

# KIDNEY TRANSPLANT 101

A Starting Point for Patients Considering Kidney Transplant

## What is Kidney Transplant?

Your kidneys filter waste from your blood and pass that waste to the bladder to be removed as urine. Kidneys also help regulate blood pressure, as well as many other things. When disease or injury damages your kidneys to the point that they are no longer working, you may want to consider a kidney transplant.

In kidney transplant surgery, a healthy donor kidney is implanted into your body. Your transplanted kidney will do the work your existing kidneys no longer do. The donor kidney comes from a person who has made the decision to become an organ donor. Deceased kidney donors must register to be an organ donor before they die. A living person may also donate a kidney. Living donation is possible because the body only needs one healthy kidney to thrive.

This is a major surgery for the recipient and any potential living donor. Extensive testing of your physical and mental health is necessary before a kidney patient or potential living donor is approved to move forward in the transplant process.

## What Happens After Transplant?

Benefits	Risks
<ul style="list-style-type: none"><li>• Studies show that people with kidney transplants live longer than those who stay on dialysis.</li><li>• After a transplant, kidney recipients generally have more freedom to enjoy the life they had before starting dialysis.</li><li>• Kidney recipients have more flexibility about what they can eat or drink within a healthy and balanced diet.</li><li>• The median (or middle average) life of a transplanted kidney from a deceased donor is 8-12 years. Living donor kidneys typically last 15-20 years.</li><li>• Taking medicines as directed and maintaining a healthy lifestyle can extend the use of your transplanted kidney.</li><li>• Some transplanted kidneys from both living and deceased donors have lasted 30+ or even 50+ years.</li></ul>	<ul style="list-style-type: none"><li>• Kidney transplant is a major surgery with long term health impacts.</li><li>• You may need more than one kidney transplant during a lifetime. Each time, you must go through the full evaluation process.</li><li>• Anti-rejection medicines can have side effects, which are usually manageable, including a higher risk for infections and certain types of cancer.</li><li>• Stopping or missing your anti-rejection medicines can cause your immune system to attack the new kidney and may lead to dialysis or kidney failure.</li></ul>

### What is Rejection and Why Does it Matter?

- Kidney rejection happens when your immune system attacks your transplanted kidney. This damages the new kidney leading to possible kidney failure and dialysis.
- After the transplant, you will need to take anti-rejection medicines, also called immunosuppressants, for as long as you have your new kidney.
- You should never stop taking your anti-rejection medicine no matter how good you feel. You must take them even if you think your transplanted kidney is working well.
- Taking your medicine as directed, and discussing any side effects with your doctor, can extend the life of your new kidney.

# Understanding the Transplant Process

## Referral

- Talk to your doctor about a kidney transplant if you have chronic kidney disease, have been told that your kidney disease is getting worse, or if you are currently (or or likely to become) a dialysis patient.
- Your doctor or dialysis social worker can refer you to a transplant center; you may also reach out to a transplant center yourself.
- You can start the conversation!**

## Screening (Intake)

- The screening or intake process varies by transplant center.
- Generally, you will start on the phone with one or more calls from an intake coordinator. You will likely fill out a questionnaire and forms with basic health information.
- The transplant center will check coverage options with your insurance.
- Stay on track by answering calls and returning forms promptly!**

## Evaluation

- A series of tests will determine if you are ready for all parts of a kidney transplant. This includes the surgery, recovery, and taking care of your new kidney.
- You will spend 1-2 days at the transplant center for evaluation. They will check your medical history, physical and mental health, and compatibility tests to match you to a kidney donor.
- Your personalized testing will be based on your individual risks and chosen transplant center.
- You may need to schedule some tests outside of the transplant center.
- Schedule tests as soon as you can and arrive early for appointments!**

## Approval

- The transplant team will meet to discuss your results and determine if you are a candidate for transplant. You may be approved, denied, or advised on other next steps.
- If approved, you will be added to the kidney waiting list. The wait for a deceased donor is based on many factors including how long you have been on dialysis, where you live, and your blood type. The average wait in Wisconsin is 3-5 years.
- Answer your calls and return messages!**

## Waiting

- Surgery for living kidney donation is scheduled in advance. Deceased kidney donation is based on when a kidney becomes available; you may have only a few hours to go to the hospital.
- While waiting, you may search for a living kidney donor.
- You must maintain contact with your transplant center, monitor your health, and be ready for the call when a kidney is available.
- Stay as healthy as you can and keep in touch with your transplant center!**

## Surgery

- Kidney transplant surgery generally takes 3-4 hours.
- The donated kidney is placed into your lower abdomen (belly area), where it is easiest to connect it to your blood vessels and bladder.
- Immediately after your surgery, you will be sore. Depending on how you feel, you may be able stand or walk the same day.
- You will stay at the hospital for a few days to be sure that your new kidney is working and you are on the path to recovery.
- Arrive on time and talk to your health team!**

## Follow-up and Recovery

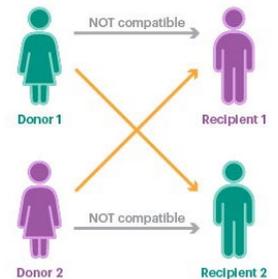
- This is a major surgery. Your body will need time to recover. You will need a support person (or people) at home to help you through the first few weeks.
- You will have limits on what you can lift and how active you can be for several weeks. You may feel tired for longer as your body heals.
- After your kidney transplant is complete you will start on anti-rejection medicine, also called immunosuppressants.
- You will have many appointments at your transplant center following your surgery. Over time, these appointments will be less frequent.
- Stay on top of taking your medicines and scheduling appointments!**

