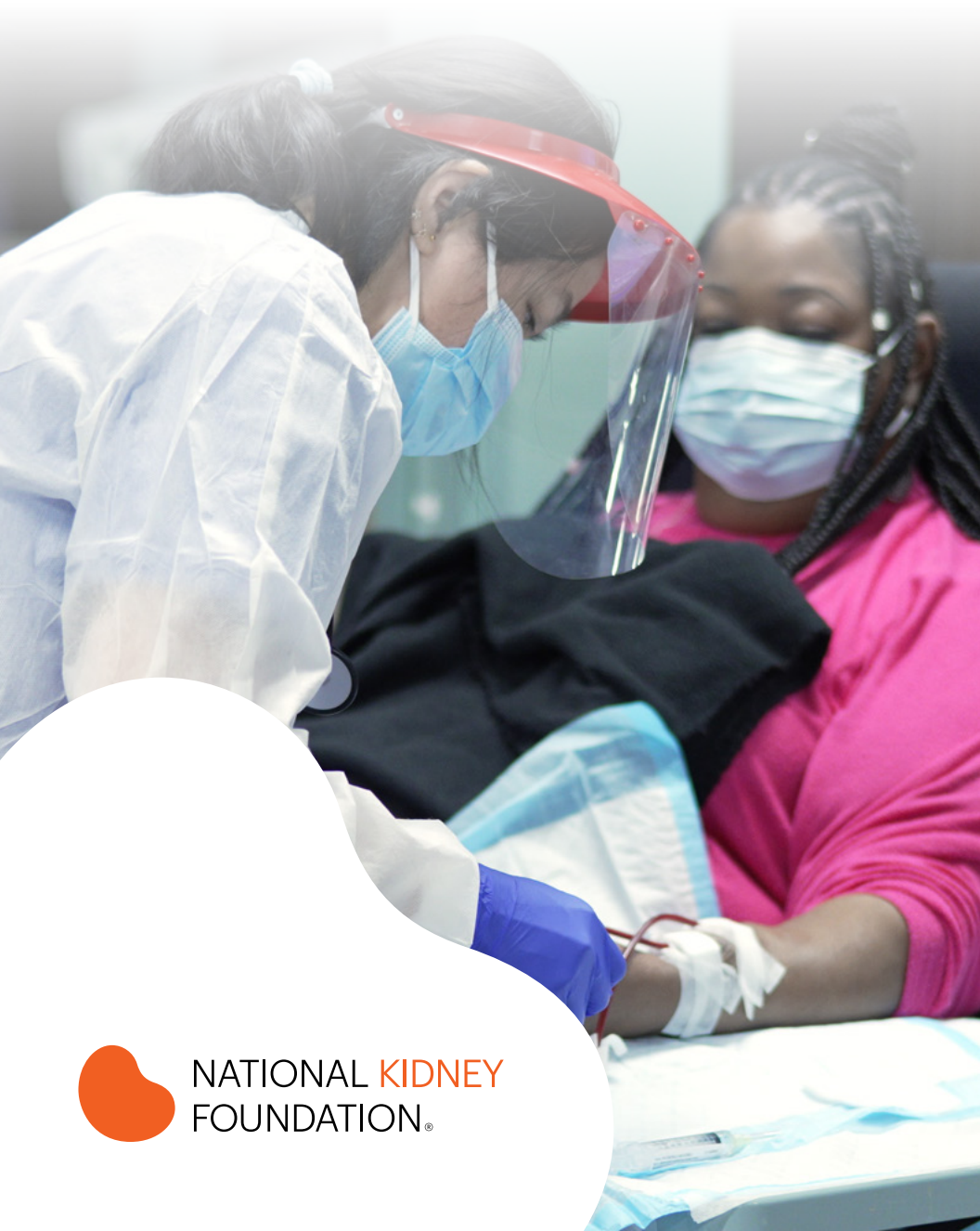


Dialysis and You

What you need to know



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Kidney Failure

Stage 5 chronic kidney disease, also known as kidney failure, means your kidneys are functioning at less than 15% of a healthy kidney. For most, loss of kidney function is a slow process that can take many years. Since early chronic kidney disease (CKD) does not usually have any symptoms, many people learn they have CKD when their kidney function is very low.

