Dear Reader,

The Centers for Medicare & Medicaid Services is pleased to provide you with this booklet. Medicare wants to make sure that you get good care and the information you need to make informed choices about the treatment of kidney failure. The information in this booklet was reviewed by doctors, nurses, and patients and will help new kidney failure patients as they begin dialysis or prepare for transplantation.

If you are a kidney patient, it's important for you to learn as much as you can about your illness and to take an active role in your care. If you are a family member or caregiver, learning about kidney disease and its treatment will help both you and the person with kidney failure. If you have questions, don't be afraid to ask your health care team for help.

Your local End Stage Renal Disease (ESRD) Network can help you if you have a problem. Their phone number is on page 39. ESRD Networks assist patients needing information, help with care concerns, and with resolving complaints. ESRD Networks also work on improving the quality of care in dialysis facilities and keep your facility aware of important dialysis and transplant issues.

We hope this booklet will be helpful to you as you start dialysis or prepare for a transplant.

Best Regards,

Centers for Medicare & Medicaid Services

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Living with Kidney Failure: You Are Not Alone

"Understanding kidney failure and

What You May Be Feeling

Kidney failure may mean some changes in your life, but you can still do many of the things that you enjoy. Try to stay positive, and talk to someone who understands what you are going through, such as another person with kidney failure or a counselor. You can also set goals to

- stay active.
- do the things you did and enjoyed before kidney failure.
- return to work, school, or volunteering.
- pursue new interests.
- live the best life you can.

Learning to live with kidney failure can take time, so don't be discouraged. Talk with your loved ones about how you feel. Listen to what they have to say too. Some days you may feel like giving up or may be angry that your life isn't the same as it was before. See your doctor or social worker right away if these feelings of sadness or anger don't go away, if you are using drugs or alcohol to cope, or if you have thoughts of taking your life. You don't have to deal with your feelings alone. Your loved ones, others with kidney failure, and your health care team can help. Dealing with your feelings will help you live a full life.

"Kidney failure may mean some changes in your life, but you can still do many of the things that you enjoy."

Treating Kidney Failure

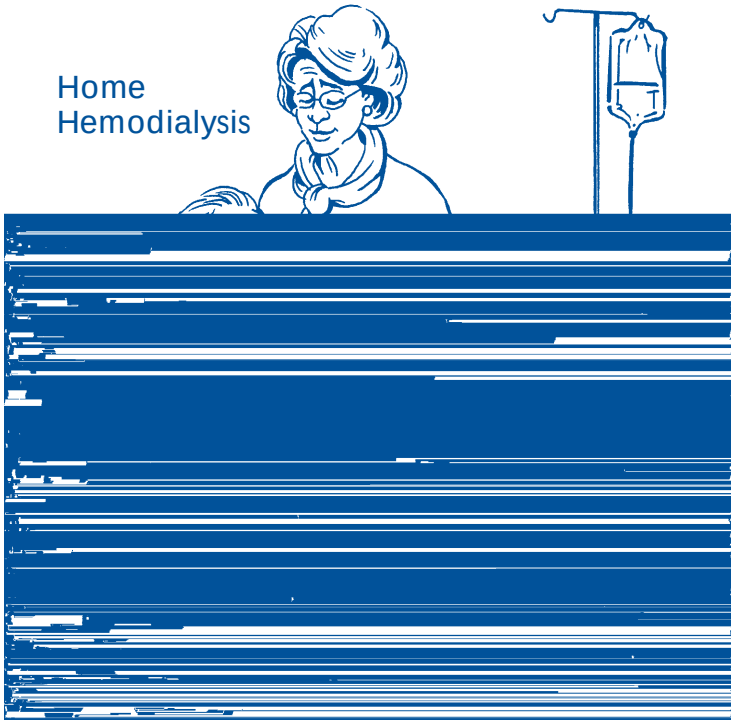
"Kidney failure is also called End Stage Renal Disease or ESRD."

When Kidneys Fail

Your kidneys are just below your rib cage in the middle of your back. They are twin organs shaped like kidney beans. Healthy kidneys work all day, everyday, to clean your blood and make urine that flows into your bladder. Kidneys also make hormones that help control your blood pressure and help make red blood cells, which carry oxygen through your body. They also help balance the level of many minerals and chemicals in your body.

