



A VIDEO SERIES



living
WELL
with kidney failure

KIDNEY TRANSPLANT



National **Kidney** Foundation™

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Introduction

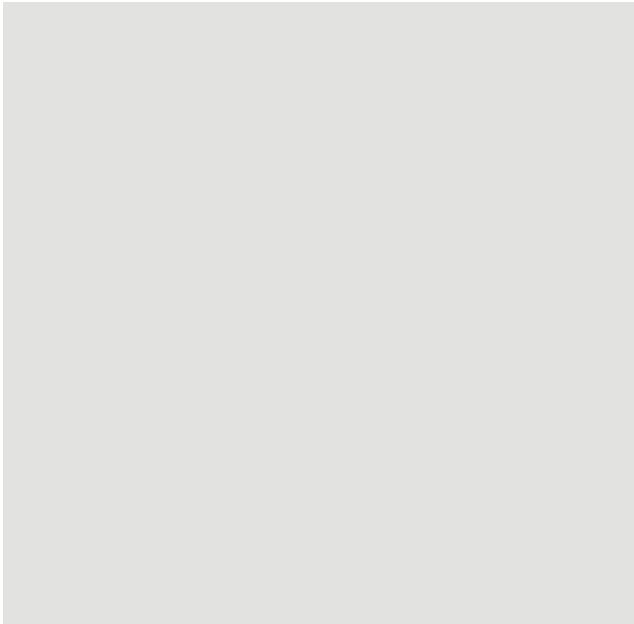
“Living Well with Kidney Failure” is a video series created by the National Kidney Foundation to help you understand kidney failure and its treatments. There are six videos. Each video has a companion booklet to provide more information and to help you review what you’ve learned. The six videos and booklets are:



This booklet will introduce you to kidney transplantation as a treatment choice. It also describes the healthcare professionals who make up the healthcare team in transplant centers. But, more importantly, it focuses on the role you play in your own care. That role begins with learning as much as you can about kidney failure and its treatment.

What will I learn?

You'll learn about kidney failure, and what it means when your kidneys don't work. This is discussed in the video and booklet called, "What is Kidney Failure?"



You'll learn about other health problems that can happen as a result of having kidney failure, and what you can do about them. These are discussed in the video and booklet called "How Kidney Failure Affects Your Body."

You'll learn about the two basic treatments available—kidney transplant and dialysis. There are two kinds of dialysis—peritoneal dialysis and hemodialysis. Each treatment is discussed in this booklet, and also in the videos and booklets called "Peritoneal Dialysis," and "Hemodialysis."

You'll also learn about some lifestyle changes you can expect, and how you and your loved ones can learn to cope with them. These are discussed in the video and booklet called "Living Well."

Finally, you will be introduced to some medical terms and important words that may be new to you. To help you get to know them, there's a list of "Words to Know" at the end of each booklet.

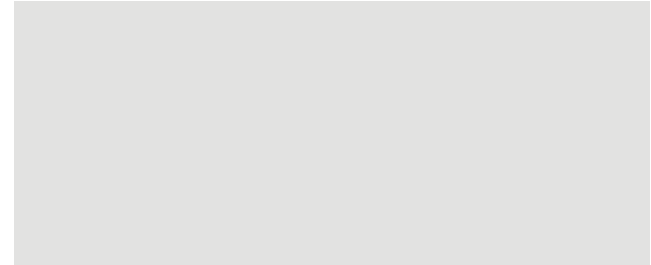
*“Kidney
transplantation
puts a lot of
responsibility on you
to take extra care
of yourself.”*

Who is on my healthcare team?

Your healthcare team does its job best when you work with them as part of the team. You do that by telling them what your concerns are, what questions you have, and by learning as much as you can about kidney failure and its treatments. If you choose transplantation as your treatment, then a team of transplant specialists at a transplant center will work with you.

Nephrologists, transplant physicians, and transplant surgeons are part of the transplant team. These doctors will work with you to help you decide whether a kidney transplant might be a good treatment choice for you. They're responsible for all medical care related to your transplant, and doing the transplant operation.

Advanced practitioners are also part of your team. They work together with your nephrologists, transplant physicians, and surgeons to give you your medical care.



Transplant coordinators are registered nurses with a specialty in transplantation. They work with all members of the healthcare team to see if transplantation is right for you, and if it is, they'll help you prepare for surgery and see that all goes well afterwards.