Healthy kidneys are responsible for:

- Removing waste products and extra fluid from the body
- Filtering about 190 quarts of blood to produce about two quarts of urine (pee) every 24 hours
- Making enzymes, called renin, that work with hormones to control blood pressure

- Releasing a hormone called erythropoietin, that tells the bone marrow (a spongy substance that is inside bones) to make more red blood cells
- Creating an active form of vitamin D to keep calcium at steady levels
- Removing excess phosphorus in the blood
- Keeping important chemicals well-balanced in the body

When you have kidney failure, you will need either dialysis or a kidney transplant to survive.

DIALYSIS

Dialysis (hemodialysis and peritoneal dialysis) is a treatment that does some of the work that is normally done by healthy kidneys. Dialysis is needed when your own kidneys can no longer take care of your body's needs. Dialysis allows your body to:

- Remove waste and extra water to prevent them from building up
- Keep a safe level of certain chemicals in your blood such as potassium, sodium, and bicarbonate
- Help to regulate blood pressure

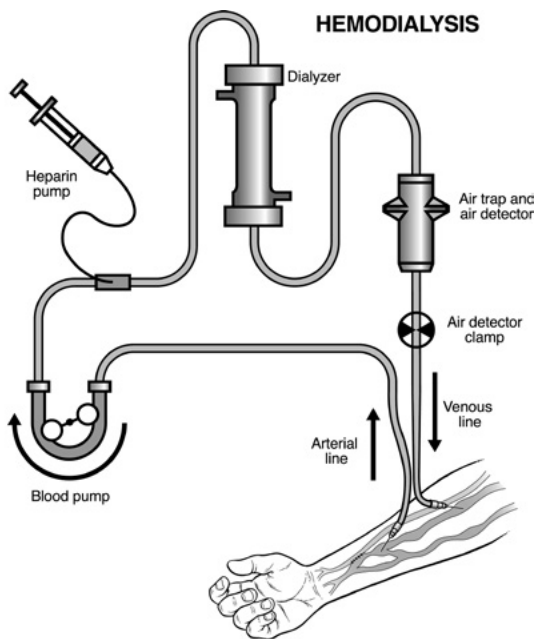
HEMODIALYSIS

Hemodialysis is a life-saving treatment for people with kidney failure. A hemodialysis machine works as an artificial kidney by removing wastes and extra fluid from your blood.

During hemodialysis, your blood is pumped through soft tubes to a hemodialysis machine where it goes through a special filter called a dialyzer. 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.

A vascular access, which is an opening made in your skin and into a blood vessel, is the way you are connected to the hemodialysis machine. A surgeon creates a vascular access during a short surgical procedure.

When you have dialysis, your blood flows out of the access through soft tubes and into a hemodialysis machine. After your blood is filtered in the machine, it goes through a soft tube to the access and back into your body.



Hemodialysis can be done at a hospital, a dialysis center, or at home. Hemodialysis treatments at a dialysis center are usually done 3 times a week and each treatment takes 3 to 4 hours to complete. Home hemodialysis treatments may be performed more frequently, usually 5 to 6 days a week.

You and your healthcare provider should work together to decide the best location for your hemodialysis treatment.

PERITONEAL DIALYSIS

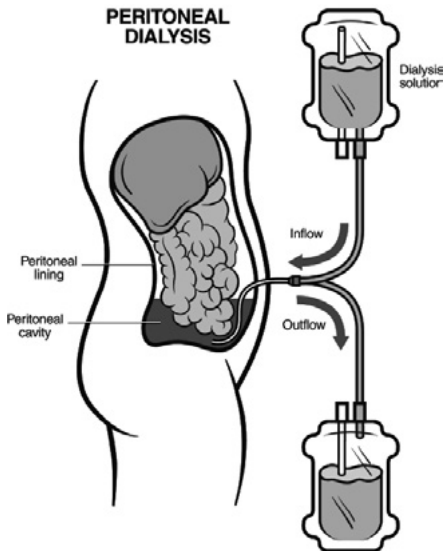
There are two kinds of peritoneal dialysis (PD) -- continuous ambulatory peritoneal dialysis (CAPD) and automated peritoneal dialysis (APD).