## Tips for Success

- **Be Easy to Reach** – You are going to get a lot of calls and messages during this process. Set up your voicemail and learn to use your health messaging apps (LiveWell/MyChart/etc.) with your transplant center. Check your messages often and open your mail. Being responsive and returning forms on time will keep the process on track.
- **Keep Good Notes** – Use a notebook or digital file to write down your questions or concerns. Bring that list to appointments and take notes during your appointments. A trusted support person can come with you or call in on your cell phone to help you take notes.
- **Talk to Your Team** – Always tell your transplant center about changes in your health as you go through this process. Make sure that your dialysis center and doctors know that you are working with a transplant center and how to reach your transplant team.
- **Know Your Costs** - The financial coordinator at the transplant center will check your insurance coverage for transplant. Ask what your insurance company covers and what you are responsible for paying including co-pays and deductibles.
- **Take Healthy Steps** – Do what you can to keep (or get) your body well enough for surgery. Take medicine or treatments as directed, eat a kidney-friendly diet, be as active as you can, and keep up with routine medical care like vaccines and going to the dentist. Quitting smoking and managing your weight are part of being healthy enough for a kidney transplant.

## Did You Know?

- **You can be evaluated for a kidney transplant at more than one center.** This is true even if you have been denied for transplant by a different center. Each transplant center has its own requirements. Asking about those requirements early in your transplant process can help you choose the best center(s) for you.
- **Living donors have few out-of-pocket expenses.** The recipient's health insurance typically covers medical expenses for living donors. All transplant centers in Wisconsin participate in DonorShield. This is a program of the National Kidney Registry. DonorShield offsets lost wages, travel costs and other non-medical expenses. Wisconsin also offers living donors a state tax credit of up to \$10,000.
- **You do not need a perfect match to find a living kidney donor.** Through paired exchange programs, including the National Kidney Registry, living donors and transplant candidates are matched with others around the country based on kidney compatibility. When your paired donor gives their kidney, it goes to the best possible match for that kidney. In exchange, you are matched with a living donor who is the best match for you.



## Questions to Explore with Your Healthcare Team

- Is my kidney disease getting worse? Can you explain my labs?
- When will we talk about my treatment choices, including kidney transplant?
- Do you think kidney transplant could be a good option for me? What about living donation?
- Can you tell me more about life on dialysis vs. life with a transplant, based on my health?
- Share what a good or “normal” life looks like to you – what do you care about? What is most important to you? This can help you make shared decisions with your doctor about your treatment.

### National Kidney Foundation

#### Patient Support Line

855.NKF.CARES (855.653.2273)

#### Transplant Resources

[www.kidney.org/transplantation](http://www.kidney.org/transplantation)

### Local Programs and Events

#### National Kidney Foundation of WI

414.897.8669 or [info@kidneywi.org](mailto:info@kidneywi.org)

# Find a Living Kidney Donor

## Start a Conversation

Many people are not comfortable asking someone to donate a kidney. You may find it easier to share how you've been doing. Say that you need a kidney transplant, and that your doctors have said a living donor kidney is the best option for you. If someone is interested in getting evaluated for living donation, or wants to learn more, you can point them to a trustworthy source, like National Kidney Foundation or your transplant center.

## Seek Out a Champion

You don't have to do this alone. Family and friends who may not be able to donate themselves are often the best champions for transplant candidates seeking a living donor. Sharing your story is an easy way for loved ones to support you. The more people that know you are in need, the more likely it is that someone will come forward to be your living donor.

A good place to start the conversation is with family and friends. As you feel comfortable, you can share with a wider audience. You may want to include:

- Co-workers, community organizations, and social groups
- People who belong to your place of worship
- Local newspapers or magazines
- Social media to share your story

## Things to Keep in Mind

- Many people are unaware that one healthy kidney is enough to live a healthy life. You can direct them to trustworthy websites, like the National Kidney Foundation and your transplant center, for unbiased information and next steps.
- Only a transplant center can determine if somebody is able to donate a kidney. Interested living donors go through many tests to be sure they are physically and emotionally ready to donate an organ. The process is similar to your evaluation as a transplant candidate. There is no limit on the number of potential living donors who can be evaluated on your behalf; however, each transplant center is different on how many potential living donors can be in process at the same time.

## Benefits of Finding a Living Kidney Donor

1. Kidneys from living donors typically (median average) last for 15-20 years. One Wisconsin recipient has had the same living donor kidney since 1966.
2. A kidney from a living donor usually works immediately because the kidney is out of the body for a short time. This is not always the case for deceased donor kidneys.
3. A donor's blood type and compatibility don't matter. Kidney exchange programs are available to help match incompatible pairs.

## Additional Resources

National Kidney Foundation		Local Programs and Events
<b>Patient Support Line</b> 855.NKF.CARES (855.653.2273)	<b>Transplant Resources</b> <a href="http://www.kidney.org/transplantation">www.kidney.org/transplantation</a>	<b>National Kidney Foundation of WI</b> 414.897.8669 or <a href="mailto:info@kidneywi.org">info@kidneywi.org</a>