

Choosing a Treatment for Kidney Failure









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Stages of chronic kidney disease

There are 5 stages of kidney disease as shown in the table below. Your healthcare provider will tell you the stage of kidney disease, based on how well your kidneys are working and your estimated glomerular filtration rate (eGFR). The eGFR number comes from a lab test that measures the amount of blood your kidneys are filtering each minute. As CKD gets worse, the eGFR number goes down.

STAGES OF KIDNEY DISEASE

STAGE	DESCRIPTION	ESTIMATED GLOMERULAR FILTRATION RATE (eGFR)	KIDNEY FUNCTION
1	Kidney damage (e.g., protein in the urine) with normal kidney function	90 or above	 90-100%
2	Kidney damage with mild loss of kidney function	60 to 89	 60-89%
3a	Mild to moderate loss of kidney function	45 to 59	 45-59%
3b	Moderate to severe loss of kidney function	30 to 44	 30-44%
4	Severe loss of kidney function	15 to 29	 15-29%
5	Kidney failure	Less than 15	 Less than 15%

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Introduction

If your healthcare professional said you may need dialysis or a kidney transplant soon, you are probably wondering how to decide on the best choice for you. This booklet has general information to help you and your family make this decision. You should talk about the pros and cons of each treatment option with your family, and healthcare professionals. They will help you decide which treatment is best for you.

Kidney Failure

What happens when your kidneys fail?

Your kidneys normally remove wastes and extra fluid from your blood. When your kidneys fail because of disease or injury, wastes and extra fluid can build up in your blood and make you sick. Some of the symptoms of kidney failure include:

- nausea
- trouble sleeping
- poor appetite
- fatigue
- hiccups
- dry, itchy skin
- weight loss
- muscle cramping at night
- abnormal bleeding or bruising easily
- swelling of your feet or ankles
- puffiness around your eyes
- anemia (low red blood cell count)
- trouble breathing or feeling short of breath

When is treatment needed?

Your healthcare professional will help you decide when you need to start treatment. This decision is based on:

- your symptoms
- other health problems you have
- how much kidney function you have left
- your nutritional health



How do I know which treatment is best for me?

The two treatments for kidney failure are dialysis and kidney transplantation. Two different kinds of dialysis can be done—hemodialysis and peritoneal dialysis. Both types of treatment has pros and cons. You can also choose not to do dialysis or have a transplant, or you may decide to have comfort care only. As you learn more about each one, speaking with your healthcare professional and your family can help you decide which treatment is best for you.

Your decision should be based on many things:

- medical condition
- lifestyle
- personal preference

No matter which treatment you choose, you need to make a commitment to follow your treatment plan.

This involves:

- following your treatment schedule
- following your special diet
- taking all your medicines as instructed

Following your treatment plan will help you live longer and feel better.



Kidney Transplant

What is a kidney transplant?

A kidney transplant is an operation that places a healthy kidney from another person into your body. The kidney may come from someone who has died or from a living person who may be a close relative, spouse, or friend. It can even come from someone who wishes to donate a kidney to anyone in need of a transplant. Your new kidney will be placed in your lower abdomen and connected to your bladder and blood vessels.

The transplant operation takes about 3 hours and you will be in the hospital for about 5 to 7 days. After the transplant, you will need to take special medications to prevent your body from rejecting the new kidney. You will have to take these medications for as long as you have the transplant. Many patients prefer a transplant over dialysis because it gives them more freedom, allows for a less restricted diet, and may improve their quality and length of life.

A kidney transplant is a treatment, not a cure. A person with a kidney transplant still has kidney disease, and may need some of the other medicines they took before the transplant.

Can I get a transplant before going on dialysis?

Yes. In fact there are long-term benefits to having a transplant without having dialysis first. Your healthcare professional can refer you to a transplant center for tests. Or you can contact a local transplant center directly. For help finding a local transplant center, call NKF CARES **855.653.2273**.