The basic treatment for CAPD and APD is the same. However, the number of treatments and the way the treatments are done make each method different.

CAPD is a continuous, machine-free treatment and it is done while you go about your normal activities such as working, attending school, or traveling.

With CAPD, about two quarts of cleansing fluid flows through a tube that goes into your belly and then draining the fluid through a second tube. This process is called an exchange (putting in and taking out the fluid).

With CAPD, you raise the plastic bag of cleansing fluid to shoulder level, which allows the fluid to flow into your belly. When empty, the plastic bag is removed and thrown away.



When an exchange is finished, the fluid (which now has wastes removed from your blood) is drained from your belly (into another plastic bag) and thrown away.

Each exchange takes about 30 to 40 minutes and is usually done three to five times in a 24-hour period while you are awake. Some patients like to do their exchanges at mealtimes and before going to bed.

APD differs from CAPD in that a machine (cycler) delivers and then drains the cleansing fluid for you. This treatment is usually done at night while you sleep.

TRANSPLANTATION

Transplantation is when a healthy kidney from a donor (living or deceased) is surgically placed inside your body. Kidney transplant surgery usually lasts 3 to 4 hours. A kidney transplant is not a cure for kidney failure, it is a treatment.

When you have a kidney transplant, the new kidney functions as a normal kidney. Usually, your damaged kidneys are left in place and not removed. Only one donor kidney is transplanted, and it is placed in the lower part of the abdomen.

For the rest of your life, you will need to take immunosuppressant medication, which lowers the risk of your body rejecting the transplanted kidney. Side effects of immunosuppressant medication can include weight gain, acne, upset stomach, and facial hair. Long-term side effects of immunosuppressant medication include a weak immune system.

CONSERVATIVE MANAGEMENT

Conservative management focuses on your quality of life and managing symptoms without dialysis or a kidney transplant. Conservative management is also called comfort care, non-dialytic care, supportive care, or comprehensive conservative care.

The goals of conservative management are to:

- Preserve kidney function for as long as possible
- Manage symptoms (nausea, loss of appetite, and depression) and other kidney-failure-associated problems, such as anemia
- Maintain a good quality of life for as long as possible
- Prepare for end-of-life care



Dialysis Care Team

The dialysis care team consists of your doctor (nephrologist) or advanced practitioner, nephrology nurse, kidney dietitian, nephrology social worker, and dialysis technician.

NEPHROLOGIST

The team leaders in many clinics are doctors called nephrologists—or kidney doctors. They have advanced training in treating kidney disease. They are responsible for your care during dialysis treatments. Nephrologists also may take care of patients before and after a kidney transplant.

ADVANCED PRACTITIONER

Your team may also include advanced practitioners. nurse practitioners (NP) and physician assistants (PA) collaborate with the doctors in caring for kidney patients both in medical offices or in the dialysis unit.



NEPHROLOGY NURSE

Nephrology nurses are registered nurses (RNs) or licensed nurses (LVNs/LPNs) with education, training, and experience in caring for people at all stages of CKD, including stage 5 or kidney failure. They follow the rules, guidelines, and regulations set forth by the State Board of Nursing and described in the State Nurse Practice Act.

Medicare requires that each dialysis center have a full-time RN with experience in dialysis. The RN is responsible for nursing services and home training programs for patients.

REGISTERED KIDNEY (RENAL) DIETITIAN

Registered kidney dietitians can help you plan healthy meals based on your personal lab reports. Your kidney dietitian will review your monthly labs and show you how different foods can affect how you are feeling.

They can also recommend the best types of supplements to prevent and treat malnutrition, bone problems, and anemia.