Dietitians will work with you, too, teaching you to eat and drink the right things in the right amounts.

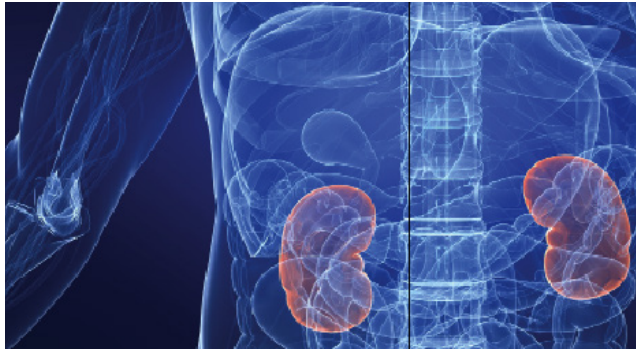
Social workers help you and your family cope with kidney disease. They provide counseling, identify sources of emotional support, and help you access services provided by federal, state, and community agencies.

What is kidney failure?

You have two kidneys. Each is about the size of your fist, and they're on both sides of your spine at the bottom of your rib cage. Together, they weigh about one pound.

When your body uses the food you eat and the liquids you drink, there are waste products that your kidneys filter out as urine.

When your kidneys are healthy, they keep your whole system in balance. They help your body to make red blood cells. They also release hormones



that help to regulate blood pressure and keep your bones healthy and strong.

Usually you don't have to worry about any of this. But when your kidneys fail, it's a different story.

Waste products and fluids build up in your body. You may feel weak or tired. You may feel sick to your stomach. You may lose your appetite, feel irritable, or have trouble thinking clearly. And, you'll need dialysis treatment or a kidney transplant to stay alive.

What treatments are available for kidney failure?

There are two treatments for kidney failure—dialysis and transplantation.

In dialysis, the job of your kidneys is done in one of two ways—hemodialysis or peritoneal dialysis.

In hemodialysis, waste products and extra fluid are removed from your blood by a dialysis machine.

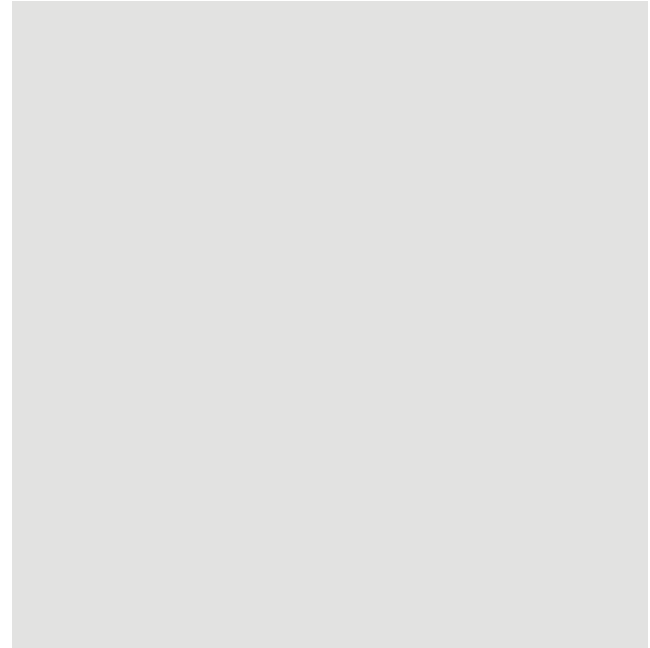
Hemodialysis can be done at a dialysis center or at home. On average, the process takes four hours. Most people have treatment three to four times a week.

In peritoneal dialysis, your blood is cleaned inside your body, not outside your body. Peritoneal dialysis is usually done every day, seven days a week, and you do it yourself. However, because your blood is cleaned inside your body, it can be done continuously each day—while you work, play, go to school, or sleep.

