Is a kidney transplant right for me?

Your guide to the transplant process

ESRD NCC
NATIONAL COORDINATING CENTER

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Introduction

When you find out that your kidneys are failing, you may wonder about a kidney transplant. Would you qualify for a kidney transplant? Is a transplant right for you? Everyone is different. What is right for one person is not always right for another. Before you make any decisions about your treatment options, learn the facts about getting a kidney transplant and how it might affect you.

What are my options for treatment?

Healthy kidneys clean your blood by taking out excess fluid, minerals and wastes. They also produce hormones that keep your bones strong and your blood healthy. When your kidneys fail, harmful wastes build up in your body. Your blood pressure may rise. Your body may retain extra fluid and not make enough red blood cells. When this happens, you need treatment to replace the work of your failed kidneys. There are several types of treatment for kidney failure Hemodialysis, either at home or at a dialysis clinic; peritoneal dialysis, which is done at home; and kidney transplant.

Getting a kidney transplant is the most effective treatment. A kidney transplant is the only treatment that will work 24 hours a day, just like your own kidneys.

Not everyone can get a transplant. Patients must be healthy enough to have the surgery. They must also be able to take the medications which will help them accept the new kidney. These medications must be taken for the rest of the patient's life (or at least as long as the kidney transplant is working and sometimes longer). Some patients have a condition that would make a transplant dangerous or unlikely to work. Some patients are told that they have to lose weight or have their heart checked out before they can qualify for a transplant.

If you can't have a kidney transplant or if you don't want to have one, there are types of dialysis treatments that may fit your lifestyle.

How does a kidney transplant work?

A kidney transplant is a surgery done for some patients with kidney disease. During the surgery, a healthy donor organ is placed into the patient with kidney disease.

Only one kidney is transplanted. A person can live a healthy life with only one working kidney.

What is a Transplant Center?

To find out if you can have a kidney transplant, you will need to be assessed by the transplant team at a transplant center. A transplant center is a department in a hospital with staff that specializes in kidney transplants.

One of the biggest decisions you will make as a kidney transplant candidate is choosing a transplant center. There are nearly 250 transplant centers in the U.S. Each one of these centers must meet strict professional standards. Your nephrologist or dialysis care team may recommend one for you. Most patients can choose the center closest to their homes. Some insurers may require you to use certain transplant centers. Your dialysis care team can help you with this.

When selecting a transplant center, there are several questions you should ask yourself and the staff at the center:

- Will you be able to easily get to the transplant center for all of your appointments before and after the transplant?
- If you are on the transplant list, will you be able to get to the transplant center when they call to tell you that they have a kidney for you?
- If the center is not near your home, will your family or caregivers be able to stay nearby?
- Does the transplant center take your type of insurance?
- Do you feel comfortable with the transplant team?

There are two types of donors: living donors and non-living donors.

A living donor could be anyone who is a match to you and wants to donate. A non-living donor is someone who has passed away but had previously agreed to donate a healthy kidney after their death. There is a waiting list for kidneys from non-living donors. There are more people in need of kidneys than there are kidneys available.