NEPHROLOGY SOCIAL WORKER

Nephrology social workers provide emotional support as you adjust to your dialysis routine. They are also available to assist with travel arrangements so you can get to your treatments and make sure that you have access to your medications, appropriate housing, and help you to fully understand all your treatment options.

PATIENT CARE AND BIOMEDICAL TECHNICIANS

There are two kinds of technicians in your dialysis center—patient care technicians (PCTs) and biomedical technicians. Both work under the guidance of the nephrology nurse or nephrologist.

PCTs perform your dialysis treatment. In many dialysis centers, they are responsible for starting and ending each treatment and for monitoring you before, during, and after treatments. PCTs complete an in-depth training program. Some states require that they have state or national certification.

Biomedical technicians are responsible for maintaining dialysis machines and water quality in your center. They order dialysis supplies and reprocess dialyzers for reuse.



Adjusting to Dialysis—Your New Normal

Getting used to the routines of dialysis will likely take some getting used to. There are a number of things you will need to learn and many new experiences to adjust to in the first few weeks.

EMOTIONAL HEALTH

Dialysis is a life-changing process and learning how to cope is important. Many people on dialysis say that fear and confusion are two very common feelings when they first started. Others felt odd seeing their blood going through the dialysis machine. Just remember, whatever you are feeling, there are people on your dialysis team who can answer questions and help support you when you are anxious.



Almost everyone gets past their initial fears of being on dialysis. Most say they are now doing fine and are comfortable with dialysis. Becoming more knowledgeable and more experienced—knowing what to expect—often helps a person cope better.

Dialysis is not only new for you—but also for those closest to you, your family and friends will also want to support you. In addition, your loved ones may have questions about kidney failure and dialysis treatment.

It's best to be honest and transparent with them. You will feel better and they will be in a better position to help and support you. Tell them when you need help with transportation, driving your kids to school, or going to doctor appointments.

PHYSICAL HEALTH

People on dialysis are much more likely to develop heart and blood vessel disease (also called cardiovascular disease). This higher risk is due to other health problems that often accompany kidney failure, such as diabetes and high blood pressure. It is very important that you do what you can to prevent or manage heart and blood vessel problems.

Some of the ways to stay healthy while on dialysis include:

- Stay on your dialysis treatment
- Follow the prescribed diet as much as possible
- Plan out meals with a kidney dietitian
- Take all of your medications exactly as prescribed
- Exercise regularly
- Manage your stress
- Socialize with family and friends
- Speak to a nephrology social worker about support groups for people on dialysis
- Seek help to stop smoking

In addition, after a dialysis treatment, you may have low blood pressure (hypotension) if too much fluid is removed from your body. Muscle cramps can also occur if too much fluid is removed or if the fluid is removed too fast. If your blood pressure drops, you may experience nausea and/or dizziness due to low blood pressure.



Nutrition

Your diet is an important part of your treatment. Your kidneys cannot get rid of enough waste products and fluids from your blood so you may need to limit fluids and change certain foods in your diet. You may need to:

- Eat more high-protein foods
- Eat less high-salt, -potassium, and -phosphorus foods
- Change the amount of fluid you drink (including coffee, tea, water, and any food that is liquid at room temperature).

Your kidney dietitian at your dialysis center will help you plan a healthy diet.

PROTEIN

People on dialysis need to eat more protein. Protein can help keep healthy blood protein levels and improve health. Protein also helps keep your muscles strong, heal wounds faster, strengthen your immune system, and helps improve overall health. Eat a high-protein food (meat, fish, poultry, fresh pork, or eggs) at every meal, or about 8–10 ounces of high-protein foods every day. Here are some examples of portion sizes:

- 3 ounces = the size of a deck of cards: a medium pork chop, a $\frac{1}{4}$ pound hamburger patty, $\frac{1}{2}$ chicken breast, or a medium fish fillet
- 1 ounce = 1 egg or $\frac{1}{4}$ -cup egg substitute, $\frac{1}{4}$ -cup tuna, $\frac{1}{4}$ -cup ricotta cheese, 1 slice of low sodium lunchmeat, 1 tablespoon peanut butter, $\frac{1}{2}$ ounce of nuts or seeds

Note: Highly processed foods should be avoided because of their *high phosphorus and sodium content*. Whole plant-based foods such as nuts and beans can be high in phosphorus but they are less absorbed than phosphorus amounts in *processed foods*.

