



# Kidney Care Guide

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# What is your stage of kidney disease?

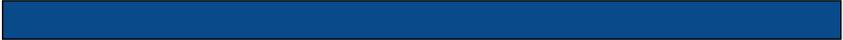
There are 5 stages of kidney disease. They are shown in the table below. Your doctor determines your stage of kidney disease based on the presence of kidney damage and your glomerular filtration rate (GFR), which is a measure of your level of kidney function. Your treatment is based on your stage of kidney disease. Speak to your doctor if you have any questions about your stage of kidney disease or your treatment.

## STAGES OF KIDNEY DISEASE

Stage	Description	Glomerular Filtration Rate (GFR)
1	Kidney damage (e.g., protein in the urine) with normal GFR	90 or above
2	Kidney damage with mild decrease in GFR	60 to 89
3	Moderate decrease in GFR	30 to 59
4	Severe reduction in GFR	15 to 29
5	Kidney failure	Less than 15

**\*\* Your GFR number tells your doctor how much kidney function you have. As chronic kidney disease progresses, your GFR number decreases.**

If your doctor 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 if your kidney's 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. You may have some of the following symptoms:

- 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 doctor 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

To help know when you need to start treatment, your doctor should give you a simple blood test to estimate your glomerular filtration rate (GFR). This tells how much function your kidneys have.

## How is GFR calculated?

Your doctor can estimate your GFR from the results of a simple blood test for creatinine. Creatinine is a waste product of your body's muscle activity. Your kidneys usually keep the level of creatinine just right. Your creatinine result is used in a math formula with your age, race and gender to determine your GFR. If your GFR falls below 30, your doctor should give you information about treatments for kidney failure. If your GFR is below 15, you will need to start one of these treatments soon.

## 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. Each type of treatment has pros and cons. As you find out more about each one, speaking with your doctor and your family can help you decide which treatment is best for you.

# Your decision should be based on many things:

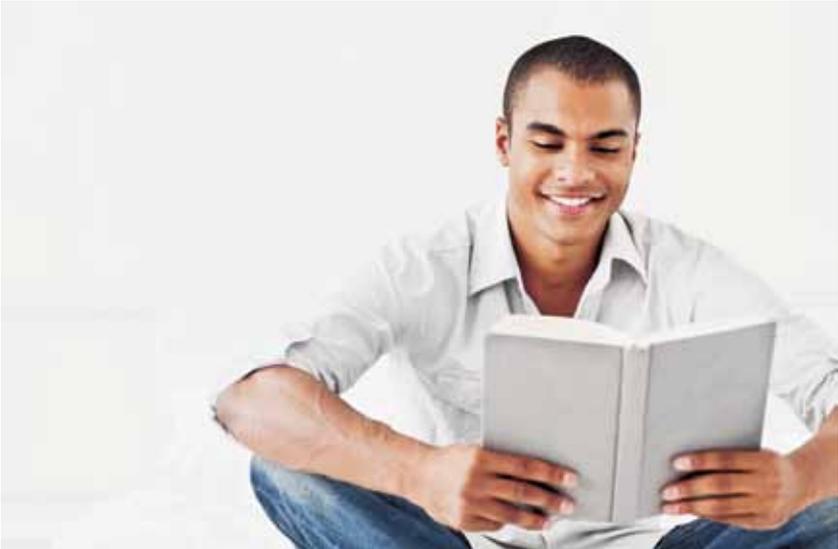
- Medical condition
- Lifestyle
- Personal preference

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.



# 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 12, “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.

## What is required to do hemodialysis at home?

Your home must have enough space for the equipment and enough water drainage and electric 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. You will also need 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 in how to do hemodialysis at home.

## Are there different types of home hemodialysis?

With home hemodialysis, you will have 3 different types of treatment schedules to choose from. These choices are:

- **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

## Advantages:

1. Dialysis is done in the comfort of your own home.
2. You do not need to travel to a dialysis center.
3. You have more flexibility to choose a time of day to do dialysis.
4. You and your dialysis partner learn how to do treatments independent of the center staff.
5. There is a greater sense of control from having independence with the treatment schedule in relation to your life and work schedule.

