

# UNDERSTANDING KIDNEY TRANSPLANTATION





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## WHAT IS CHRONIC KIDNEY DISEASE (CKD)?

When someone has CKD, it means that their kidney function has slowed down. These changes usually take place over time. There are a variety of diseases or conditions that can lead to CKD. Two of these are diabetes and high blood pressure. A lot of people have those diseases and are at risk for CKD. Other diseases present at birth can cause CKD. Examples are *Polycystic Kidney Disease*, *Fabry Disease*, *Alport Syndrome* among others.

There are five stages of CKD. The stages show how well the kidneys are doing their job. Your healthcare provider can do a blood test to see what stage you are in. In Stage 1 there is very little kidney damage. By Stage 5 the kidneys will have lost most of their function. CKD Stage 3 or 4 is a good time to learn more about your treatment options. Ask your healthcare provider to help you with this. They can help you decide the type of treatment that will be the best for you. You and your healthcare team can work together to slow down the progression of CKD.

## TREATMENT OPTIONS FOR KIDNEY FAILURE?

There are four types of treatment:

- Hemodialysis (HD)
- Peritoneal dialysis (PD)
- Kidney transplant
- Medical management

Most people on HD or PD can consider getting a kidney transplant. Some in CKD Stage 4 or 5 may be able to get a transplant and not have to go on any type of dialysis.

This brochure will help you learn more about the option of kidney transplantation.

## KIDNEY TRANSPLANTATION

There is a national transplant waiting list for people who are waiting for all types of transplants. Every 10 minutes, a new person is added to the list. Most of the people on the list are waiting for a kidney transplant. How long one has to wait is different for each person. The average time to wait for a kidney is 3-5 years. For some it might be shorter and for others it might be longer.

You should ask your kidney care team to tell you about kidney transplant. If you think this might be right for you, ask them to send you to a transplant center. Some insurers only cover transplants at a center they approve. You will need to check with them to find out what centers they will approve. If you are on dialysis, ask the social worker to help you with this. You can use the internet to find out where the transplant centers are. Here are two links you may find helpful: [www.optn.transplant.hrsa.gov](http://www.optn.transplant.hrsa.gov) and [www.srtr.org](http://www.srtr.org).

Some things for you to think about before choosing a transplant center:

- Will you be able to go back and forth to your appointments?
- Will you be able to get to the transplant center when they have a kidney for you?
- Will they take your insurance?
- What are the transplant outcomes at this center?

When you go to the transplant center, the transplant team will tell you what comes next. If you want to get a transplant, they will start the transplant evaluation. The team may decide that you need additional tests.

The evaluation can take several months. This is not uncommon so don't give up. After everything is done, the team will tell you if you can go onto the transplant list.

People on the transplant list get kidneys from a person who has died and donated their organs.

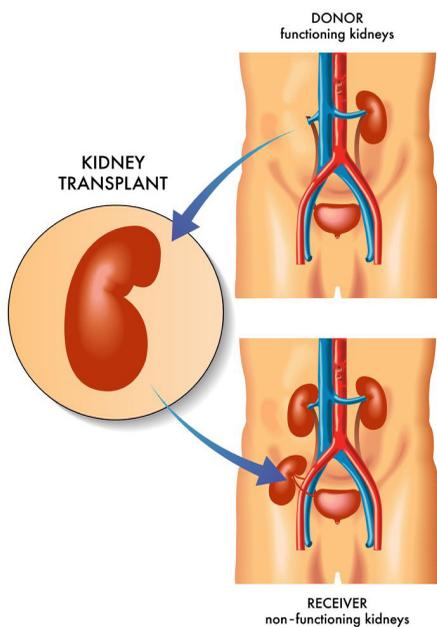
There are a lot of things that go into deciding who will get a kidney. Some are:

- Your blood type
- How long you have been on dialysis
- How healthy you are when you are called in for a transplant
- How close you live to the transplant center

National transplant policy allows a patient to be on the list for more than one transplant center. This gives more options for where you can go for a transplant. Centers may have their own rules for whether a person can be listed at other centers. Be sure to ask about their policy.

If a person wants to give you a kidney, they will need to have an evaluation. If they are approved, the transplant team will work with both of you to schedule the transplant. This means you may not need to go onto the transplant

list and wait for a kidney. The person who wants to give you a kidney might not be a match for you. But they may be able to give a kidney to someone else. Often both transplants can occur at the same time. Ask the transplant team if they do paired transplants. If so, there may be another living donor that is the right one for you.



## WHO IS ON THE TRANSPLANT TEAM

You are the most important member of the team. Staying involved in your care will help you to stay healthy and live a

better life. The other members of the team want you to have a successful transplant and a good life too.