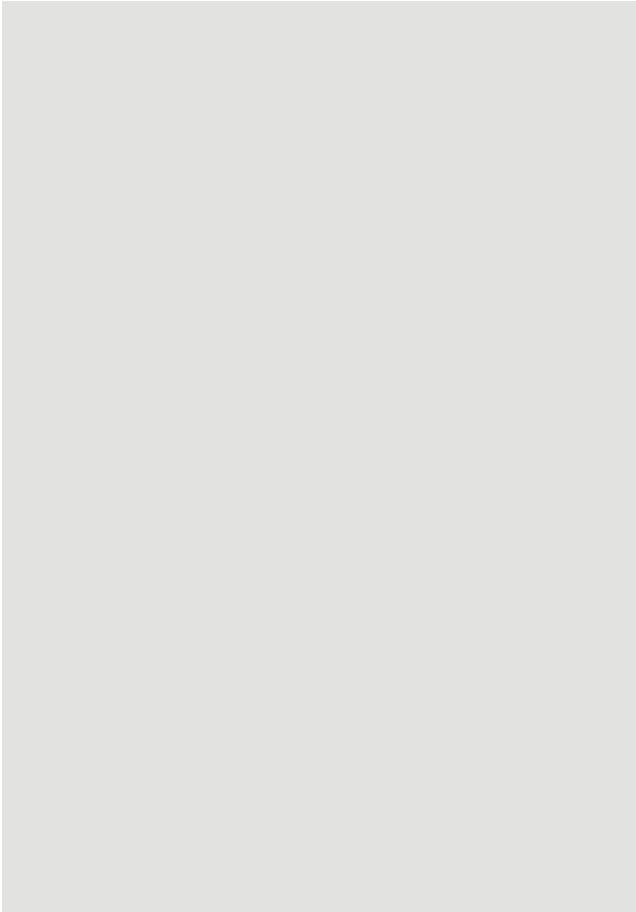
To learn more about hemodialysis or peritoneal dialysis, see the videos and booklets on those subjects in this program.

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.



Kidney transplantation puts a lot of responsibility on you to take extra care of yourself, to stay as healthy as you can, and to take all your medicines every day.



What are the pluses and minuses of getting a transplant?

On the plus side, there are few restrictions on what you can eat and drink. There will probably be an improvement in your health and the way you feel. In fact, a successful transplant may allow you to live pretty much the kind of life you were living before you got kidney disease.

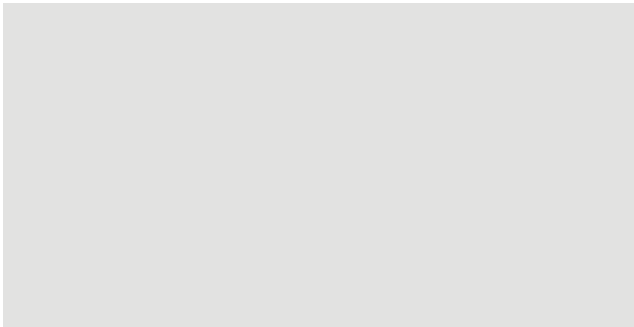
On the minus side, there are the risks of surgery and the side effects of the strong medicines you'll have to take for as long as your new kidney is working.

Finally, it's also important for you to understand that most transplants do work 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.

Who can get a kidney transplant?

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

You have to be healthy enough to have the operation. You must also be free from cancer and infection. Aside from that, there are few reasons why you can't have one. Some patients have other medical conditions that mean they shouldn't take the medicines needed after a transplant. But for many kidney patients, getting a transplant can be a real treatment choice.



What's the first step in getting a transplant?

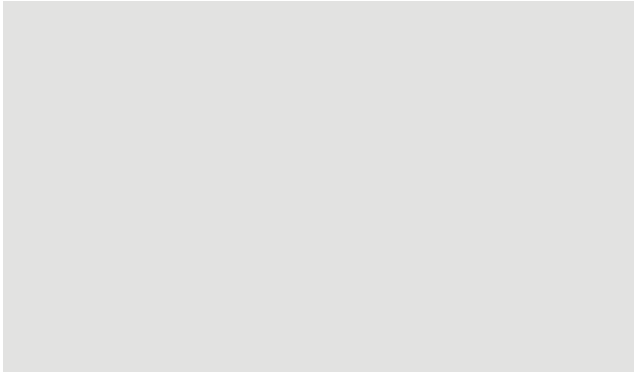
The first step in getting a transplant is to ask your kidney doctor or any member of your healthcare team about an evaluation. Any kidney patient can ask for an evaluation.