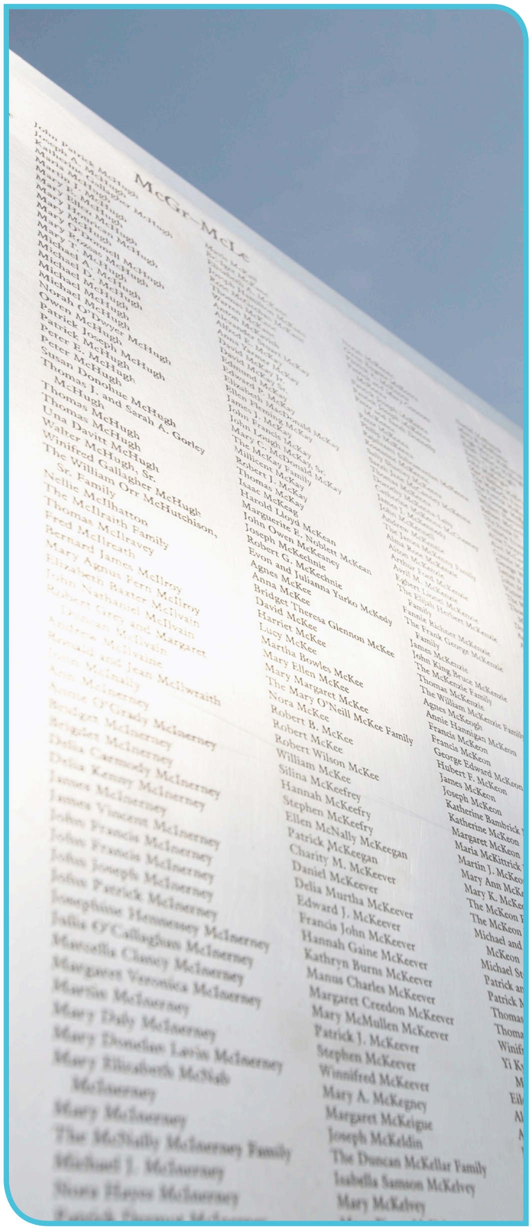
A donor kidney must meet certain standards. The donor kidney also must match the blood and tissue types of the person who is to receive the kidney. Patients and potential live donors have to undergo several medical tests to find out if the kidney will be a good match. If a patient is going to get a kidney from someone who is deceased, he or she will be placed on a waiting list. Their blood and tissue types will be listed in their file.

What is the Waiting List?

If you need a deceased donor kidney, you will be placed on a waiting list until a kidney is available. Waiting time can depend on several factors. These include your age, how long you have been on dialysis, your health history, and how long you have been on the waiting list. When a donor organ becomes available, the person who is the best match will receive the transplant.

The transplant must take place very soon after the kidney becomes available. A member of the transplant staff usually calls the person who needs a kidney. He or she must go immediately to the hospital transplant center. The transplant team can tell you more about how the waiting list works.

Some people may want to place their name on more than one transplant list. For more information visit the United Network for Organ Sharing (UNOS) website at ***www.unos.org.***



What is the Surgery Like?

When a donor kidney is available, doctors carry out more tests to confirm that it will be accepted by the recipient. Once they decide it is a good match, the patient will be taken to surgery.

The surgery takes approximately two to four hours and is done under general anesthesia. The donor kidney is placed in the lower abdomen. It is attached to blood vessels and the tube that drains urine into the bladder. Most of the time the old kidneys are not taken out unless they are infected or too large.

What Happens After the Surgery?

After surgery, you will be given medications that help prevent rejection of the donor kidney. Your transplant team will check to make sure the new kidney is working. Your new kidney may start to work and produce urine immediately. If it doesn't, you may have to go on dialysis for a while until your new kidney begins to work.

You will probably have to stay in the hospital for five to ten days after your surgery. If you have problems, you may have to stay longer, depending on your medical condition and needs. After you recover from the surgery you will be able to go home. Your transplant team will follow you closely. You will take medications to prevent rejection as long as your transplant is working. Your medications will be adjusted as your kidney function changes.

It is very important to visit the transplant team for regular checkups. This allows any problems to be found early. Rejection of the kidney is always possible.

The medications you must take after the transplant will weaken your immune system. This can lead to infections. You should ask a member of your transplant team about which medications you will need to take after the transplant. Make sure you ask about any side effects.

Over time, these medications may also increase the risk of cancer. People who take them should never suntan or use tanning beds because of the increased risk of skin cancer.

Your diet will change, depending on how your new kidney is working. You may be able to eat different foods and drink more fluid. Your dietitian will help you understand your new diet.