## Disadvantages:

1. Space in the home needs to be dedicated to the machine, water system (if needed) and supplies.
2. A dialysis partner must be present while you are on dialysis.
3. Both you and your dialysis partner must take time off work or regular routine to attend training.

## Notes:

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# In Dialysis Center

## Advantages:

1. Trained staff performs all aspects of treatment. (You may be able to do some things yourself, like insert the needles.)
2. Since other people are dialyzing at same time, friendships may develop.

## Disadvantages:

1. Treatment day and times are scheduled by the center.
2. You must travel to the center at least three times weekly.
3. Other people are doing dialysis at same time, so you have less privacy.
4. Loved ones may worry if they can't be with you during treatment.
5. There may be rules against eating and drinking while on dialysis.

## Notes:

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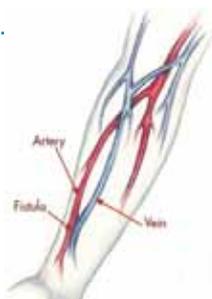
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# What is a hemodialysis access?

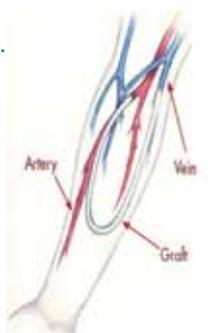
If you choose hemodialysis, you need to have a permanent access, or entrance, to your bloodstream. This is done with minor surgery, usually to your arm.

## There are three different types of access:



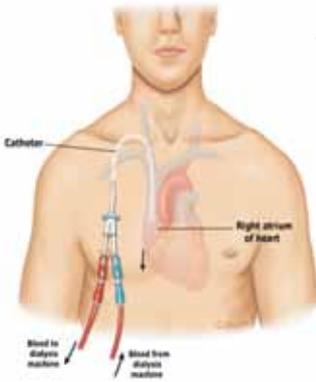
### • **Fistula**

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 doctor called a vascular surgeon at least 6 months before you will need to start dialysis. Your kidney doctor or the surgeon may order an ultrasound evaluation of your blood vessels to see the ideal ones 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 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 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. Catheters are 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.

### TIP

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?

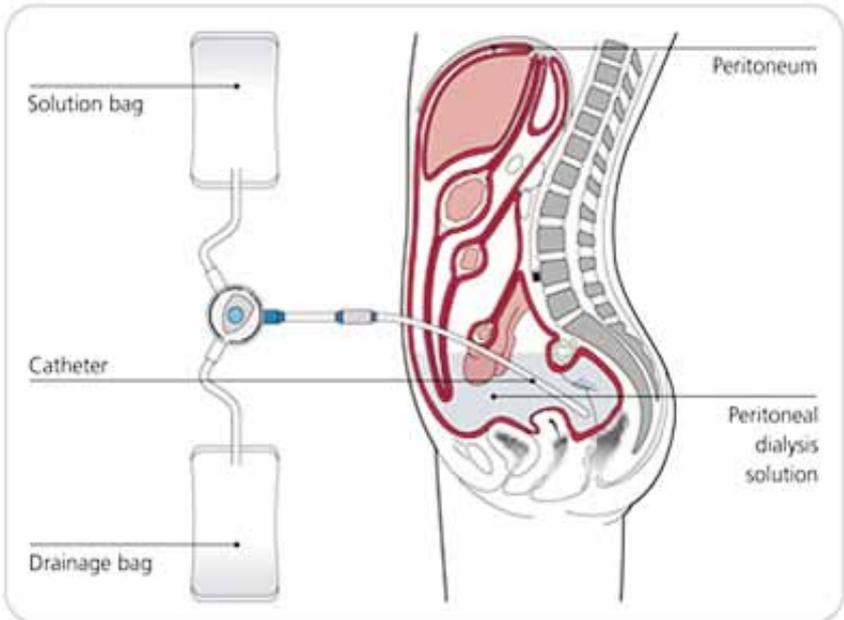
Yes. The major ones are:

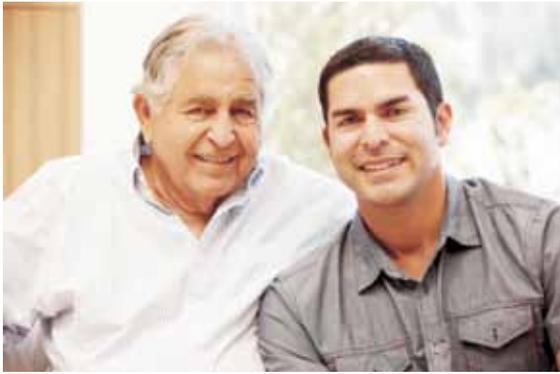
- **Continuous Ambulatory Peritoneal Dialysis (CAPD).**

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.





