

KIDNEY TRANSPLANT

What you need to know



National
Kidney
Foundation®

#BigAskBigGive
kidney.org/livingdonation

National Kidney Foundation's Kidney Disease Outcomes Quality Initiative

Did you know that the National Kidney Foundation's Kidney Disease Outcomes Quality Initiative (KDOQI®) offers guidelines and commentaries that help your doctor and healthcare team make important decisions about your medical treatment? The information in this booklet is based on those recommended guidelines.

Stages of Kidney Disease

There are five stages of kidney disease. They are shown in the table below. Your doctor determines your stage of kidney disease, based on the presence of kidney damage and your glomerular filtration rate (GFR), which is a measure of your level of kidney function. Your treatment is based on your stage of kidney disease. Speak to your healthcare provider if you have any questions about your stage of kidney disease or your treatment.

STAGES OF KIDNEY DISEASE

Stage	Description	Glomerular Filtration Rate (GFR)*
1	Kidney damage (e.g., protein in the urine) with normal GFR	90 or above
2	Kidney damage with mild decrease in GFR	60 to 89
3a	Moderate decrease in GFR	45 to 59
3b	Moderate decrease in GFR	30 to 44
4	Severe reduction in GFR	15 to 29
5	Kidney failure	Less than 15

*Your GFR number tells your healthcare provider how much kidney function you have. As chronic kidney disease progresses, your GFR number decreases.

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About Kidney Transplantation

When your kidneys fail, treatment is needed to replace the work your own kidneys can no longer do. There are two types of treatment for kidney failure—dialysis and kidney transplantation. This brochure can help you decide if a kidney transplant is the best choice for you.

What is a kidney transplant?

When you get a kidney transplant, a healthy kidney is placed inside your body to do the work your own kidneys can no longer do. Many people feel that a kidney transplant offers more freedom and a better quality of life than dialysis.

On the plus side, there are fewer limits on what you can eat and drink, but you should follow a heart-healthy diet. Your health and energy should improve. In fact, a successful kidney transplant may allow you to live the kind of life you were living before you got kidney disease. Studies show that people with kidney transplants live longer than those who remain on dialysis.

On the minus side, there are the risks of surgery. You will also need to take anti-rejection medicines for as long as your new kidney is working, which can have side effects. You will have a higher risk for infections and certain types of cancer.

Although most transplants are successful and last for many years, how long they last can vary from one person to the next. Many people will need more than one kidney transplant during a lifetime.



What is a “preemptive” or “early” transplant?

Getting a transplant before you need to start dialysis is called a *preemptive transplant*. It allows you to avoid dialysis altogether. Getting a transplant not long after kidneys fail (but with some time on dialysis) is referred to as an *early transplant*. Both have benefits. Some research shows that a preemptive or early transplant, with little or no time spent on dialysis, can lead to better long-term health. It may also allow you to keep working, save time and money, and have a better quality of life.

Who can get a kidney transplant?

Kidney patients of all ages—from children to seniors—can get a transplant.

You must be healthy enough to have the operation. You must also be free from cancer and infection. Every person being considered for transplant will get a full medical and psychosocial evaluation to make sure they are a good candidate for transplant. The evaluation helps find any problems, so they can be corrected before transplant. For most people, getting a transplant can be a good treatment choice.



What if I'm older or have other health problems?

In many cases, people who are older or have other health conditions like diabetes can still have successful kidney transplants. Careful evaluation is needed to understand and deal with any special risks. You may be asked to do some things that can lessen certain risks and improve the chances of a successful transplant. For example, you may be asked to lose weight or quit smoking.

If you have diabetes, you may also be able to have a pancreas transplant. Ask your healthcare professional about getting a pancreas transplant along with a kidney transplant.

How will I pay for a transplant?

Medicare covers about 80% of the costs associated with an evaluation, transplant operation, follow-up care, and anti-rejection medicines. Private insurers and state programs may cover some costs as well. However, your post-transplant expenses may only be covered for a limited number of years. It's important to discuss coverage with your social worker, who can answer your questions or direct you to others who can help.

Getting a Transplant

How do I start the process of getting a kidney transplant?

Ask your healthcare provider to refer you to a transplant center for an evaluation. Any kidney patient can ask for an evaluation.

How does the evaluation process work?