POTASSIUM

Potassium is a mineral that is found in dairy products and fruits and vegetables. The muscles and nerves in your body use potassium to function. Too much or too little potassium can prevent your heart muscle from working properly. Your kidney dietitian can let you know the appropriate amounts of potassium you should eat.

PHOSPHORUS

Phosphorus is a mineral found in many foods that you eat every day. It is important for strong bones and healthy blood vessels. However, if your phosphorus levels are too high, it can cause weak, brittle bones and heart problems.

SODIUM

Salt is made up of sodium and chloride, and just 1 teaspoon of salt has the daily recommended amount of sodium. About 80% of the sodium is in the food we eat. Most fast foods, foods found in convenience stores, and processed foods are very high in sodium.

When you have high levels of sodium in your blood, excess fluids start building up in your body. Having too much fluid in your body can increase blood pressure, and cause breathing trouble, heart damage, and higher fluid weight gains between dialysis treatments.

People on dialysis are encouraged to buy snacks that are low in sodium, to cook with and use less table salt at home, and to eat fewer salty foods when out. Instead, replace salt with herbs, spices, and low-salt flavor enhancers. Also, avoid salt substitutes made with potassium.

MANAGING FLUIDS

Healthy kidneys remove extra fluids from the body. Dialysis also removes excess fluids that build up in your body, but not all of the excess fluids. This is the reason why people on dialysis have frequent lab tests.



The lab results let you and your dialysis team know if you should increase or limit how much fluid you consume. It's important for your dialysis team to measure your dry weight and know whether you are still urinating.

Gaining large amounts of fluid weight between dialysis treatments is unhealthy. Having too much fluid in your body can cause swelling, high blood pressure, and congestive heart failure. Removing large amounts of fluid during dialysis can cause cramping, low blood pressure, headaches, and nausea.

SUPPLEMENTS

Typically, people on dialysis take prescription kidney vitamins to replace nutrients and minerals lost during dialysis. Some nephrologists recommend other kinds of nutritional supplements to meet individual needs. Any over-the-counter supplements you may want to take should be discussed with your dialysis team before starting.



Financial Resources

EMPLOYER GROUP HEALTH INSURANCE PROGRAM (EGHP):

If you already have commercial health insurance, you can keep it. If you are no longer able to work, you may be able to keep your benefits through COBRA.

MEDICARE

Medicare is not just for people who are age 65 and older. The government program also helps US citizens and legal residents of all ages who need dialysis or a kidney transplant. Over 90% of Americans with kidney failure, which Medicare calls End-Stage Renal Disease or ESRD, have Medicare.

If you (or your spouse or parent) have worked long enough to qualify for Medicare, it will pay most of your treatment costs, plus some or all of the costs for hospital stays, visits to doctors, and other services.



If you have insurance through your or your spouses' employer (Employee Group Health Plan), you can still apply for Medicare. Please call the NKF Cares Patient Help Line toll-free at **855.NKF.CARES** (855.653.2273) or email us at nkfcare@kidney.org to learn more.

When someone first enrolls in Medicare with a diagnosis of kidney failure (ESRD), Medicare coverage usually starts:

- On the fourth month of dialysis treatment
- Medicare coverage can start as early as the first month of dialysis if:
 - » You enroll in a home dialysis training program
 - » You start home dialysis training before the third month of dialysis; and are expected to finish home dialysis training and do dialysis at home.

MEDICAID

Medicaid is a federal, government-sponsored insurance program, which is available to people who meet income requirements. Usually, eligibility for Medicaid benefits is the same as those used for *Federal Poverty Guidelines*. There are many levels of Medicaid insurance.

