match information is shared with UNOS. They'll decide who to give the kidney to based on who on the waitlist is a match.

# On the waitlist

Getting on the kidney transplant waitlist means you're closer to life without dialysis. But, the next step in your journey can take some time. Many people wait 3 to 5 years, or longer, for a kidney to be ready for them. During this waiting time, your healthcare team wants to help you stay transplant-ready! Staying on the list takes determination and patience. Here are some tips to help:

## Keep your transplant center updated.

Tell your transplant center about anything that changes in your life. It might be a change in your phone number, insurance, address, or even marital status. It may be a change in health. Maybe you quit smoking or lost a little weight. Or maybe you had a stay in the hospital. Tell them about any changes in your personal information or health right away to avoid being made inactive.

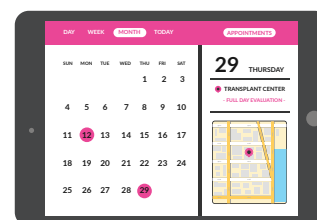


## Make sure the transplant center can contact you.

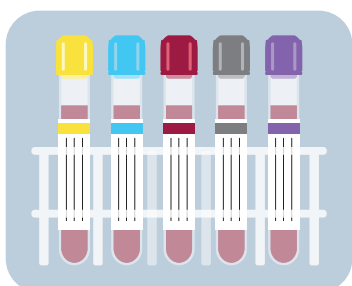


Give them many ways to contact you including all your phone numbers and email addresses. Give them your spouse, family member or care giver's contact info too. Remember, now that you're on the list, they may call anytime about a kidney. You don't want to miss that call!

Even if a kidney isn't ready yet, other calls are just as important. The transplant center may be calling to schedule an appointment for tests. Many people have testing every year or more often. If you miss an appointment, you may become inactive or taken off the list. So, it's best to answer all of their calls. When they don't reach you and leave a message, call them back right away!



## Monthly blood samples are a must.



Make sure the dialysis center is taking care of your routine blood samples for the transplant center. Certain antibodies (see page 15) in your blood can change over time. If a kidney becomes available, your transplant center will need a recent blood sample to see if you are a good match. Your job is to make sure they get this blood sample routinely.

# Staying healthy

Your time on the transplant waiting list is like a marathon. There are many steps to take before you cross the finish line. The transplant center will be keeping track of your health and how well you follow their directions. They want to make sure you can be trusted to take care of a new kidney. You want to show them you can do this.

## Eating well is key to good health.

The goal is to stay as healthy as possible on the way to transplant. Since healthy eating is a big topic, here are just some basics:



If you have diabetes, eat foods that keep your blood sugar controlled.



Eat heart-healthy foods that help keep your blood pressure controlled. Your heart and blood vessels need to stay strong and healthy for a successful transplant.



Limit your sodium (salt) to help keep fluid and blood pressure controlled.



Take your medications. They impact lab results. Also, it shows your transplant team that you can be relied upon to take your medications after transplant.

## Weight loss:

One of the most common requests from the transplant center is to lose weight. The transplant center will measure your BMI (body mass index) to see how much you weigh for your height, age, and gender. If you weigh too much, you may be asked to lose weight to get on the transplant waiting list, or stay on the list. Losing weight usually comes down to a few things:



Doing more physical activity or exercising



Eating healthier foods



Eating smaller portions



Remember, this is an evaluation to show you're ready for a kidney. Healthy weight loss occurs slowly and steadily. Your care team can help you learn more about healthy nutrition and how to reach a healthy weight. Please ask us for help, tips, recipes, and more.

# Transplant list status

Making it onto the transplant list is a great accomplishment. However, your place on the waiting list may not be permanent. It's possible to be temporarily or permanently removed.