Medical professionals will give you a complete physical exam, review your health records, and order a series of tests and X-rays to learn about your overall health. Everything that can affect how well you can handle treatment will be checked. The evaluation process for a transplant is very thorough. Your healthcare team will need to know a lot about you to help them—and you—decide if a transplant is right for you. One thing you can do to speed the process is to get all the testing done as quickly as possible and stay in close contact with the transplant team. If you're told you might not be right for a transplant, don't be afraid to ask why—or if you might be eligible at some future time or at another center. Remember, being active in your own care is one of the best ways to stay healthy.

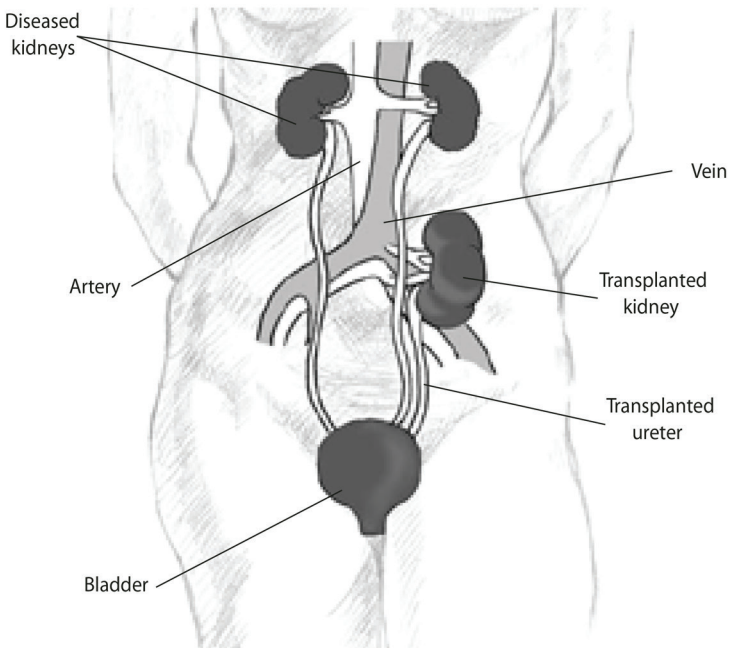
If someone you know would like to donate a kidney to you, that person will also need to go through a screening to find out if he or she is a match and healthy enough to donate.

If it's your child who has kidney disease, you'll want to give serious thought to getting a transplant evaluation for him or her. Because transplantation allows children and young adults to develop in as normal a way as possible in their formative years, it can be the best treatment for them.

If the evaluation process shows that a transplant is right for you or your child, the next step is getting a suitable kidney. (See “About Organ Donation” on page 13.)

What does the operation involve?

You may be surprised to learn that your own kidneys generally aren’t taken out when you get a transplant. The surgeon leaves them where they are unless there is a medical reason to remove them. The donated kidney is placed into your lower abdomen (belly), where it’s easiest to connect it to your important blood vessels and bladder. Putting the new kidney in your abdomen also makes it easier to take care of any problems that might come up.



The operation takes about four hours. You’ll be sore at first, but you should be out of bed in a day or so, and home within a week. If the kidney came from a living donor, it should start

to work very quickly. A kidney from a deceased donor can take longer to start working—two to four weeks or more. If that happens, you may need dialysis until the kidney begins to work.

After surgery, you'll be taught about the medicines you'll have to take and their side effects. You'll also learn about diet. If you've been on dialysis, you'll find that there are fewer restrictions on what you can eat and drink, which is one of the benefits of a transplant.

What are anti-rejection medicines?

Normally, your body fights off anything that isn't part of itself, like germs and viruses. That system of protection is called your *immune system*. To stop your body from attacking or rejecting the donated kidney, you will have to take medicines to keep your immune system less active (called *anti-rejection medicines* or *immunosuppressive medicines*). You'll need to take them as long as your new kidney is working. Without them, your immune system would see the donated kidney as "foreign," and would attack and destroy it.

Anti-rejection medicines can have some side effects. It is important to talk to your healthcare provider about them, so that you know what to expect. Fortunately, for most people, side effects are usually manageable. Changing the dose or type of medicine can often ease some of the side effects.

Besides the immunosuppressive medicines, you will take other medicines as well. You will take medicines to protect you from infection, too. Most people find taking medicines a small trade for the freedom and quality of life that a successful transplant can provide.

IMPORTANT REMINDER

You must not take any medicine or nutritional supplement that is not approved by your transplant team because of the risk of interaction with your anti-rejection medicines.

After Your Transplant

What happens after I go home?