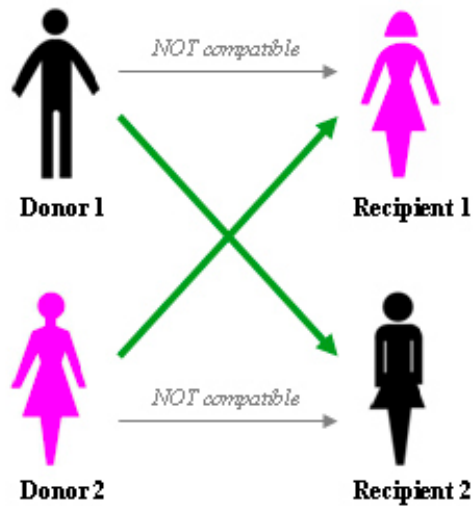
Types of kidney transplants

If a family member or friend is willing to donate a kidney, the tests can be started right away. If there is a “match,” surgery can be scheduled.

Sometimes a loved one may want to donate a kidney but their blood type is incompatible. Some transplant centers will help incompatible pairs of recipient/donors through a process called paired exchange, which involves two living donors and two recipients.

If the recipient from one pair is compatible with the donor from the other pair, and vice versa– the transplant center may arrange for a “swap”–for two simultaneous transplants to take place. This allows two transplant candidates to receive organs and two donors to give organs though the original recipient/donor pairs were unable to do so with each other.

Figure 1: Paired Exchange



In paired exchange, an incompatible donor/ recipient pair (such as a mother and son that don't have compatible blood types) are matched with another incompatible donor/recipient pair for a "swap". Each donor gives a kidney to the other person's intended recipient.

However, if you do not have a living donor, you will need to be on a waiting list until a kidney from a suitably matched deceased donor becomes available. In the meantime, you can have dialysis treatments.

Hemodialysis

What is hemodialysis?

Hemodialysis is a treatment that removes wastes and extra fluid from your blood. During hemodialysis, your blood is pumped through soft tubes to a dialysis machine where it goes through a special filter called a dialyzer (also called an artificial kidney). As your blood is filtered, it is returned to your bloodstream. Only a small amount of blood is out of your body at any time. In order to be connected to the dialysis machine, you need to have an access, or entrance, to your bloodstream. (See page 16, "What is a hemodialysis access?") Treatments are usually done 3 times a week. Each treatment lasts about 3 to 5 hours.



Where can I have hemodialysis treatment?

Hemodialysis treatments can be done at home or in a dialysis center. Dialysis centers may be located within a hospital or in a separate facility. You and your healthcare provider will decide which place is best, based on your medical condition and your wishes.

How does hemodialysis at home work?

Home hemodialysis is a great option for many patients with kidney failure. Your home must have room for the equipment and enough water drainage and electrical power to operate the dialysis machine and water purification unit. Medicare may help cover the cost of minor changes to your home for home hemodialysis.

Some home dialysis setups need you to have a dialysis care partner. Usually this is a family member or friend, but may also be someone you hire to assist you. You and your partner will be trained to do hemodialysis at home. There are also home dialysis options that do not require a treatment partner. This type of dialysis is called solo-, self- or independent-home dialysis.

Are there different types of home hemodialysis?

With home hemodialysis, you will have 3 different types of treatment options to choose from:

- **Conventional home hemodialysis.** Treatments are usually done 3 times a week, and each treatment lasts about 3 to 5 hours.
- **Short daily home hemodialysis.** This involves more treatments each week for shorter periods. For example, you might do 6 treatments a week (compared with the usual 3). Each treatment would last about 1½ to 2½ hours. Many people feel that their quality of life improves with this method of dialysis because they sleep better and have better control of blood phosphorus levels, blood pressure and anemia (low red blood cell count).
- **Nocturnal (nighttime) home hemodialysis.** This involves long, slower treatments, which are done during the sleep hours, usually for 6 to 8 hours. Many people sleep better and have better control of blood phosphorus levels, blood pressure, and anemia with this method of dialysis.



Comparing Hemodialysis: At Home Versus in a Center

HOME HEMODIALYSIS	
ADVANTAGES	DISADVANTAGES
<ul style="list-style-type: none">• Dialysis is done in the comfort of your own home.• You do not need to travel to a dialysis center.• You have more flexibility to choose a time of day to do dialysis.• You and your dialysis partner learn how to do treatments independent of the center staff.• There is a greater sense of control from having independence with the treatment schedule in relation to your life and work schedule.	<ul style="list-style-type: none">• Space in the home needs to be dedicated to the machine, water system (if needed) and supplies.