You will have to watch your weight and blood pressure. Anti-rejection medications may cause you to gain weight and/or have higher blood sugar. Avoiding salty foods will help keep your blood pressure at a healthy level and will help avoid swelling. If you have diabetes, continue to follow your diabetic diet. Other than follow-up care, a person who has had a kidney transplant is able to live a fairly normal life.

How Much Does a Kidney Transplant Cost?

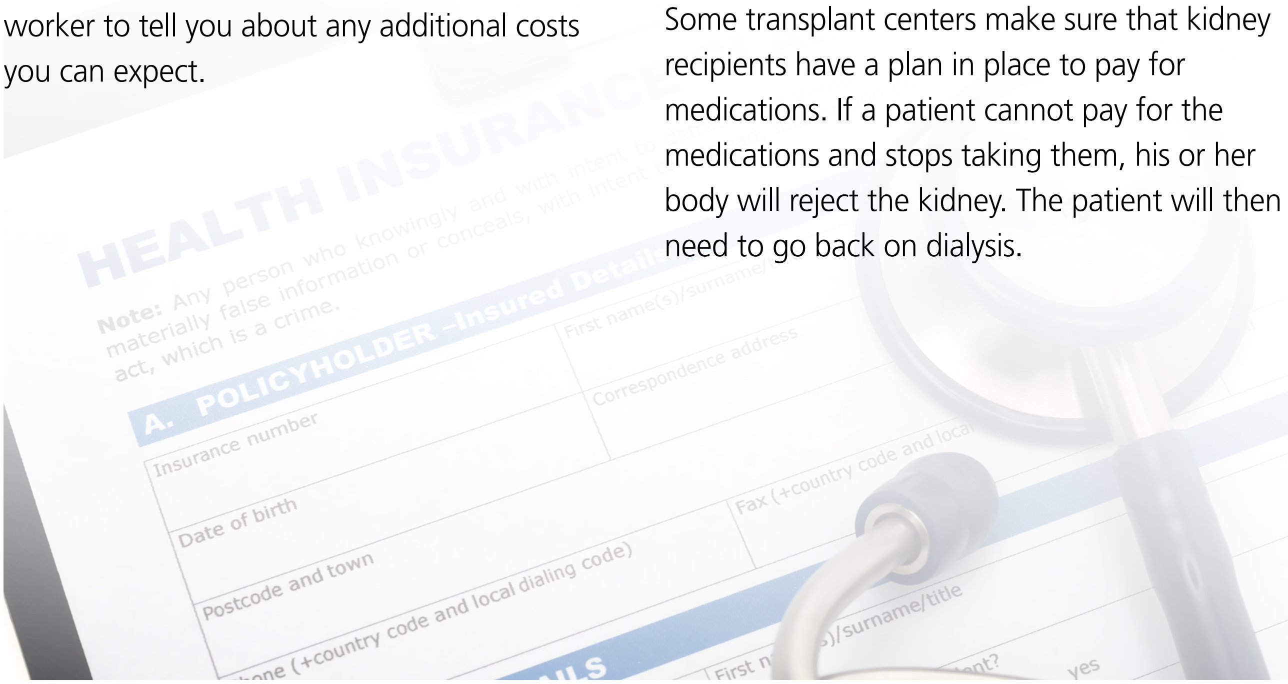
Having a kidney transplant is expensive. You can work with the transplant center team to figure out what you might have to pay. Ask them to help you make a financial plan for this. Medicare typically covers 80% of the costs if the transplant is done in a hospital approved by Medicare to do kidney transplants. Coverage by private insurers varies. A transplant team social worker or financial advisor will work with you to determine how your costs will be covered.

Patients need to know the monthly cost of the medications that keep their bodies from rejecting the transplant. With Medicare and a private insurance, there will be some out-of-pocket expenses. Ask the transplant social worker to tell you about any additional costs you can expect.

> If a person has Medicare coverage only because of kidney failure, Medicare payments will stop three years after the transplant. The patient will need to find other health insurance before Medicare coverage ends.