## What does “inactive” mean?

“Inactive” means that you are on the transplant waitlist but are not ready to get a kidney. This is usually temporary. There are a number of reasons you can be made inactive (see below). **Thankfully, you will not lose your place while inactive.**

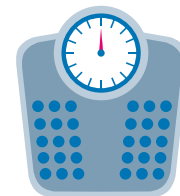


Becoming inactive is pretty common. About 30% of people on the kidney transplant waitlist are inactive right now.<sup>5</sup> Why are so many people inactive?

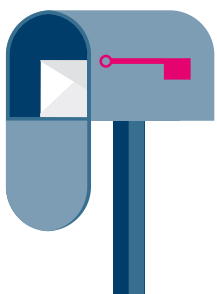
## Reasons for being “inactive”:

Transplant centers each have their own rules for what can make someone not ready for transplant. Here are some common reasons:

- Declining health or hospitalization
- Changing your phone numbers or health insurance without telling the transplant center
- Missing transplant center appointments and tests
- Missing monthly blood tests at the dialysis center
- Gaining too much weight (BMI)
- Missing dialysis treatments
- Change in family support



## How to find out if you're active or inactive:



If you are made inactive, the transplant center will write you a letter or call you. They will let you know why you were made inactive. They may also share what you need to do to remain active, and ready for a kidney. If you are made inactive, please tell your care team as soon as you find out. Your care team will do everything possible to help you get back onto the list quickly.

Ask the transplant center for your status every time you talk with them. It's always best to be sure you're active!

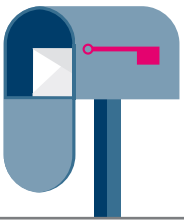
### Getting back to “active”:

The path to getting back to “active” on the transplant list depends on why you were made inactive. For example, let’s say you were made inactive because you didn’t let the transplant center know that you changed phone numbers. Getting active again can be as simple as giving the transplant center your new phone number. If you gained too much weight, it might mean losing enough weight to meet their requirements. The transplant center team is there to help you. Listen to their guidance. Ask for their help. Do all that you can to be made active again!

## Removed from waitlist (delisted)

Unfortunately, there are also reasons why someone may be permanently removed from the transplant list. This is called “delisting” or “delisted status.” It means you cannot get back on the transplant list at that transplant center. However, you may be able to try another transplant center as they could have different rules.

### How do I find out?

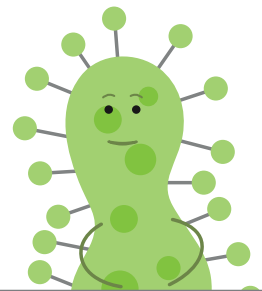


If you are delisted, the transplant center will write you a letter or call you. They will let you know why you were delisted. If you are delisted, please tell your care team as soon as you find out. Your care team can help you figure out options for next steps.

### Reasons for being delisted:

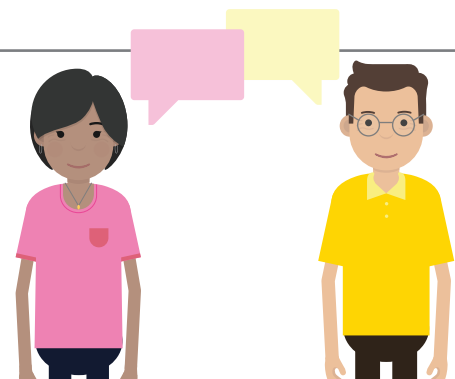
Every transplant center has their own rules on delisting. Here are some of the more common reasons:

- Active cancer: new diagnosis or recurrence
- Worsening health: no longer healthy enough for transplant
- Old age: you may have waited too long for transplant to be safe



### What to do if you are delisted:

Talk to your care team. They can help you consider your options for next steps. It may be possible to try to join the waiting list at another transplant center. If you are accepted at another transplant center, the time you waited will be transferred.





# Getting closer to transplant

## When will it be my time for transplant?

No one knows exactly when the call with their kidney will come. However, most transplant centers will let you know when it's almost time. They want to make sure you're ready for when that call comes in. Even if they don't tell you, you can usually get a rough estimate of when you are close to getting a transplant based on the average waiting time in your area. For example, if most people wait 5 years in your area and you have been waiting 4 years, you may be close. Ask your transplant center team and social worker for the average in your area.