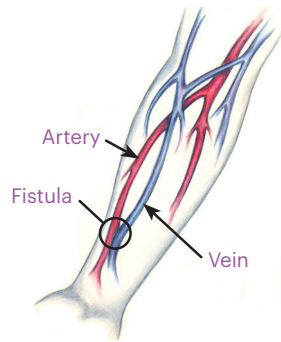
IN DIALYSIS CENTER	
ADVANTAGES:	DISADVANTAGES:
<ul style="list-style-type: none">• Trained staff performs all aspects of treatment. (You may be able to do some things yourself, like inserting the needles.)• Since other people are dialyzing at same time, friendships may develop.	<ul style="list-style-type: none">• Treatment days and times are scheduled by the center.• You must travel to the center at least three times weekly.• Other people are doing dialysis at same time, so you have less privacy.• Loved ones may worry if they can't be with you during treatment.• There may be rules against eating and drinking while on dialysis.

What is a hemodialysis access?

If you choose hemodialysis, you need to have a permanent access, or entrance, to your bloodstream. This is done with minor surgery, usually to your arm.

There are three different types of access:

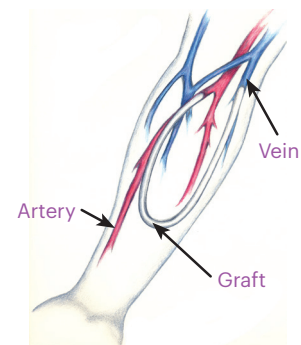
FISTULA



A fistula is the recommended choice for an access. It is made by joining an artery to a nearby vein under your skin to make a bigger blood vessel. This type of access is recommended because it has fewer problems and lasts longer. You should be looked at by a special healthcare

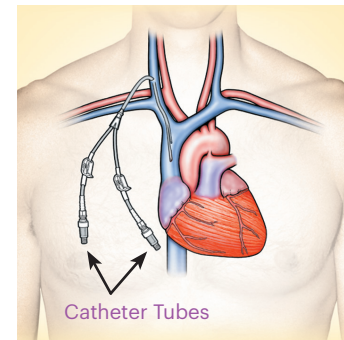
professional, called a vascular surgeon, at least 6 months before you will need to start dialysis. Your kidney healthcare professional or surgeon may order an ultrasound evaluation of your blood vessels to see which ones will work best for the fistula. This is called “vessel mapping.” A fistula should be placed early (several months before starting dialysis), so it has plenty of time to heal and will be ready for use by the time you begin hemodialysis.

GRAFT



If your blood vessels are not suitable for a fistula, a graft may be used. This involves joining an artery and nearby vein with a small, soft tube made of synthetic material. The graft is placed entirely beneath your skin.

CATHETER



The third type of access, called a catheter, is inserted into a large vein in your neck or chest. The ends of the tubes sit on your skin outside your body. This type of access is generally used when you need dialysis for a short period of time.

However, catheters are also used as a permanent access when a fistula or a graft cannot be placed.

What happens after the fistula or graft heals?

After the fistula or graft has healed and dialysis is started, two needles will be placed—one in the artery side and one in the vein side of the access—every time you have treatment. The needles are then connected to soft plastic tubes. One tube carries your blood from the needle to the dialyzer (the artificial kidney) where it is cleaned. The cleaned blood is returned to you through the other tubing.

Peritoneal Dialysis

What is peritoneal dialysis?

In peritoneal dialysis (PD), your blood is cleaned inside your body, not outside your body. The lining of your abdomen (the peritoneum) acts as a natural filter.

A cleansing solution, called dialysate, flows into your abdomen (your belly) through a soft tube called a PD catheter. The PD catheter is placed during minor surgery. Wastes and extra fluid pass from your blood into the cleansing solution.

After several hours, you drain the used solution from your abdomen and refill with fresh cleansing solution to begin the process again. Removing the used solution and adding fresh solution takes about a half hour and is called an “exchange.” Peritoneal dialysis can be done at home, at work, at school, or even during travel.

Peritoneal dialysis is a home-based treatment. Many people who choose peritoneal dialysis feel it allows them greater flexibility and independence.