Once you are home from the hospital, the most important work begins—the follow-up. For your transplant to be successful, you will have regular checkups, especially during the first year. At first, you may need blood tests several times a week. After that, you'll need fewer checkups, but enough to make sure that your kidney is working well and that you have the right amount of anti-rejection medication in your body.

What if my body tries to reject the new kidney?

One thing that you and your healthcare team will watch for is *acute rejection*, which means that your body is suddenly trying to reject the transplanted kidney. A rejection episode may not have any clear signs or symptoms. That is why it is so important to have regular blood tests to check how well your kidney is working. Things you might notice that can let you know you are having rejection are fevers, decreased urine output, swelling, weight gain, and pain over your kidney.

The chances of having a rejection episode are highest right after your surgery. The longer you have the kidney, the lower the chance that this will happen. Unfortunately, sometimes a rejection episode happens even if you're doing everything you're supposed to do. Sometimes the body just doesn't accept the transplanted kidney. But even if a rejection episode happens, there are many ways to treat it so you do

not lose your transplant. Letting your transplant team know right away that you think you have symptoms of rejection is very important.

How often do rejection episodes happen?

Rejections happen much less often nowadays. That's because there have been many improvements in immunosuppressive medicines. However, the risk of rejection is different for every person. For most people, rejection can be stopped with special anti-rejection medicines. It's very important to have regular checkups to see how well your kidney is working, and make sure you are not having rejection.



When can I return to work?

How soon you can return to work depends on your recovery, the kind of work you do, and your other medical conditions. Many people can return to work eight weeks or more after their transplant. Your transplant team will help you decide when you can go back to work.

Will my sex life be affected?

People who have not had satisfactory sexual relations due to kidney disease may notice an improvement as they begin to feel better. In addition, fertility (the ability to conceive children) tends to increase. Men who have had a kidney transplant have fathered healthy children, and women with kidney transplants have had successful pregnancies. It's best to talk to your healthcare practitioner when considering having a child.

Women should avoid becoming pregnant too soon after a transplant. Most centers want women to wait a year or more. All pregnancies must be planned. Certain medications that can harm a developing baby must be stopped six weeks before trying to get pregnant. Birth control counseling may be helpful. It's important to protect yourself against sexually transmitted diseases (STDs). Be sure to use protection during sexual activity.

Will I need to follow a special diet?

In general, transplant recipients should eat a heart-healthy diet (low fat, low salt) and drink plenty of fluids. If you have diabetes or other health problems, you may still have some dietary restrictions. A dietitian can help you plan meals that are right for you.

About Organ Donation

Where do donated kidneys come from?

A donated kidney may come from someone who died and donated a healthy kidney. A person who has died and donated a kidney is called a *deceased donor*.

Donated kidneys also can come from a living donor. This person may be a blood relative (like a brother or sister) or non-blood relative (like a husband or wife). They can also come from a friend or even a stranger.

When a kidney is donated by a living person, the operations are done on the same day and can be scheduled at a convenient time for both the patient and the donor. A healthy person who donates a kidney can live a normal life with the one kidney that is left. But the operation is major surgery for the donor, as well as the recipient. As in any operation, there are some risks that you will need to consider.

Is it better to get a kidney from a living donor?

Kidneys from living or deceased donors both work well, but getting a kidney from a living donor can work faster and be better. A kidney from a living donor may last longer than one from a deceased donor.

To get a deceased donor kidney, you will be placed on a waiting list once you have been cleared for a transplant. It can take many years for a good donor kidney to be offered to you. From the time you go on the list until a kidney is found, you may have to be on some form of dialysis. While you're waiting, you'll need regular blood tests to make sure you are ready when a kidney is found. If you're on dialysis, your center will make the arrangements for these tests. Your

transplant center should know how to reach you at all times. Once a kidney become available, the surgery must be done as soon as possible.

Are there disadvantages to living donation?

A disadvantage of living donation is that a healthy person must undergo surgery to remove a healthy kidney. The donor will need some recovery time before returning to work and other activities. However, recent advances in surgery (often called *minimally invasive* or *laparoscopic surgery*) allow for very small incisions. This means shorter hospital stays and recovery time, less pain, and a quicker return to usual activities. Living donors often experience positive feelings about their courageous gift.

What are the financial costs to the living donor?

The surgery and evaluation is covered by Medicare or the recipient's insurance. The living donor will not pay for anything related to the surgery. However, neither Medicare nor insurance covers time off from work, travel expenses, lodging, or other incidentals. The National Living Donor Assistance Program (livingdonorassistance.org) or other programs may help cover travel and lodging costs.