Kidney failure occurs when kidneys can't clean your blood or rid

Hemodialysis can't do all the work your kidneys did. Healthy kidneys work all day, everyday. Hemodialysis usually occurs three times a week for about four hours each time. Your time is based on your needs. Your kidney doctor orders the length of your treatment in order to help meet your body's needs.



During a hemodialysis treatment, your blood is carried through plastic tubes to the dialyzer to be cleaned. Once your blood is cleaned, it's returned from the dialyzer to your body through another plastic tube. Only about one cup of blood travels through the dialysis machine at a time.

Hemodialysis can be done at an outpatient treatment center or in your home. For home hemodialysis, you and a family member or caregiver will need to be trained on how to safely do each step of the treatment. Equipment and supplies are sent to you if you dialyze at home. Not all centers offer home hemodialysis training and support. Ask your kidney doctor if this is an option for you.

In a center, nurses and technicians with special training carry out the steps of your treatment. In some centers, you can also be trained to do some or all of the steps of your treatment. Taking an active role in your treatment may help you feel more in control. At the center, your dialyzer may or may not be re-used. Re-use is when the dialyzer is specialourto8king

"There are three kinds of access—Fistula, Graft, and Catheter."

There are three kinds of access—Fistula, Graft, and Catheter.

- A fistula or arteriovenous fistula (AVF) surgically connects an artery and a vein. A fistula needs weeks to months to heal and "mature" before it can be used. When a fistula matures, it becomes larger and stronger and better for dialysis. It's considered the best access because it lasts longer, has fewer problems, gives better hemodialysis results, and can lower the risk of infection. With a fistula, you can improve your quality of life and length of life. A fistula isn't right for everyone, but you should be evaluated for a fistula, and given one if it's the best access for you. It's best to get a fistula before you need dialysis so that it can be ready for use when you need it.
- A graft or arteriovenous graft (AVG) uses special tubing to surgically connect an artery and vein. A graft needs less healing time than a fistula. However, a graft must be replaced every so often.
- A catheter makes a temporary access by inserting a soft, flexible tube into a vein in the neck, chest, or groin. A catheter can be used as soon as it's in place.

Hemodialysis Checklist

Before every hemodialysis treatment, you should

- ¢ wash your hands before going to your chair.
- ¢ if you have fistula or graft access, clean your access before going to your chair. If you have a catheter, keep the dressing clean and dry. Be sure a member of your health care team cleans and changes the dressing at each treatment.
- ¢ tell your nurse or doctor if you have concerns about how you are feeling.
- ¢ tell your nurse if you have any nausea, pain, vomiting, diarrhea, or constipation.
- ¢ check that your dialyzer has your name on it if your center re-uses dialyzers.

For every hemodialysis treatment, your nurse or technician should

- ¢ wash his or her hands and put on new gloves before putting in your needles.
- ¢ ask how you have been feeling and eating.
- ¢ check your access -oi2.,1d3 Tr -m Tr -flyou ing. rly sigt h.

Questions to Ask your Hemodialysis Center Staff

- Does my treatment time affect when I should take my prescribed medicines?
- How should I plan what I eat around my treatment time?
- Do I have to get treatment at the center my doctor recommends?
- Does the center set times for treatment or is it first come, first serve?
- Can I ask for a treatment time that works best for me?
- Are there staff who speak the same language as I do?
- Who reviews my monthly lab work with me?
- If the center re-uses dialyzers, how will I know the dialyzer is mine?
- How often does the doctor see people during treatment?
- What kind of patient education does the center offer?
- Does the center teach home dialysis?
- Will the center allow me to do some or all of my treatment steps?
- What are the times that the social worker or dietitian can see patients?
- Can I get help with care planning and making an advanced directive?
- Does the center have an exercise program or a place and equipment for exercise?
- What are the center's hours during a holiday?
- What things will I be billed for that are not covered by Medicare or my insurance?
- What are my transportation options for getting to and from the dialysis center?
- Can I have visitors during my treatment?
- Is there a staff member or patient that will talk to me if I get depressed?
- Will I have my own TV? Are there headphones to keep out noise?
- If I go on a trip or have to go to the hospital, will the center hold my treatment

Peritoneal Dialysis

Peritoneal dialysis (PD) uses the space in your belly called the peritoneal cavity to clean your blood. PD doesn't use a dialyzer. This space is lined with a membrane called the peritoneum. It surrounds and protects your intestines, bowel, and other organs. The membrane has many tiny holes that can be used to filter waste out of your blood while keeping blood cells and proteins in your vessels.