## Why is it important to know when?

When you know it is almost your time for transplant, you can get ready for it. There are very important things that you should do including:



Make sure the transplant and dialysis centers have your most updated contact information. Include your spouse's number and dependable family members.



Pick up your phone for every call. Answer blocked calls and unrecognized numbers. You don't want to miss your call.



Keep making your dialysis treatments and staying healthy. You don't want to be made "inactive" last minute for reasons you can control.



Plan your transportation. What happens if a kidney is available in the middle of the night? How will you get to the center?



Talk to your loved ones. Decide who will come with you.



Pack a bag for the hospital. Take comfortable clothes, books, slippers, and whatever else you'll want during your stay.

**Being ready is the best way to make sure you get a kidney when it's your turn.**

# The call

## When a kidney is ready for you:

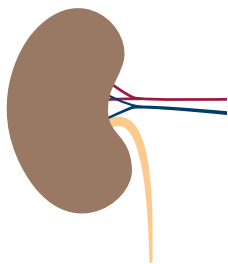
When it is your turn on the list and a matching kidney is available, the transplant center will call you. You may never get a more exciting call in your life! Here is what to expect:



The call may come any time of day or night. Keep a phone close by!



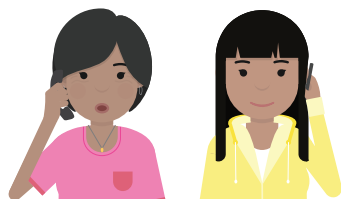
Keep a note pad and pen next to your phone. It can be helpful to take notes.



On the call, the transplant center will usually give you some information about the available kidney. This might be the age of the donor and other important health history. They may give you the option to take the kidney or pass on it.



If you choose to accept the kidney, the transplant center will give you a time limit to get to the transplant center.



Contact your family right away. Let them know it's your time!



Get to the transplant center as quickly as possible. Don't forget your bag!

Remember to pick up your phone! Answer every call that comes in, especially if you are close to the top of the list. And, be ready to go into surgery.

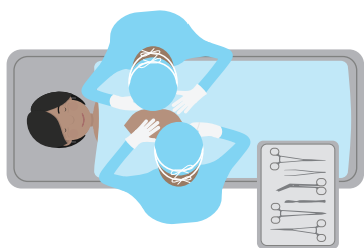
# Transplant surgery & recovery

The thought of kidney transplant surgery can be both exciting and a little scary. While kidney transplant is a serious surgery, it has a very high success rate. Let's look at how the surgery usually goes.

## The surgery:

While kidney transplant surgery is common, there are items unique to each person. Your surgeon will discuss your personal plan before the surgery. Here are the usual steps:

- When you get to the hospital, you will likely be admitted to a room.
- The hospital may do some final tests to make sure you are ready for the surgery and the kidney is the right match. It's possible that the tests show you are sick or the kidney is not the right match. If this is the case, you may be sent home and asked to wait a little longer to try again with another kidney.
- Once the hospital gets the approval to go forward with the surgery, you will be brought into the operating room/area.
- You will then be given general anesthesia and fall asleep. You won't wake up or feel anything during surgery.
- The surgeon and team will then begin your surgery.
- What the surgeon does first will depend on your situation. In most cases, the surgeon will just leave your kidneys alone.
- To add the new kidney to your body, a cut is usually made on the lower belly (abdomen).
- The new kidney is placed in your body through this opening. The kidney is then connected to your blood vessels and bladder.
- Once everything is connected, the cut is sewn up. You'll be watched closely afterwards to make sure everything is OK.
- Most surgeries take 2–4 hours to perform. Setup for surgery and the recovery may take some extra time.



## The recovery:



Many people stay in the hospital for a few days to a week after surgery. You may start making urine immediately. You may not be able to lift heavy objects or exercise hard for some time after surgery. This is usually a month or two months. Many people can return to normal activities, including work, in a month or two after.

