

Seeking a Kidney Transplant?

How to start & what to know

By Lori Hartwell

If you have decided to explore the possibility of a kidney transplant, congratulations! That is a wonderful goal. However, pursuing a transplant is a process, and that process takes time, preparation, planning, and patience. It is real work! Here are some tips to help you navigate the process more easily.

1

Get a referral to a transplant center

If you want to receive a transplant, you can either ask your nephrologist for a referral, or refer yourself.

For some people, a diagnosis of kidney failure can lead to a direct referral for transplantation. But there are many who are either not identified as early prospects for a transplant, are just not told about this option, or have underlying health issues that prevent it. If you are dealing with kidney failure as a chronic condition, ask your doctor for a referral to a transplant center. If your doctor does not refer you, you can self-refer to a transplant physician or center. Find the transplant center nearest you and visit their website for details on how to set up an appointment.

You can get on a transplant wait list at multiple centers – it's called "multiple listing" – but be aware that you may incur additional costs for testing and evaluation. Also, matching kidneys are offered first to local residents, then regional residents, and then made available nationally. The only exception to this is if the kidney is a six-antigen (or "perfect") match.

2

Find a transplant center that meets your needs

A transplant center needs to work with your insurance, and understand your transportation, communication, and follow-up needs. There are over 250 kidney transplant programs in the United States. The one closest to you might be across a state line and have different insurance requirements. Or the one that works best with your insurance might be further away. Make sure you understand your insurance benefits and your own financial picture. These will be thoroughly evaluated by the center.

Transportation is a big factor. You'll need to get to and from the center several times before and after your transplant. How will your distance from the center affect you if a kidney becomes available there? Some centers provide tips on transportation resources or places to stay if you need lodging. Ask where you should park as well as this can be very costly! Work this out ahead of time.

How does the center communicate with clients? Will its primary method work for you? Follow-up is vital both while waiting for and living with a transplant. Be sure to ask who to contact if you have questions.

3

Get your medical records in shape

You need to be in good physical and mental shape to qualify for a transplant. Each transplant center has its own set of requirements. Find out what they are and try to get any tests you need before your initial transplant evaluation.

Among the standard requirements are dental health, gender-specific check-ups (gynecological or prostate), colonoscopy, and blood tests. Let your dentist and doctor(s) know that your medical records will be requested because you are seeking a transplant. The center will also evaluate your ability to care for yourself.

Some problems that will keep you from being approved include other serious health conditions, drug or alcohol abuse, untreated mental health disorders, a history of missing treatment sessions or not taking medications as prescribed.

If you do your best yet are still not accepted by a particular center, you can apply to another one and get a second opinion.



4 Know what questions to ask

Your initial evaluation will be a long appointment and you will see several people: a social worker, transplant nephrologist, a transplant coordinator, medical staff, and specialists.

Prepare in advance by making a list of questions to ask. At the appointment, make sure you get answers to all your questions. You are making a big decision, and you need to feel comfortable about every aspect. Most transplant centers allow time for your questions, so do not be shy! See the list of questions on this page you may want to ask.

5 Ask someone to help you navigate the process

Take a trusted care partner along to your initial evaluation. It is going to be a long appointment as specialists and other members of the transplant team do physical examinations and ask you questions. A friend or family member can take notes and remind you of questions you want to ask. Select this person carefully – you will need personal support throughout the transplant process. When you get the call that your kidney is ready, this person should know what needs to happen and be ready to assist you.

6 Be patient, proactive, and flexible

If you pass all the transplant center's tests, you will be placed on the United Network for Organ Sharing (UNOS) transplant list. This triggers a notification to your health insurance provider that requires them to pay for your transplant (also your living donor if you have one). From this point on, you will hold tight and wait. Many transplant centers have educational materials, professional staff, and resources to help you through this time. Some centers will connect you with mentors who have been through the process.

Let your workplace know that you may be called on a moment's notice. Keep your cell phone charged and answer any number you may not recognize. Be sure to put the transplant center number in your phone for easy identification. Stay current on all your medical tests, transplant center blood tests, and other requirements.

You will be able to expedite getting a kidney if a family member or friend is able to donate and is a good match. Your insurance pays all the costs for living donor medical care. Studies show that people do better when they receive a live donor's kidney. The living donor has thorough medical testing and exams to ensure they are in good health and can donate. If you want to seek a living donor, look into Renal Support Network's Share Your Spare conversation kit to help break the ice. If you have a donor and they are not a match, look into paired kidney donation or exchange programs.

Explore Renal Support Network's online support groups and many resources on kidney transplantation. You are part of a community!

Questions to Ask Your Transplant Center

1. How often will you need to do blood tests to check for possible cross-matches prior to a transplant?
2. How will I know when I am listed and active on the waiting list?
3. How long is the average wait for an available kidney in my area? Are there any factors that affect this wait time?
4. How will you notify me if a kidney becomes available?
5. How much time do you allow for travel to the transplant clinic after notifying me of an available kidney? (Ask this if you do not live close by, or need to fly there.)
6. Will there be physical restrictions after I am discharged, such as driving or doing other physical tasks? How long will I need assistance with these things?
7. How many hours is the surgery and will I be given pain medication?
8. How long will I be in the hospital and can I have visitors?
9. How long will I need to be off work or need help?
10. What medications will I need to take? If my insurance does not offset the cost, are there grant programs to help me pay for them?
11. What updates and information do you need from me once I am accepted?
12. How will you communicate with me on the status of my eligibility? For instance, what else I may need to do, whether I am currently active, or how I get back on the list if I am taken off due to illness? (NOTE: Make sure you tell them your full medical history, because if they find out something you did not tell them, you will have to do additional tests and evaluations.)
13. After I get transplanted, what is the process and schedule for both short term and long-term follow-up? How often, and for how many months, do I need to come for follow-up appointments?
14. Do you perform living donation or paired-exchange transplants?
15. If I have a potential living donor, what do they need to do?
16. How do you bill for your services and work with my insurance provider? (Make sure you get ALL your financial questions answered!)
17. Are there nearby places to stay that have discounted rates for your clients and accompanying family members?
18. If you decide not to accept me for any reason, how can I go about requesting a re-evaluation? Where else could I apply?