Donors may be eligible for sick leave, state disability, and benefits under the federal Family Medical Leave Act. In addition, federal employees, some state employees, and certain other workers may be eligible for 30 days paid leave.

Finding a Living Donor

How do I ask someone to consider donating a kidney to me?

Asking someone to donate a kidney to you can feel scary and overwhelming. You may be asking yourself, “Where do I start? How do I ask?” Here are some suggestions to help make it easier for you.

Learn All You Can.

The first step is to learn as much as you can about living kidney donation and transplant. This will help you explain it to your friends and family. You may want to let people know that there’s no cure for kidney disease and tell them about your options for treating your condition.

Sharing as many facts as you can, along with your thoughts about your condition and treatment options, is one way to open a conversation.

A friend or family member might be willing to help you talk to others about your needs—don’t be afraid to ask! This may relieve some pressure of having to ask people directly. Discussing your need for a kidney in everyday conversation helps get the word out—and makes people more comfortable asking you questions about your health. Go to [**www.kidney.org/livingdonation**](http://www.kidney.org/livingdonation)

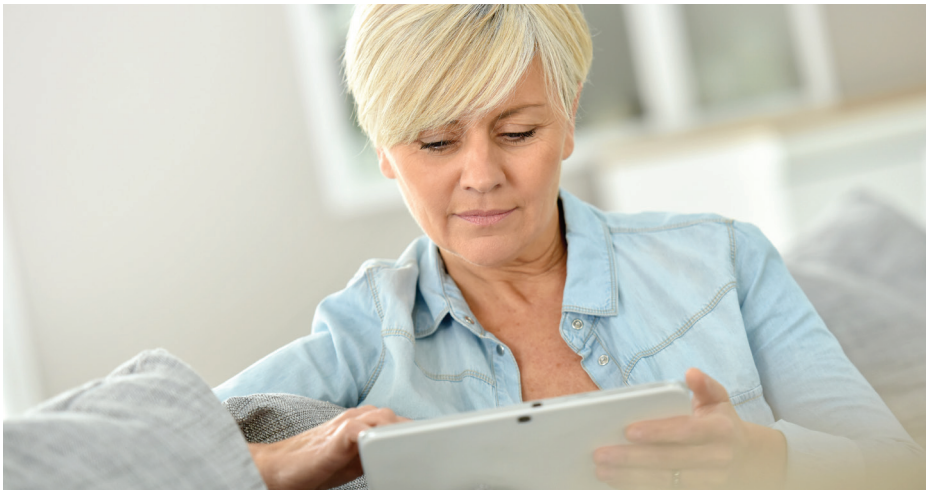
Raise Awareness—Share Your Story!

Sharing your story is very important. You should speak from the heart, and tell people as much as you can about kidney disease. If you are on dialysis, you could include details about what a typical week is like for you on dialysis, the complications caused by kidney disease, and why a transplant is a better long-term option for you. Remember, no one will offer to help unless they understand the need.

As you share your story and describe what it's like to live with kidney disease, try to be open and honest about your situation and your feelings.

In sharing your story, you might be fortunate enough to get offers from people who are willing to be tested as a match. Accepting such a big gift may feel difficult, but keep in mind that potential donors are screened carefully to make sure they are healthy enough to donate and are doing it for the right reasons.

If there are no potential donors within your family or friends, you should widen your search. Think about your relationship to your community. Do you belong to a religious organization or community center? Would your employer help (sending a company-wide email, for instance, to let people know you're waiting for a transplant)? People have been known to find a living donor where they least expected it, such as a high school reunion or school event. You never know when you might cross paths with someone who could be a match and is willing to donate!



Use Technology.

From email to social media, it's easy to connect with people outside of your closest family and friends. For example, you could send an email to all your contacts, sharing your story, and encourage to spread the word by forwarding it to people they know.

Social media is another great tool that shouldn't be overlooked. You can write a message that tells your story and can easily be shared. Even if you do not find a potential donor, you are still raising awareness about kidney disease and the need for organ donors, which is an important message that needs to be heard.

Be Cautious.

It takes bravery to ask for a kidney on social media or in any public forum. At the same time, it can be scary to reveal very personal details about your life and health.

Be careful and use common sense. Ask your transplant center for advice. Don't put yourself in a vulnerable situation where someone can try and take advantage of your situation. The issue of buying and selling organs may come up. This practice has been illegal in the U.S. since 1984, when it was outlawed by the National Organ Transplant Act.