Many of the companies that make the anti-rejection medications will work with patients, their doctors and pharmacists to help pay for medications. The transplant team social worker can help find local resources and programs to assist patients. There are also many generic drugs that might work. Each patient will need to discuss this with the transplant team.

Some transplant centers make sure that kidney recipients have a plan in place to pay for medications. If a patient cannot pay for the medications and stops taking them, his or her body will reject the kidney. The patient will then need to go back on dialysis.



Who Are the Members of the Transplant Team and What Do They Do?

As the patient, YOU are the most important member of the team because you know your body best.

Your transplant team will work with you to make sure your transplant is as successful as possible.

It is important that you know the people on your team. They will help you through the transplant process.

You need to feel comfortable talking with them and asking them questions. Each team member is an expert in a different area of the transplant process.

Before the transplant takes place, you will be called a "transplant candidate." After the transplant operation, you will be called a "transplant recipient." Along with you, your transplant team will include all or some of the following health professionals.

- **Transplant Coordinator**
  The coordinator is usually a nurse or Advanced Practitioner. He or she will be responsible for the recipient's evaluation, treatment and follow-up care.
- **Transplant Surgeon**
  The doctor who performs the transplant surgery. Transplant surgeons have received specialized training to perform transplants.
- **Transplant Practitioners (or Transplant Nephrology practitioner)**
  Practitioners at the transplant center who manage your medical care, tests and medications. They do not perform surgery. Transplant practitioners work closely with the coordinator to manage your care before and after the surgery.
- **Transplant Unit Staff Nurses**
  The staff nurses work closely with you while you are in the hospital. They take care of you and explain your tests, medications, and follow-up care.
- **Financial Coordinators**
  They help you with financial matters and hospital billing related to your transplant. They will work with other members of the team. This may include the transplant team, insurers and administrative personnel. They will help coordinate how you can best pay for your care before, during and after your transplant.

- **Social Worker**
  The social worker helps you and your family know about what to expect and how best to cope with problems that may be associated with the transplant process. He or she may also handle some of the work that is sometimes done by the financial coordinator.
- **Your Healthcare Team**
  Members of your healthcare team, may include your family doctor, a specialist or your primary care provider. They can help coordinate medical care with your transplant team.
- **Pharmacist**
  If your transplant team has a pharmacist, he or she will review your medications with you. They will make sure you and the members of your healthcare team know what you are taking and help make sure that you have all of your prescriptions.
- **Dietitian**
  This is an expert in nutrition who will help you plan the kinds and amounts of foods to eat. He or she will help you choose foods based on your current health, other medical conditions and blood test results. Making better food choices will help you live an active and healthier lifestyle.

More questions?

Some more specific questions that you may need to ask your transplant team include:

- What does the evaluation process include at this center?
- How will the evaluation affect whether or not I am put on the waiting list?
- How will I know that I am definitely on the waiting list?
- How long do most patients with my blood type and organ type (kidney) wait for a transplant at this hospital?
- How long has this hospital been doing kidney transplants?
- How many kidney transplants do this hospital and/or surgeon perform each year?
- What are the organ and patient survival rates for kidney transplants at this hospital, and how do these rates compare with rates at other hospitals?
- How many surgeons at this hospital perform kidney transplants, and will there be someone available to perform the surgery if an organ is offered to me?
- Does this hospital perform living donor transplants?
- If someone donates a kidney to me, how can they learn more about what that will mean for them?
- Can I tour the transplant center?
- Can I meet other transplant recipients?
- How long do kidney recipients normally stay at this hospital after the transplant?
- Will I be asked to take part in any research studies?
- I am a diabetic. Does this hospital perform pancreas/kidney transplants, and what would be the advantage for me to consider this?

Do not be afraid to ask ANY questions!

Please feel free to talk with a member of your care team or contact your local ESRD Network for more information. For help finding your Network visit *www.esrdncc.org.*

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