# Life after successful transplant

Successful kidney transplant means your life is about to change. You will look and feel better. You will not need dialysis while the kidney is working. This can mean more freedom, time, and diet flexibility. But, it's not the end of your responsibilities. A new kidney should be treasured. It's a gift that needs proper care to keep working as long as possible.

## Let's look at how to care for your new kidney.

### Anti-rejection medications:



Take your anti-rejection (immunosuppressant) medications every day, or as directed. Missing even one dose may harm your new kidney. Missing many doses may cause your body to attack the new kidney and stop it from working.

### Medical conditions:



Diabetes and high blood pressure cause most cases of kidney failure. Unfortunately, these conditions also can cause transplanted kidneys to decline and fail. The key is to control these conditions as best you can. *Always*, take all of your medications as prescribed. Work with your doctor closely to keep things under control.

### Diet:



After getting a kidney transplant, your diet may be less restricted. You'll be able to eat some of the foods you've limited. However, it is best to eat a sensible, kidney-friendly diet. Some foods are better for your body than others. What you eat and drink can make a big difference in how long your new kidney lasts. Talk to your doctor about the best foods and any foods to watch out for. Follow your doctor's guidance.

Many people with kidney disease say they “wish they could go back in time and take better care of their kidneys.” When you get a kidney transplant, you have this chance. You can treat your new kidney well and keep it going as long as possible. Take this chance!



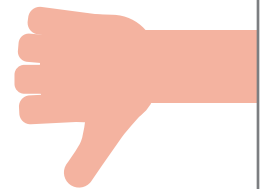
# What if the new kidney fails?

Kidney transplant surgery is usually successful. 97% of transplanted kidneys are working 30 days after surgery. However, it's possible that a surgery can fail or a new kidney does not work properly. Here is what you may expect if this happens.

## Kidney fails within 90 days:

Here are situations that fall into this category:

- The transplant surgery is unsuccessful.
- The surgery is successful but the kidney never works properly.
- The kidney starts working properly but stops working within 90 days.



When this happens, here are the usual next steps:

- You will receive dialysis to stay healthy.
- You may have the option to try for another transplant. If you do, the transplant center can work to get you back onto the transplant list.
- You may even go right back on top of the list. A new transplant could be just around the corner.

## Kidney fails after 90 days:

Transplanted kidneys can last many years, but the kidney may not work forever. When a transplanted kidney stops working after 90 days in the body, these are usually the next steps:

- You will receive dialysis to stay healthy.
- You can decide whether or not you want to go for another transplant. If you do, you will restart the transplant journey. This includes going through evaluation again at a transplant center and joining the list. The wait time for a kidney will be the same as all new patients joining the list for the first time. Remember, you can always look for a living donation which can make the wait much shorter.



Remember, 97% of transplanted kidneys are working 30 days after surgery and most last many years. But if a kidney fails, it is not the end of the road. There are options!

# Anti-rejection medications

## What are anti-rejection medications?



When you receive a kidney transplant, there will almost always be new medications you will have to take. Among these medications will likely be anti-rejection medications. These are sometimes called immunosuppressants. These medications play a critical role in keeping your new kidney healthy. They also cause changes in your body and may come with side effects. Let's look at why and how they work.

## Putting the brakes on the immune system:

Each of us has an immune system. It's the part of the body that fights off conditions like the flu, infections, and diseases. It's like our own internal army. It goes to war with anything that your body sees as a threat. Normally, this is a good thing. We want our bodies to get rid of anything that shouldn't be there.

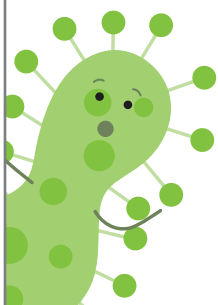


Unfortunately, the immune system can be a little too good at its job. It can see a newly transplanted kidney as a foreign invader. To deal with the invader, the body calls in the immune system to attack it. Obviously, this isn't good for your new kidney.