Handling Responses.

Asking for a kidney takes courage, and you may feel disappointed when someone doesn't offer or says no. Remember, this does not mean the person does not love you or care about your circumstances. Most likely, the reasons why someone doesn't donate may have nothing to do with you. It may not be the right decision at the right time

for them. Moving on may feel challenging for you, but it's important to focus on finding someone who is willing and ready to be your donor.

It can be equally challenging to accept when someone says yes. It can feel overwhelming to realize that your potential donor is willing to sacrifice a kidney for you. Be gracious and express your gratitude, regardless of whether it works out after testing or not.



How can I overcome my fear of asking for a kidney?

Asking someone to consider kidney donation may be one of the hardest questions you ever face. You may be reluctant for any number of reasons; however, you may also be surprised by how many people are willing to learn more about the process and go forward with testing.

The National Kidney Foundation did some research to learn what held most people back from asking. Here's what our members told us—along with some tips to overcome these barriers.

“I am afraid that my donor’s health will suffer.”

People who choose to become kidney donors are usually much healthier than the general population. Potential kidney donors are evaluated carefully (both physically and mentally) before they're able to donate. Research shows that, as with any surgery, there is a small risk of complications for the donor. You can learn more about the potential risks at [kidney.org](https://www.kidney.org). To donate a kidney to a loved one, friend, or even a stranger, is truly to give the gift of life. Living donation can be a positive experience for both the giver and the receiver. Typically, people who donate kidneys report they would do so again.

“I am afraid that medical bills and time off from work will cause a financial hardship for a potential living donor.”

Generally, if the donation is to a family member or friend, the recipient's insurance, Medicare, or a combination of both, will pay for testing and surgery expenses. However, the donor might be responsible for travel expenses (if the donor and recipient live in different states or towns) and follow-up care, in addition to lost wages from taking time off work. If you have questions about the costs associated with donation, ask the financial counselor or social worker at the transplant center for help.

Donors may be eligible for sick leave, state disability and the Family and Medical Leave Act (FMLA). The National Living Donor Assistance Program provides financial assistance to

those who want to donate an organ but are not able to afford the travel and living expenses associated with donation. (To learn more about financial issues, see page 6.)

“I do not like to ask anyone for anything.”

Asking for help can be daunting to some, but you can start by telling your story. This opens the lines of communication. Many people in your circle may not know about your condition or that being a living kidney donor is even an option. By starting a dialogue and educating those around you, you may find that many people will ask how they can help.

Ask your family and friends to spread the word. It's important to keep your options open as you never know when a potential donor is going to walk through the door!

How do I write a letter or email to my friends and family?

One way to spread the word is to share your story by letter or email. Here are some tips for writing to your friends, family, or community:

- Make it personal; tell *your* story (what is treatment like, how do you feel).
- Use information on kidney.org to include facts on kidney disease, living donation, and transplant.
- Invite people to learn more and provide contact details.
- Ask your transplant center if they want their contact number posted in your letters. They may have a special line, or prefer that people call you first.

Sample letter

Dear Friends,

Some of you may know that I have kidney disease. Over time, my kidney disease has gotten worse, causing my kidneys not to work well enough to keep me alive. This is what I am facing now, and my treatment options are limited to dialysis treatments or a kidney transplant.

Getting regular dialysis treatments, usually three times a week for four hours at a time, will help my kidneys do their job and keep me alive, but a transplant would offer me more freedom and the ability to live a longer, healthier, more normal life. A transplant would also give me more time to do the fun things I enjoy most, like spending time with my family and friends.

However, finding a kidney for a transplant is not easy. Just ask the 100,000+ people on the waiting list for a deceased donor kidney like me. Time is not on our side. Some wait for years; many die while waiting. The average wait time is five years or more for a kidney from a deceased donor. However, there is another option: receiving a kidney from a living donor.

Asking a family member or a friend to consider donating a kidney to me is difficult, but it greatly improves my chances of getting a transplant. A living kidney donation typically lasts longer and has better function.

You might not know a lot about living donation—I know I didn't before kidney disease affected my life. Understandably, some people are afraid about the surgery and what living with one kidney will mean for them.