TIPS

Peritoneal dialysis might be a good choice if you:

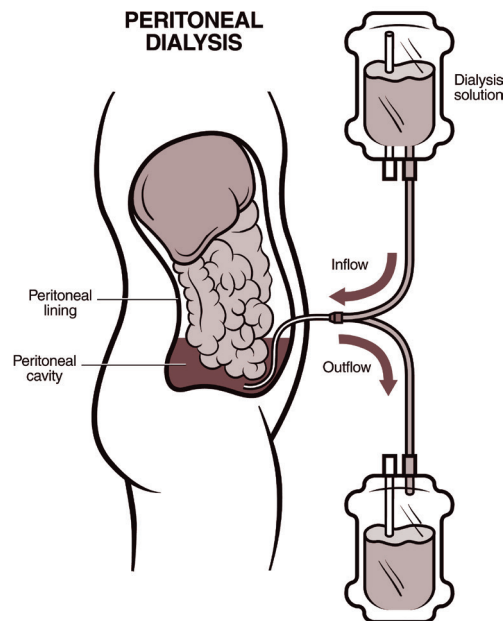
- live far from a clinic or have no reliable transportation to a dialysis center
- are working or are in school
- like to travel
- prefer to be in control of your treatment
- fear needles
- are soon expecting a transplant



Are there different types of peritoneal dialysis?

Yes. The most common ones are:

- **Continuous Ambulatory Peritoneal Dialysis (CAPD).** With CAPD, you do the exchanges yourself 4 to 6 times a day.
- **Automated Peritoneal Dialysis (APD).** With APD, a machine called a cycler does the exchanges automatically once you have set up the equipment. APD can be done while you sleep. However, if you do APD, you may also need to do 1 or 2 exchanges yourself during the day to make sure enough wastes and extra fluid are being cleared from your blood.



Living With Your Treatment Choice

Will I feel better after I start treatment?

Once you get used to your treatment, you should begin to feel better. The dialysis treatments or transplanted kidney will take over some of the work of your damaged kidneys and remove wastes and extra fluid from your body. This will make many of your symptoms better.

Will I be able to change to another treatment type?

If you start on one type of treatment but feel you would like to try something else, you can speak to your healthcare professional. For example, if you choose hemodialysis, it doesn't mean you can't ask to switch to peritoneal dialysis at a later date. Even if you choose to have a kidney transplant, you may need a period of dialysis until you can be transplanted with a new kidney. It is not uncommon for people who have had kidney failure for many years to have had more than one type of treatment in that time.

Will I need to take special medications?

You may need to take:

- **Phosphate binders.** These medicines keep your bones strong by helping your body balance two important minerals—calcium and phosphorus.
- **A special prescription form of vitamin D.** This medicine also helps to keep your bones healthy.
- **Drugs called ESAs (erythropoiesis-stimulating agents).** ESAs act like a natural hormone made by your kidneys called erythropoietin. This hormone tells your body to make red blood cells. Not having enough of it can cause anemia (low red blood cell count). Treatment with an ESA can help your body make red blood cells.
- **Extra iron.** Your body also needs iron to make red blood cells, especially if you are receiving ESAs. Without enough iron, your ESA treatment will not work as well.

TIP

Part of the reason you feel so tired may be due to anemia (low red blood cell count). Treatment to correct anemia will help you feel stronger and have more energy.

- **Vitamin and mineral supplements.** You may need to take some vitamins and minerals that you are not getting in your diet, or that are lost during dialysis. Your healthcare provider or kidney dietitian will tell you which ones you need.
- **Other medicines.** You may need to take medicines for other health conditions such as to lower high blood pressure, high cholesterol, or diabetes.

If you have a transplant, you will also need to take:

- **Anti-rejection medicines.** These medicines help keep your body from rejecting the new kidney.



Will my diet need to change?

Yes. The type of diet you follow will depend on the treatment you receive. Your dialysis or transplant center will have a kidney dietitian who will help you plan your food choices to make sure you are getting the right amount of protein, calories, vitamins, minerals and fluids. The dietitian will help you with creating a nutrition plan so you can continue enjoying your favorite foods and be as healthy as possible.