Most transplant teams consist of:

- **Clinical transplant coordinators** coordinate the evaluation and follow-up care. They work closely with the transplant clinicians.
- **Transplant clinicians** manage a patient's medical care, order tests, and prescribe medications.
- **Transplant surgeons** are specially trained doctors who do the transplant surgery.
- **Financial coordinators** help patients with issues related to the cost of the transplant. They can help with hospital bills, Medicare and insurance plans. They are there to help you before, during and after surgery.
- **Social Workers** help you and your family know what to expect and how to cope. They are there to help you before and after the transplant.
- **Dietitians** work with you and your family on your diet and food intake. They are

there to help you before and after the transplant.

**Your Caregivers** are the unsung heroes!

- They can help you with medications, diet and exercise
- They may want to go with you to your appointments
- They may worry about how you are doing

Don't forget to thank them for their help and support along the way.

## WHAT ARE THE TYPES OF KIDNEY TRANSPLANTS?

**Living Donation** is when a person donates a kidney to a friend or someone related to them. Living donated kidneys take away the long wait for a transplant. These kidneys usually function longer than a kidney from someone who has died.

A donor will be told about any risks related to donating a kidney. Living donors can live a healthy life with one kidney. They can apply for money to help cover travel and lodging. There are living donor assistance programs such as, [www.livingdonorassistance.org](http://www.livingdonorassistance.org)

and [www.transplantfoundation.org](http://www.transplantfoundation.org) where the donor may find help.

Help for a donor might include:

- Lost wages
- Travel expenses
- Food and lodging
- Medications
- Hospital and physician charges
- Lab tests
- Child care

**Paired/Exchange Donation** may be an option for those who know someone who wants to donate a kidney. Sometimes the donor is cleared to donate but is not a good match for the patient. If this happens, the patient and donor may be able to enter into a paired kidney donation program. These programs pair the kidney and the patient with the best kidney match. This can start a "chain" of kidney donations. Ask the transplant team if they have a program like this. If they don't, they can tell you about transplant centers who do.

**Deceased Donation** is the most common form of kidney donation. These kidneys come from people who have died and donated their organs for transplant. These kidneys need to be transplanted

soon after the donor has died. It is important for their family to know that they want to be a donor. If not, the family may decide not to donate their organs. Anyone can sign up to be an organ donor. Go to the link DonateLife America [www.donatelife.net](http://www.donatelife.net) to find out more.

**Altruistic Donation** is when someone donates a kidney to any patient on the wait list. These kidneys might be given to a patient on the wait list at a transplant center. They might be used for a paired kidney transplant chain. These donors usually do not know the person they are giving a kidney to.

**Pre-emptive Transplant** is when a patient gets a transplant before they have to go on dialysis. Studies show this can result in better kidney and health outcomes. This type of transplant is more likely if a person has a living donor. The sooner you learn about your treatment choices, the better. This will give you time to decide if a transplant is best for you.

## **AFTER YOU GET YOUR TRANSPLANT**

### **Transplant Medications**

You will need to take medications to keep your body from rejecting the kidney. You will need to take these medications for the life of the kidney. Some of the medications can be costly. Ask the financial coordinator to help you find out how much your insurance plan and/or Medicare will pay. This can help you plan ahead.

### **Patient Assistance Programs**

These are programs that can help with the cost of the medications. Some of these programs are limited and can change over time. So don't count on them as your only or main source of help. Your transplant social worker, financial coordinator and clinical transplant coordinator can help you apply to these programs.

## **TRANSPLANT SURGERY**

### **The Transplant Experience**

The surgery will be the same whether your kidney comes from a living donor or someone who has died. Kidney transplant surgery usually takes 2-4 hours. You will be put to sleep. The surgery team will monitor you and your vital signs during the surgery. You will spend a few days to a week in the hospital while you recover.

## THE SURGERY

- The surgeon makes a small cut and places the kidney in the lower part of your abdomen.
- Next the surgeon will sew the blood vessels of the donated kidney to your blood vessels.
- The last step is to hook the kidney to the tube (ureter).
- The urine from the kidney will flow through the tube (ureter) into your bladder.
- Most transplanted kidneys make urine right away.
- Sometimes it can take several days.
- It is rare that a patient's native kidneys have to be removed.

## AFTER SURGERY

- You will stay in the hospital for several days to a week.
- The transplant team will help you learn how to take care of your new kidney and yourself.
- They will tell you when you can return to work.

## AFTER YOU GO HOME

- You will need to return to see the transplant team for regular checkups.
- They will check you over and look for any signs of infection or rejection.
- They will take blood from you to check how you and the kidney are doing.
- They will make changes to your medications.

Getting a new kidney is a big change. You may notice changes in how you feel.

It is normal to go through ups and downs.

### *Physical changes you might have*

- More energy
- Surgery scar reminds you of how far you have come
- Trouble sleeping due to medications
- Changes in your weight
- Mood swings

### *Common Worries*

- Losing or harming the kidney
- Afraid that you might get sick
- Cost of your medications
- Adapting to a new routine
- Others may treat you differently
- Friends and family may expect more from you

There are support groups especially for those who have had organ transplants. In these groups, people can talk about their feelings and how things have changed. Remember you are not alone.