Here's some basic information about kidney donation:

- You only need one kidney to live a healthy, long life.*
- Most donor surgery is done laparoscopically, meaning through tiny incisions.*
- The recuperation period is usually fairly quick (generally two weeks).*
- The cost of your evaluation and surgery will be covered by my insurance. The hospital can give you extensive information on this.*
- You will have a separate team of healthcare professionals to evaluate you as a living donor. Their job is to help you understand the risks and benefits and look out for YOUR best interests.*



You can also learn more about living donation on the National Kidney Foundation (NKF) website: [kidney.org/livingdonation](https://www.kidney.org/livingdonation) or by contacting the NKF's free, confidential helpline at **844.2BIGASK** (844.224.4275) or bigask@kidney.org. If you want to talk to someone who's already donated a kidney, NKF can also help.

Thank you for taking the time to read my story. If donating a kidney to me is something you would like to consider, I would be happy to tell you more about my story and explore the process of determining if you are a match for me. You can also contact my transplant center directly at _____.

However, I know living donation may not be right for everyone—but you can still help! Consider being an organ donor after death, and help me by sharing my story with everyone you know. At the very least I want to bring awareness of kidney disease and living donation. I am hopeful my efforts will help me receive a kidney sooner and encourage others to consider helping the many people on the wait list.

Thank you, (your name)



Five Ways to Inspire Living Kidney Donation

By Risa Simon, Author, Shift Your Fate

It takes courage to ask others for help—and there’s no bigger thing to ask for than a kidney. The mere thought can put you outside your comfort zone.

Begin by sharing your story. If you don’t feel comfortable telling your story, consider having a family member or friend become your donor advocate to help you spread the word and raise awareness about living donation and your need for a kidney.

It may also help to share with people that the need for kidneys is nationwide. Let it be known that over 100,000 people wait alongside you for a deceased donor’s kidney.

By making the message bigger than yourself, you are creating an opportunity to help more people by educating the public, while potentially finding a willing donor.

Cultivate the call to action by describing how kidneys from living donors offer better outcomes and a life-saving alternative to the long, uncertain wait. More people may be willing to consider living donation if they are aware of the need, process, risks and benefits of living kidney donation.

Your job is to enlighten as many people as possible without pressuring someone to feel that they “have to” do something. The objective is pure and simple: To create interest and awareness in this altruistic path. If you’re asking for anything, you’re asking people to consider becoming your donor advocate by increasing awareness. The more people that increase awareness about living kidney donation, the greater the potential for saving lives.

It may be difficult, but try your best to remain emotionally neutral to the different types of responses you’ll receive. Do not be surprised if some individuals act as if they’re going to help you, but never follow through. There may be overzealous offers from individuals who think they can help you, but can’t. You might also observe a lack of interest from individuals who assume they cannot help you, though they actually could. This can be difficult to witness; however, living donation is a choice that people must make for themselves. The best you can do is to provide information about living donation and your personal experience with kidney disease.

It's important to remember that individual responses are not a reflection of how much someone cares about you. Recognize that living kidney donation isn't for everyone. It takes a very special person to step up, and an extremely healthy person to pass the qualification process. Don't take responses personally. Your ideal donor is out there. They just need to be exposed to this extraordinary opportunity to help.



Where can I find more information?

The National Kidney Foundation

844.2BIGASK (844.224.4275) | bigask@kidney.org

kidney.org/livingdonation

NKF Cares

The National Kidney Foundation offers a toll-free patient help line for people affected by kidney disease, organ donation, or kidney transplant. Patients, families, and caregivers can speak with a trained specialist who will help answer questions and listen to concerns. You can also find free publications and other resources by calling, emailing, or visiting the website.

NKF Peers

Preparing for and having a kidney transplant is associated with a range of questions and emotions. You can talk to a peer mentor who has been in a similar situation by contacting NKF Peers. Call 855.NKF.PEER (855.653.7337) or email nkfpeers@kidney.org to find out more. If you are considering donating a kidney, you can be connected with a living donor.

Transplant Council

Membership in NKF's Transplant Council is free and open to those who have received organ transplants, as well as their families and friends. Membership benefits include: a voice in legislative and public policy issues affecting transplant recipients; information on other NKF programs and services of interest to transplant recipients.

The Big Ask: The Big Give

A free, educational initiative that teaches kidney patients in need of a transplant how to ask their friends and loved ones to consider living organ donation. It provides factual, unbiased information that addresses many common concerns, and offers support to those who are making a decision about living kidney donation. Contact NKF or visit kidney.org/livingdonation for more information.

The **National Kidney Foundation** (NKF) is the largest, most comprehensive and longstanding, patient centric organization dedicated to the awareness, prevention and treatment of kidney disease in the US.

Help us fight kidney disease. Learn more at [kidney.org](https://www.kidney.org)



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