If you aren't in treatment yet, but would like to learn about transplantation, you can contact any transplant hospital or the National Kidney Foundation office at **1.855.NKF.Cares (1.855.653.2273)**.

How does the evaluation process work?

The evaluation process 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.

Medical professionals will give you 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 reviewed.



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.

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. Remember, being active in your own care is one of the best ways to better health.

If it's your child who has kidney disease, you'll want to give serious thought to getting an 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 most preferred 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.

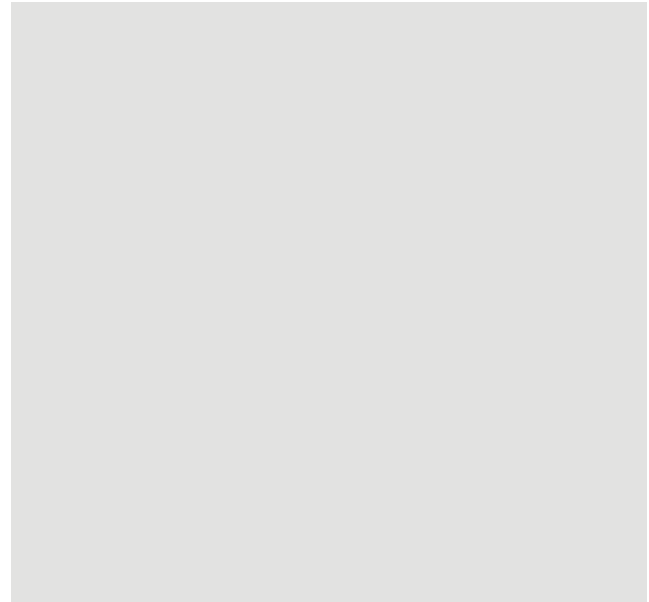
Where do transplanted kidneys come from?

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

A donated kidney can also come from someone who has died and had a healthy kidney. A person who has died and donated a kidney is called a deceased donor.

For your body to accept the new kidney, it must agree with your blood and tissue types.

When a kidney is donated by a living relative or loved one, the operations are done on the same day and can often 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's left. But keep in mind that the transplant 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.

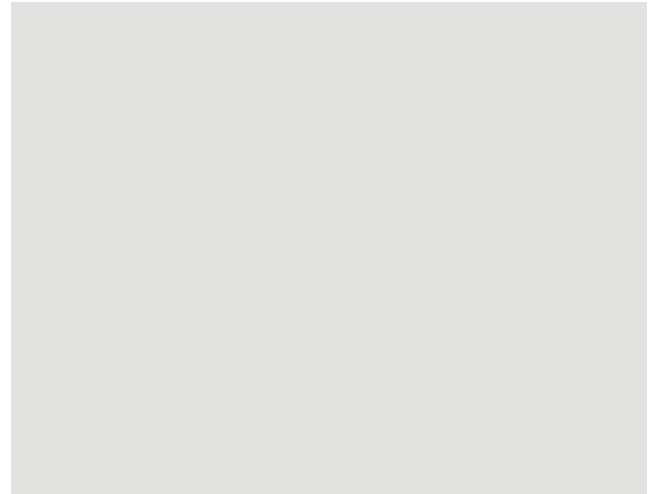
Is it better to get a kidney from a living donor?

Kidneys from living or deceased donors both work well in a transplant, but getting a kidney from a living donor can be better.

For one thing, you won't have to go on a waiting list for a kidney. Also, a kidney from a living donor may last twice as long as one from a deceased donor.

The waiting list for a kidney from a deceased donor is linked to a computer that compares your blood and tissue type to available kidneys, and keeps track of how long you've been on the list.

Because a kidney that agrees with your own blood and tissue type must be found, the waiting time for a new kidney can take many years. 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 arrangements for these tests.

You'll have to be reachable when a kidney is found, because the surgery must be done as quickly as possible.

How is a kidney transplant done?

You may be surprised to learn that your own kidneys generally aren't taken out when you get a transplant. The surgeon leaves them right where they are because there's no medical reason to remove them.

The donated kidney is placed into your lower abdomen, where it's easiest to connect it to your important blood vessels and to your bladder. Putting the new kidney in your abdomen also makes it easier to take care of any problems that might develop.