# 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 the 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.

## Could I get a transplant before going on dialysis?

Yes. In fact there are long-term benefits of 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. (To locate a transplant center, see page 25.) 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. 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.

# 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.

## If I choose one type of treatment for kidney failure, will I be able to change to another 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 about the possibility of changing. 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 keep the right balance of 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 because of anemia (low red blood cell count). Treatment to correct anemia will help you to feel stronger and have more energy.

- Vitamin and mineral supplements. You may need to replace some vitamins and minerals that you are not getting in your diet, or that are lost during dialysis. Your healthcare provider or dietitian will tell you which ones you need to take.
- Other medicines. You may need to take other medicines, depending on your own medical needs. These could be medicines to control high blood pressure, high cholesterol, or diabetes.

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

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

## **Will my diet have to change?**

Yes. The type of diet you follow will depend on the treatment you receive. Your dialysis or transplant center will have a 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 make a nutrition plan that helps you continue to enjoy your favorite foods and be as healthy as possible.

## **Can exercise help me?**

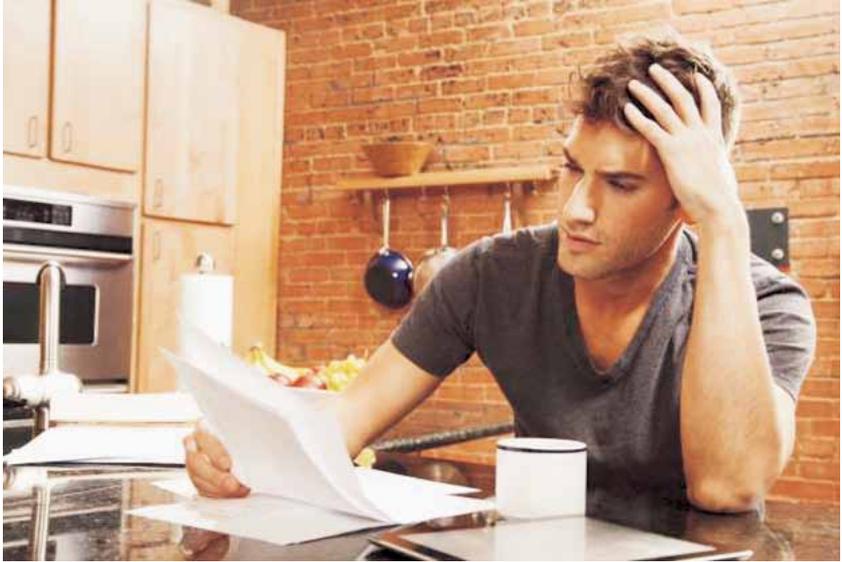
Yes. Exercise can help you feel stronger and improve your overall well-being. Walking is a good way to exercise. You should speak to your doctor about an exercise program that is right for you.

## **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.

# 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.



## 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 qualify for coverage. People with kidney failure can enroll in Medicare at their local Social Security office, or by calling **1.800.772.1213** 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 doctor, 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 **[www.socialsecurity.gov/locator](http://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 begun
- 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's 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
- A financial aid coordinator at your dialysis center or transplant center
- Your county or state social service department or Medicaid office

## 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 doctor 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.

## 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. The social worker at your dialysis center is trained to provide counseling to help you make the transition to dialysis or transplantation.

The healthcare team (social workers, dietitians, doctors, 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 the disease.

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 choices.
- 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 make a list of questions.
- Speak to others who have been through the same experience.
- Discuss all your concerns with the healthcare team at the treatment center

### Notes:

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