Can exercise help me?

Yes. Exercise can help you feel stronger and improve your overall well-being. Walking is good way to exercise. You should speak to your healthcare professional about an exercise program that is right for you.

How long can I live on dialysis?

Now that we know more about how to care for people with kidney failure, they live longer, feel better, and have more active lives. Your overall health and how well you follow your treatment plan are important in how well you do. If you choose dialysis, it is important to get the right dose of dialysis. Studies have shown that dialysis patients do better and live longer when they get enough treatment. Your dialysis care team can measure how much dialysis you receive. This should be done on a regular basis to make sure treatments are cleaning enough wastes out of your blood.



Can I work if I am on dialysis or have a transplant?

Yes. It is possible to work with dialysis or after a transplant. Returning to work may help you feel more positive and independent. If you get in-center dialysis, the staff may be able to arrange your treatments to fit your work schedule. If you do home dialysis, you can fit your treatments into your own schedule.

TIP

To learn more about treatment choices for kidney failure, speak to your healthcare professional or other members of your healthcare team. Ask them to arrange for you to meet with a person who is on dialysis or who has had a kidney transplant. If information seminars are available, try to attend—and take a family member or close friend.



What insurance coverage is available?

Many of the costs of dialysis and kidney transplant are covered by the federal government through Medicare. Medicare is not just for people who are 65 and older. The program also helps Americans and legal residents of all ages who need dialysis or a kidney transplant and who qualify for coverage.

People with kidney failure can enroll in Medicare at their local Social Security office, or by calling **800.772.1213** and making an appointment to enroll. Before signing up, your dialysis clinic or transplant program must complete a form and have it signed by your healthcare professional, verifying you have started dialysis or received a kidney transplant. To find your local office, look for Social Security Administration in the government pages of your phone book or go to **[socialsecurity.gov/locator](https://www.socialsecurity.gov/locator)**.

When does Medicare begin to pay?

Medicare will begin to cover dialysis treatments or a kidney transplant when:

- You start your third full month of in-center hemodialysis
- You start a home dialysis training course at a Medicare-approved facility within the first three months of treatment, and you plan to do home dialysis
- You are admitted to a Medicare-approved hospital for a transplant, or up to two months before admittance if pre-transplant healthcare and testing are started
- You are already on Medicare

How much will Medicare cover?

Medicare may pay up to 80% of the costs associated with dialysis and kidney transplant. But Medicare alone is not enough. Many other sources of coverage are available to help pay for what Medicare does not cover, including:

- Employer health insurance, private health insurance, COBRA
- State programs such as Medicaid and high-risk insurance pools
- Veteran benefits
- State kidney programs
- Medigap (Medicare supplemental health insurance)

To learn more about all your options for insurance coverage, you can speak to:

- Your state insurance commissioner and ask what options are available to you where you live
- An independent insurance broker
- The NKF Cares Patient Help Line toll-free at **855.NKF.CARES** (855.653.2273) or email **nkfcares@kidney.org**
- A financial aid coordinator at your dialysis center or transplant center
- Your county or state social service department or Medicaid office

Does Medicare pay for home hemodialysis?

The federal government's Medicare program covers the cost of home hemodialysis, just as they do for dialysis in a hospital or other treatment center. However, Medicare will not cover the cost of a home health aide if you have no one who can be a care partner for you.

How can my family and I cope with kidney failure?

You and your family may have difficulty accepting the changes in your lives caused by kidney failure, which can be a lot to handle. You may have feelings of frustration, guilt, denial, anger and depression. You and your family may find it helpful to share your questions and concerns with each other and with people who are willing to offer support. These can include close friends

and members of the healthcare team. Social workers at dialysis centers are trained to provide counseling to help people make the transition to dialysis or transplantation.

Some of the biggest changes are:

- getting used to a new routine with peritoneal dialysis or hemodialysis
- following your diet and nutrition plan
- taking all your medicines exactly as instructed by your healthcare professional (including anti-rejection medicines if you have a transplant)
- continuing with your work, studies, school, family commitments, and hobbies

The healthcare team (social workers, dietitians, healthcare professionals, nurses, technicians, and other staff) are trained to help you make these changes and to help you understand all areas of your care.