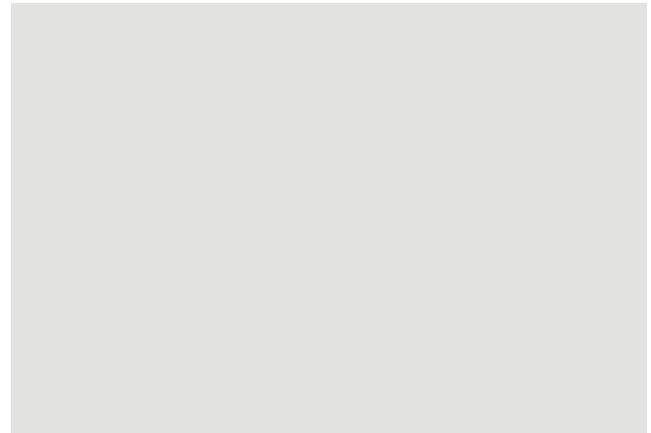
The operation takes from two to four hours. You'll be sore at first, but you should be out of bed in a day or so, and home within a week.

The new kidney should start to work very quickly. A kidney from a deceased donor can take longer to work—up to a few weeks in some cases. If that

happens, you may have to go on (or continue) dialysis until the kidney begins to work on its own.

After surgery, you'll be taught about the medicines you'll have to take and their side effects, if any.

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.



Why the need for strong 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 fighting off or rejecting the donated kidney, you'll have to take medicines to hold your immune system back. They're called immunosuppressive medicines.

Without these medicines, your immune system would see the donated kidney as "foreign," and would attack and destroy it.

Holding your immune system back is safe for most people. But what if you need it working at full strength because of other medical problems? If that's the case, it isn't safe to have a transplant until those other problems have cleared up.

Besides the immunosuppressive medicines, you may need to take other medicines as well. Most people find taking medicines a small price to pay for the freedom and quality of life that a successful transplant can provide.

After your transplant, making sure you take all your medicines on schedule—every day, without fail—is probably the single most important thing you can do. You'll need to take these medicines for as long as your kidney is working. You should understand that no matter how good you feel after your transplant, taking your medicines on schedule is a necessary part of your treatment.

That's why you'll be watched on a regular basis for the first three months after your transplant. After that, you'll be seen less often, but enough to make sure that your kidney is working well and that you're still taking all your medicines on schedule.

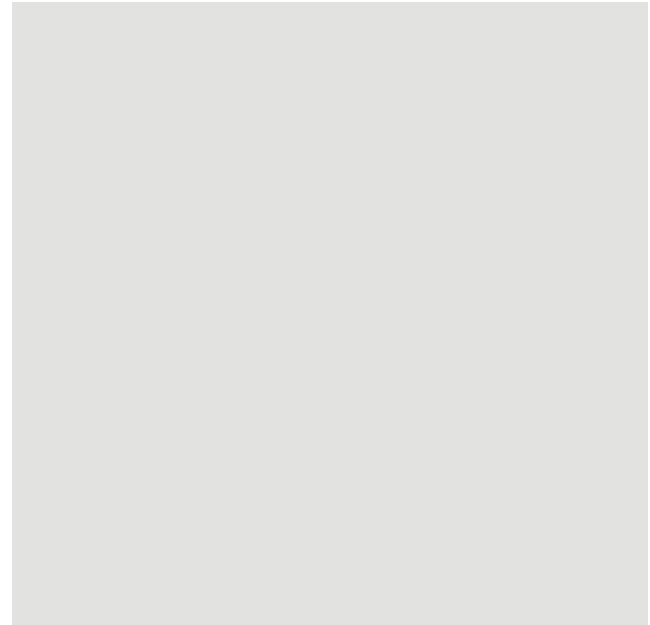
What if my body tries to reject the new kidney?

One thing that you and your healthcare team will need to watch out for is something called an acute rejection episode, which means that your body is 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.

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. So, as long as you take your medicines and keep to a sensible diet, you can feel more secure as time goes on.

Unfortunately, sometimes a rejection episode happens even if you're doing everything you're



supposed to. Sometimes the body just doesn't want to accept the transplanted kidney. But even if a rejection episode happens, it doesn't necessarily mean that you'll lose your transplant. Most transplants do last.

How often do rejection episodes happen?