"Your kidney doctor will tell you how many exchanges you should do each day."

PD usually works all day, everyday. To have PD you must have an access, which is a soft, flexible tube called a catheter surgically placed in your belly. The bottom part of the tube is put into the peritoneal cavity. The middle part of the tube runs under your skin. The top part stays outside of your body and can be taped against your skin.

A liquid called dialysate travels through the catheter and fills the empty space in your belly. This liquid stays in the space while waste products and extra fluid move from your blood through the membrane into the dialysate. The dialysate with the waste products and extra fluid is then drained out of your body. Next the space in your belly is refilled with the clean dialysate and the cleaning process begins again. The process is called an exchange. Your kidney doctor will tell you how many exchanges you should do each day and how long the dialysate should stay in your belly for it to work.

There are two kinds of PD: Continuous Ambulatory Peritoneal Dialysis (CAPD) or Continuous Cycling Peritoneal Dialysis (CCPD), sometimes called Automated Peritoneal Dialysis (APD). You and your kidney doctor can talk about what kind of PD can work for you.

To determine what type of PD treatment is best for you, your kidney doctor needs to consider your

- body size,
- lifestyle,
- lab test results, and
- ability to do the steps in dialysis.

How you feel is not a good way to tell if you are getting enough dialysis to stay healthy. Do not skip CAPD exchanges or shorten your CCPD treatment. Doing so could be harmful to your health.

CCPD is done at home with a machine called a cycler. The cycler connects to your access and works at night while you sleep. For eight to ten hours each night the machine fills your belly with clean dialysate and then it drains the used dialysate from your belly. In the morning, clean dialysate is put in your

Continuous Ambulatory Peritoneal Dialysis (CAPD)

4) The used dialysate from inside your belly flows into the

To help stay healthy, keep your access clean and dry and keep the tube taped to your body. To help with this, taking a shower is better than taking a bath. A bath exposes your access to germs that have washed off your body. Also, you should not swim in lakes, rivers, ponds, pools, or spas because of the chance of getting an infection. If you want to swim, ask your kidney doctor about ways to swim in the ocean or in clean, chlorinated swimming pools.