Is it normal to have fears about beginning treatment?

Yes. It is normal to have concerns about how you will feel, whether the treatment will hurt, what the staff and other patients will think of you, and how long you can live with kidney failure.

The following steps can help you cope with your feelings:

- Ask your healthcare provider if you can visit a dialysis center. Visiting the center can help you make decisions.
- If you are interested in a kidney transplant, ask your healthcare provider for a referral to a transplant center. Set up an appointment to visit with the staff and get answers to your questions.
- Speak to others who have been through the same experience.
- Discuss all your concerns with the healthcare team at the treatment center.
- Call your local National Kidney Foundation (NKF) office for information and a list of the programs and services available. Find your local NKF office by visiting the NKF website at **kidney.org** or by calling the NKF Cares Patient Help Line toll-free at **855.NKF.CARES** (855.653.2273) or emailing **nkfcares@kidney.org**



Comfort Care: Choosing Not to Start Dialysis

What if I do not want to do dialysis or have a transplant?

You have the right to decide whether or not to start dialysis. Some people feel that the burdens outweigh the benefits for them. Often this is due to other health conditions. If you are eligible for a transplant, you also have the right to decide if this is the right option for you. You should discuss your thoughts carefully with people you trust and seek advice from your healthcare provider, family member(s), and others who have your best interests at heart.

What will happen if I don't start dialysis?

Choosing not to start dialysis once your healthcare provider has determined you need dialysis means that you are choosing to let your kidney failure take its natural course. This will ultimately lead to your death.

How long will I live if I choose not to start dialysis?

People with kidney failure may survive for a few days to several weeks without dialysis, depending on the amount of kidney function they have, how severe their symptoms are, and their overall medical condition.

What if I'm not sure if dialysis could help me?

Sometimes it may not be clear if the benefits of dialysis outweigh the burdens. Each person's situation is different. If you are uncertain, you may be able to start treatment for a trial period—for example, one to three months. During and after the trial period, your healthcare professional and the other members of your dialysis team will talk with you about how you are feeling and coping with the treatment routine. Ask as many questions as you need to help with your decision to continue or to stop treatment. It's important to note that you always have the right to stop dialysis at any time.



Will my healthcare team continue to help me?

Yes. Your healthcare professional, advanced practitioner, social worker, nurse, and other healthcare team members should be available to you and your family to discuss your concerns and advise you about the type of care you might need. Your healthcare team will help arrange the necessary referrals or consultations for your circumstances. Supportive care or palliative care can assist you to make sure you are comfortable. Many people choose to remain at home, and services are available to support you and your family.

How do I discuss this decision with my family and friends?

Many people find it difficult to talk about whether or not to start treatment, and they worry about how others will feel and react. The best approach is to discuss your feelings openly with your loved ones. Your family will most likely feel very emotional too, and may have questions. You may wish to consult with your religious or spiritual advisor, social worker, healthcare professional, or other healthcare worker before making a decision.

Where can I learn more?

There are many things to consider when choosing comfort care only. The National Kidney Foundation has a brochure called *If You Choose Not to Start Dialysis Treatment*, which is specifically dedicated to this topic; call the NKF CARES Patient Help Line toll-free at **855.NKF.CARES** (855.653.2273) or email **nkfcares@kidney.org** to request your free copy.

Setting a standard for care

The National Kidney Foundation, through its *Kidney Disease Outcomes Quality Initiative* (KDOQI®), defines stages of kidney disease and offers guidelines that help your healthcare professional and healthcare team make important decisions about your medical treatment.

The information in this booklet is based on those recommended guidelines.



The information contained in this publication is based on current data and expert guidance available at the time of publication. The information is intended to help patients become aware of their disease and its management. This publication is not intended to set out a preferred standard of care and should not be construed as one. Neither should the information be interpreted as prescribing an exclusive course of management. Patients should always consult with their healthcare providers regarding decisions about their individual plan of care.



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Fueled by passion and urgency, the National Kidney Foundation (NKF) is a lifeline for all people affected by kidney disease. As pioneers of scientific research and innovation, we focus on the whole patient through the lens of kidney health. Relentless in our work, we enhance lives through action, education, and accelerating change.

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