Rejections happen much less often nowadays. That's because there have been many improvements in immunosuppressive medicines. In the past, most patients had at least one rejection episode. Fortunately, that is no longer the case, but rejections can still happen. For most people, rejection can be stopped with special anti-rejection medicines. That's why it's so important that you are checked often at first.

But you'll always need to be checked from time to time to see how well your kidney is working, and if you're experiencing any side effects from your medicines.

If you lose your transplanted kidney, you may still be eligible to get another one, if that's what you want. Though you may have to go on dialysis while you wait for another kidney.

How will I pay for a transplant?

Some of the medical costs for donors and patients are covered by Medicare. Private insurers and state programs may cover some costs as well. Coverage may only be for a limited number of years. It's important to discuss coverage with your social worker, who can answer questions you may have or direct you to others who can help.

What is the best treatment choice?

Learning about your treatment choices will help you decide which one is best for you. Your decision should be based on more than your medical history and your doctor's opinion. It should also be based on what you and your family want as you first start treatment or later on. Your life and health may change with time, and so can your treatment.

You should consider many things in choosing

*“You should consider
many things
in choosing
a treatment.”*

Review

In this booklet, you've learned that:

- A kidney transplant is the **TREATMENT CHOICE** that allows you to feel as close to the way you did before you had kidney disease.
- The first step in getting a transplant is to **ASK FOR AN EVALUATION.**
- People who take their medicines and **FOLLOW THEIR TREATMENT PLAN** closely get the most benefit from a transplant.
- Transplantation is **ESPECIALLY BENEFICIAL** to children and young adults because it helps them grow naturally.
- You'll still need **REGULAR MEDICAL CARE** after your transplant; the first three months are especially important.
- You'll have to take **ANTIREJECTION MEDICINES** for as long as your transplant is working, and these may have some side effects.

- **DONATED KIDNEYS** can come from living donors, such as a relative, spouse, friend, or even a stranger. They can also come from someone who has died and wished to donate a kidney.
- If you don't know anyone willing to donate kidney, you'll be put on a **WAITING LIST**. How long you'll have to wait for a kidney will depend on many things, including how well your blood and tissue type compares to the available kidneys, and how long you've been on the list.
- In a transplant operation, your own **KIDNEYS ARE USUALLY NOT REMOVED**. The new kidney is placed in your abdomen.
- **REJECTION EPISODES** can happen; but they don't mean you have to lose your transplanted kidney.
- If you do lose your transplant, you may be able to be **RE-EVALUATED** for another one.
- A post-transplant diet has **FEWER RULES** than a dialysis diet.
- After you've gotten a transplant, it's very important that you **TAKE ALL YOUR MEDICINES** on schedule, that you learn about any danger signs, and that you work to stay in the best of health.

True or false

1. Many transplant patients are able to live as well as they did before getting kidney disease. **T F**
2. Transplantation is not a good treatment choice for children and young adults. **T F**
3. Every kidney patient can ask to be evaluated for a transplant. **T F**
4. If you get a transplant, your own kidneys will be removed during surgery. **T F**
5. After a transplant, it is very important to take all your medicines on schedule. **T F**
6. Immunosuppressive drugs help your body accept a transplanted kidney. **T F**
7. If your body rejects a transplanted kidney, you'll never be able to have another transplant. **T F**
8. Chances of finding a compatible kidney are best with a blood relative. **T F**
9. The transplant operation is not a major operation for the donor. **T F**
10. After a successful transplant, your diet is still as restricted as it was before you had the transplant. **T F**

1. True 2. False 3. True 4. False 5. True 6. True 7. False 8. True 9. True 10. False

Words to Know

acute rejection episode

An attempt by your body's immune system to reject a transplanted kidney.

advanced practitioners

Members of your healthcare team who work closely with your nephrologists, transplant physicians, and surgeons. Advanced practitioners include nurse practitioners, physician assistants, and clinical nurse specialists.

bacteria

Small, single-celled organisms that can sometimes cause disease or sickness.

blood pressure

Pressure of blood against the inner walls of your blood vessels as it is pumped through your body.

compatible

A match between your own blood and tissue type and that of a donor or donor organ.

dialysis

A process that filters waste products and extra fluid from your blood when your kidneys are no longer doing their job.

dialysis machine

A special machine that uses an artificial kidney to filter waste products and extra fluid from your blood.

dietitian

The member of your healthcare team who will help you plan what to eat and drink to help you feel your best.