This is where anti-rejection medications go to work. They hide the new kidney from your immune system to limit the immune system's attacks. This lets the new kidney live in peace.

## The big side effect:



Your immune system is a very important part of keeping you healthy. Taking anti-rejection medications keeps the immune system restricted. This gives your new kidney protection. Unfortunately, it also may limit your immune system from attacking actual invaders like the flu and infections. Your doctors will work to keep your immune system balanced so it can fight off germs and diseases, but not bother your new kidney. It's a delicate balance. Your job is to take your medications on-time, every time.



If you have concerns about anti-rejection medications and possible side effects, talk to your doctor. Also, make sure to tell your doctor if any of your medications change or if you start taking any supplements.

# Understanding insurance for your transplant

Choices about our health care are some of the most important decisions we can make. As a patient, you have the right to pick the best insurance that meets your needs. Here are some health insurance basics to consider when choosing your health care plan.

## Types of health insurance:

There are different types of health insurance designed to meet different needs. The most common insurance for people with kidney disease are:



- Employer group health plans
- Individual coverage
- Medicare, including Original Medicare and Medicare Advantage
- Medicaid
- Medicare supplement plans ("Medigap")

## Considerations for choosing a health insurance plan:

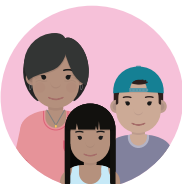
Here are some insurance-related considerations if you want to get a transplant:



- **Transplant coverage:** Make sure your plan covers transplant services and your preferred transplant center is in network. Consider what pre- and post-transplant costs and expenses for transplant-related services are not covered by insurance, as they may vary by plan. Typically, insurance pays for some, if not all, of your transplant.



- **Provider network and access:** Review the plan's provider network to ensure your preferred providers are covered. This includes your dialysis center, kidney doctor, primary care physician, and any other services you need.



- **Family vs. individual coverage:** Consider if you want insurance coverage for just yourself, or for your family members as well.



- **Prescription benefits:** Not all plans cover the same medications, so make sure to review the prescription benefits and medication list for each plan. It is especially important to check if the plan covers anti-rejection medications.

Continue on page 38

## Considerations for choosing a health insurance plan continued



- **Other benefits:** Check what other benefits are covered, such as dental and vision.



- **Out-of-pocket costs:** Review what costs will be out-of-pocket, meaning you will have to pay. This can include your deductible, coinsurance, copays and premium.



Contact your transplant center immediately if you plan to make an insurance change. That way, you will stay active on the transplant waitlist.

## Information you should know about your insurance

There are certain things about your insurance policy that you will need to know for doctors visits. Be sure to know the answers to these questions:

- What type of insurance do you have? (Employer group health plan, Medicare, Medicaid, etc.)
- Who is the policy holder? (You, your spouse, a parent, etc.)
- Where does the coverage come from? (Through active employment, retirement policy, COBRA or government insurance such as Medicare or Medicaid, etc.)



Health care decisions are some of the most important choices we make. Having an insurance plan that covers your needs and a care team that listens to your concerns are very important. Talk to your care team or transplant center if you have any questions about understanding your insurance options, coverage, or benefits.



# Notes

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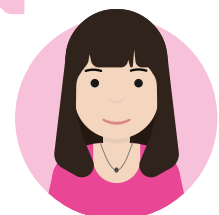
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"After getting a transplant, things start working that you forgot used to work before...I still walk on the clouds every day. It's been almost a year and a half, and I'm just so grateful."



John

"It's truly a gift to be an organ donor. I don't think that people realize the amazing gift that they're giving...we're so humbled and very blessed that John had a transplant and is doing as well as he is."



Myrna



## Transplant Smart

This workbook is for informational purposes only and is not intended to be a substitute for medical advice from a physician. Please check with a physician if you need a diagnosis and/or for treatments as well as information regarding your specific condition. If you are experiencing urgent medical conditions, call 9-1-1.