In addition to federal Medicaid insurance, you may be eligible for additional coverage issued by your state and county. Some counties offer assistance with transportation and may help you qualify for Supplemental Nutrition Assistance Program (SNAP, formerly called the Food Stamp Program).

SOCIAL SECURITY DISABILITY (SSD)

Usually, 20 work credits earned in the last 10 years are needed to qualify. However, younger workers may be eligible for disability benefits with fewer work credits. If you are disabled before the age of 24, you will need 6 earned credits in the three years prior to the start of your disability.

If you do not have enough work credits but have a long-term or permanent disability, you may be able to qualify for Supplemental Security Insurance benefits without any earned work credits.



Living Well on Dialysis

Starting dialysis can affect many parts of your day-to-day life. Many people find comfort in keeping their routines as close as possible to their already-established lifestyle. Others may prefer to focus on their dialysis treatment and adjusting to their routine. And, there are also those who feel kidney transplantation is their best treatment option. There are no right or wrong feelings.

Always remember, choosing to have dialysis is a personal choice and the decision is always yours.

TRAVEL

Most patients who receive dialysis can travel safely and continue their treatment while away from home. You should always consult your doctor before planning to travel. Most doctors encourage travel if your health is good. Traveling can give a big boost to your morale and sense of well-being.

Many dialysis centers have a staff member who is experienced in arranging dialysis treatments away from home (transient dialysis). Some centers will help patients make travel arrangements. Ask your social worker or nephrology nurse to assist you.

In addition, **dialysisfinder.com** is a website that has listings and contact information for dialysis centers across the US and around the world. Your Medicare and commercial insurance will likely pay the same amount as it would at your home center.

Medicaid benefits usually have limited coverage outside of your home state. When you book travel, contact the agency so you know the amount of your financial responsibility.

HOME HEMODIALYSIS

People who are on home hemodialysis can travel but may want to make plans for in-center treatments while away. Some people prefer to travel with their machine, supplies, and portable water treatment equipment.

PERITONEAL DIALYSIS

People on peritoneal dialysis (PD) should plan ahead and arrange for back-up medical care while traveling.

Contact a dialysis center that's near where you will be staying and see if you could go there if you have an emergency. The center may request a copy of medical records in advance. You should always carry a copy of your records with you.

EMPLOYMENT

Many people who are receiving dialysis treatment can go back to work after they have gotten used to their dialysis routine. However, if your job requires a lot of physical labor (heavy lifting, digging, etc), you may be unable to continue working.

You should work out your dialysis schedule with your employer. Most employers are flexible about your need for dialysis.

It is also important to understand your rights under the federal Americans with Disabilities Act (ADA). For example, working out your employment schedule with your dialysis schedule is a "reasonable accommodation" that employers are required to make under the ADA, unless they can prove it is an unnecessary hardship. Ask your nephrology social worker for more information.



Additional Resources

NKF PATIENT AND FAMILY RESOURCES

The National Kidney Foundation (NKF) has compiled a list of resources that you may find helpful. While we try to keep this list current, we cannot ensure the accuracy of information found on other websites.

[kidney.org/patients/resources](https://www.kidney.org/patients/resources)

NKF CARES

Our Patient Information Help Line, NKF Cares, offers support for people affected by kidney disease, organ donation or transplantation. It's designed just for patients, family members and care partners. Connect with a trained specialist who will answer your questions and listen to your concerns.

Call toll-free at **855.NKF.CARES** (855.653.2273) or email **nkfcare@kidney.org**

NKF PEERS

Connect with a trained peer mentor who can share their experiences about dialysis, transplant, or living kidney donation with you.

Call **855.NKF.PEER** (855.653.7337) or go online **[kidney.org/patients/peers](https://www.kidney.org/patients/peers)**

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 doctor 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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The National Kidney Foundation is revolutionizing the fight to save lives by eliminating preventable kidney disease, accelerating innovation for the dignity of the patient experience, and dismantling structural inequities in kidney care, dialysis, and transplantation.

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