| | |
|------------------------------------|--|
| deceased donor | A person who has recently died and wanted to donate a kidney. |
| donor | The person who gives a healthy kidney to someone who needs a transplant. The donor is usually a living relative, friend, or someone who has died. A donor who has recently died and wanted to donate a kidney is called a “deceased donor.” A living person who donates a kidney is called a “living donor.” |
| germs | Microscopic organisms such as bacteria or viruses. |
| healthcare team | All the people responsible for planning your care and helping you cope with kidney disease and kidney failure. Your healthcare team may include your nephrologist, advanced practitioner, nurse, dialysis technician, dietitian, social worker, transplant coordinator, and transplant surgeon. You, too, are an important member of your healthcare team. |
| hemodialysis | One of the basic forms of dialysis treatment. In hemodialysis, your blood is cleaned of waste products and extra fluid through a dialysis machine. |
| hormones | Chemicals produced by different glands and organs, including the kidneys, to trigger certain responses in your body. |
| immune system | Your body’s system for protecting itself against germs and other “foreign” things. |
| immunosuppressive medicines | Drugs that hold back your body’s immune system so that a transplanted kidney can be accepted. They are also called “antirejection medicines” or “immunosuppressants.” |

| | |
|----------------------------|---|
| kidney disease | The loss of some or all of your kidney function. Kidney disease can result from conditions such as high blood pressure, diabetes, heredity, or injury to the kidneys. |
| kidney failure | The stage of kidney disease at which dialysis or a kidney transplant is needed to stay alive. |
| kidney transplant | One of the basic forms of treating kidney failure. In transplantation, a kidney from a living donor or from someone who has recently died is surgically placed into a patient's body to do the work that diseased kidneys can no longer do. |
| living donor | A living person who donates a kidney to someone who needs a kidney transplant. |
| nephrologist | The member of your healthcare team who is a doctor specially trained in treating kidney disease and kidney failure. |
| nurse practitioner | A member of your healthcare team who works closely with your doctor to give you regular checkups, medicines, and other medical care. |
| peritoneal dialysis | One of the basic forms of dialysis treatment. In peritoneal dialysis, a solution called dialysate flows into your abdominal cavity (your belly), where it removes waste products and extra fluids from your body, and then is drained out. |
| physician assistant | A member of your healthcare team who works closely with your doctor to give you regular checkups, medicines, and other medical care. |
| red blood cells | Cells in your body that carry oxygen to all parts of your body. A loss of red blood cells can cause anemia. |

| | |
|-------------------------------|---|
| side effects | An expected or unexpected negative result of taking a medication. |
| social worker | The member of your healthcare team who is specially trained to help you cope with the non-medical problems you may have, such as the stress of a serious illness. |
| transplant center | A place where patients who are interested in getting a kidney transplant go for evaluation and surgery. |
| transplant coordinator | The member of your healthcare team who is responsible for arranging many parts of the transplant process. The transplant coordinator is usually a registered nurse. |
| transplant physician | The member of your healthcare team who will be responsible for much of your transplant care. He or she may also be a nephrologist. |
| transplant surgeon | The member of your healthcare team who will perform the transplant operation should you choose transplantation as your treatment option. |
| viruses | Infectious, microscopic organisms that multiply in the cells of the body. |

The National Kidney Foundation is grateful to the patients, clinicians, dialysis units, and transplant centers that helped make this program possible.

The People on My Healthcare Team

Nephrologist _____

Transplant physician _____

Transplant coordinator _____

Transplant surgeon _____

Advanced practitioner _____

Dietitian _____

Social worker _____

Important telephone numbers _____

Questions for My Healthcare Team

Support provided by:



About The National Kidney Foundation



The National Kidney Foundation (NKF) is a team member working behind the scenes. The NKF offers programs like “Living Well with Kidney Failure” so that you and your family can learn about kidney disease and kidney failure.

The NKF also supports patient and community services, research, professional education, organ donation and public information programs.

Please feel free to review the “Living Well with Kidney Failure” program as often as you like. There are five other videos and booklets in this program. If you have any questions at all, ask any member of your healthcare team, or you can call the National Kidney Foundation at any time.

The toll-free number is **1.855.NKF.CARES (1.855.653.2273)**
www.kidney.org



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National Kidney Foundation™

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