## **THE DONOR'S EXPERIENCE**

Most people decide to donate a kidney because they have a friend

or family member who needs one. Others donate to help a person who is not known to them. They want to help someone live their best life possible.

To donate a kidney, a person has to be in good physical and mental health. They will need to have an evaluation to make sure they are healthy. The transplant team will check to be sure they can go through the surgery without problems. The evaluation will help find any risks for them now or later in life. Who can be a kidney donor may vary by transplant center.

### **Surgery for the living donor**

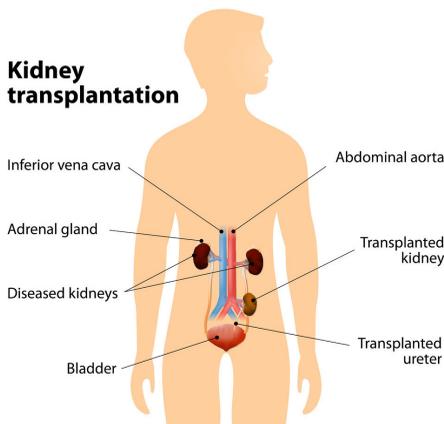
Most surgeons take out a donor's kidney using a laproscope. A laproscope is a special camera like instrument. The surgeon will make small cuts so they can put the laproscope and instruments through them. Then they will make another small cut to take out the kidney. After the kidney is taken out, the surgeon will sew up the cuts they made. This is it for the donor surgery. Ask the transplant team to tell you how they remove a donor kidney. It can be different based on the transplant center.

Most donors go home a few days after surgery. The transplant team will tell them how to care for

themselves after surgery. Advice includes:

- Avoid driving for a couple of weeks.
- Avoid lifting heavy objects for a few weeks.
- When they can return to work.

Once they recover they should be able to get back to the life they led before they donated a kidney.



## HOW LONG WILL THE TRANSPLANT LAST?

There is no way to tell how long a transplanted kidney will keep working. Kidneys from a living donor tend to last longer than one from a person who has died. Once you have your new kidney, there are steps you can take to stay healthy.

- Take all medications exactly as they are prescribed.

- Go to all of your appointments.
- Do not miss any scheduled laboratory tests.
- Know what complications or problems to look for.
- Know the signs and symptoms of rejection and infection.
- Report any changes in how you are feeling to the transplant team.
- Check with your transplant team to see when you can start exercising.
- Ask the dietician to give you advice about a healthy diet.
- The dietitian can tell you what foods to watch out for that could be unsafe for you.
- Keep an eye on your weight and note any large gains or losses.

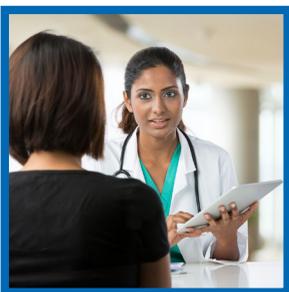
Remember, a kidney transplant is a treatment, not a cure. Living with a kidney transplant may take a bit of planning. It's important to stick with the plan to live the best life possible for you.

# QUESTIONS YOU MAY WANT TO ASK THE TRANSPLANT TEAM

- What does a transplant evaluation include?
- How long will the evaluation take?
- Will the results of the evaluation affect whether I can go on the transplant list?
- How will I know when I am on the transplant list?
- What is the usual wait time for a transplant at this center?
- Can I be taken off the transplant list? If so, why?
- Will you tell me and my kidney care team about any changes to the plan?
- Why does the kidney need to be a good match?
- What does a good match mean for me?
- Where can someone who wants to donate a kidney to me go to learn more about it?
- What if the person who wants to give me a kidney is not the best match for me?
- Can they donate their kidney to someone else?
- Can I get a kidney from someone who is a better match?
- How often will I need to come in for appointments?
- Will you let my dialysis care team know about my progress?

# HOW TO STAY HEALTHY NOW THAT YOU HAVE DECIDED TO GO FOR A TRANSPLANT

You need to take good care of yourself. The transplant evaluation will take a while. If you go on the transplant list, you will have a wait. Here are some tips:



- Keep all your appointments with the transplant team and healthcare team.
- If you are on hemodialysis dialysis, don't miss or shorten your treatments.
- If you are on peritoneal dialysis, keep doing it as instructed.
- Are you using a catheter for hemodialysis? These catheters can cause infections. Ask your dialysis care team to help you with a plan to get a fistula or graft.
- Stick to your kidney-friendly diet.
- Sometimes the transplant team will tell you to lose weight. Your dietitian can work with you on a diet that will help you reach your goal.
- Take all your medications as directed.
- Make sure you keep your flu and pneumonia shots up to date.
- Try to get some exercise every day.
- Get enough rest.

Try not to worry! The wait time for a transplant is different for each patient. Focus on living your best life while waiting for the call from your transplant team. Don't let your kidney disease limit you!





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