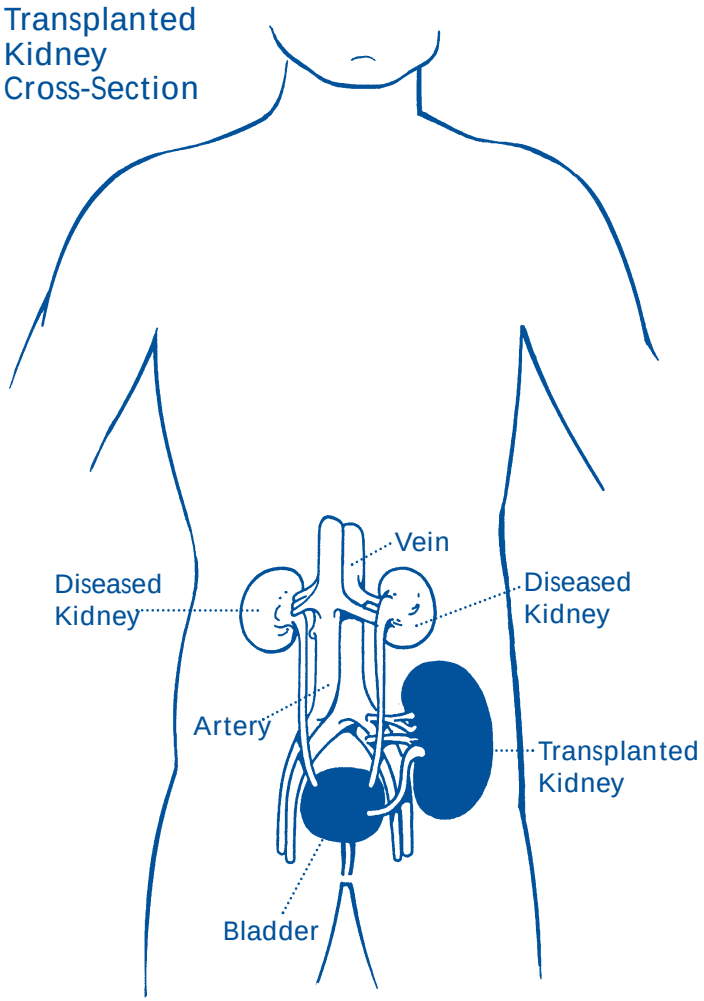
Transplant

A transplant is when you get a kidney from another person. The person who gives you the kidney is called a donor. The donor's blood type and tissue must match yours. The new kidney is put into your body through surgery and is usually placed in the lower part of your belly (see diagram below). Your old kidney may or may not be taken out during surgery. The new kidney does the work that your old kidneys did when they were working.

With a transplant, you will always need to take special medicines. Some of these medicines are called anti-rejection or immunosuppressive drugs. They help your body accept the kidney. Early signs that your body may be rejecting the new kidney can be fever, tenderness at the new kidney site, and making less urine.

To have a kidney transplant, you must be diagnosed with End Stage Renal Disease (ESRD), and you may or may not have started dialysis.

"With a transplant, you will always need to take special medicines."



When you are considered for a transplant

- your health care team will check your health to find out if your body is ready for a transplant.
- your doctor can refer you to a transplant center or you can refer yourself.
- a health care team at a transplant center will check your health to see if a new kidney would work for you. You may have medical conditions or health problems that keep you from having a transplant.
- if you are on dialysis, your health care team will look at how well you keep to your dialysis schedule and if you take your medicine when you should.
- if you don't have Medicare, your health care team will try to help you find a program that can help you pay for the anti-rejection medicines you will need to take after surgery.

"Because you are related to someone does not mean that your blood and tissue type will match."

Types of Transplants

There are three kinds of transplants:

- Living-related
- Living non-related
- Cadaver

A living-related donor is a family member who is related to you by blood and who agrees to give you one of his or her kidneys. This kind of donor could be a parent, brother, sister, or other blood relative. Blood and tissue type are always tested to see if there is a good match. Just because you are related to someone doesn't mean that your blood and tissue type will match.

A living non-related donor is a person who isn't related to you, but whose blood and tissue type matches your own. A friend, spouse, or co-worker can be a donor and agree to give you a kidney.

Cadaver donors are people who have just died and whose families have given their organs for others to use. For this kind of transplant, you need to put your name on an official list with others who also need a kidney. Talk to your health care team about what must be done to get your name on the list. When a kidney becomes available, you can always choose not to have the transplant, but you will not have this choice unless your name is on the list. When a kidney that matches your blood and tissue type becomes available, you and your doctor will be called and surgery will be done right away. Finding a kidney that is a good match may take a short time or several years.

The Choice to Stop Treatment

Just because there are treatment options doesn't mean you have to be treated. Some people choose to have no treatment or to stop treatment. This is a choice you can make, but understand that treatment is keeping you alive. When you withdraw from treatment, or choose not to follow your treatment plan, you put your life at risk. If you stop treatment completely, you will die. Your kidney doctor can give you more information about what happens when you stop treatment. This is a personal choice that may be hard to make. If the time comes that you want to consider stopping treatment, talk with your family and your health care team about counseling and programs such as hospice.

Advance Directives

If you were to have a life-threatening medical emergency, you may not be able to say what kind of treatment you would want. You have the right to choose ahead of time what you want done in case of such an emergency. An advance directive, sometimes called a "living will," is a legal paper that says what you want done for you in a life-threatening emergency. Your social worker can tell you about advance directives. Tell your kidney doctor and center if you have an advance directive. Make sure your doctor writes in your orders that you have one and that an original copy is in your files.

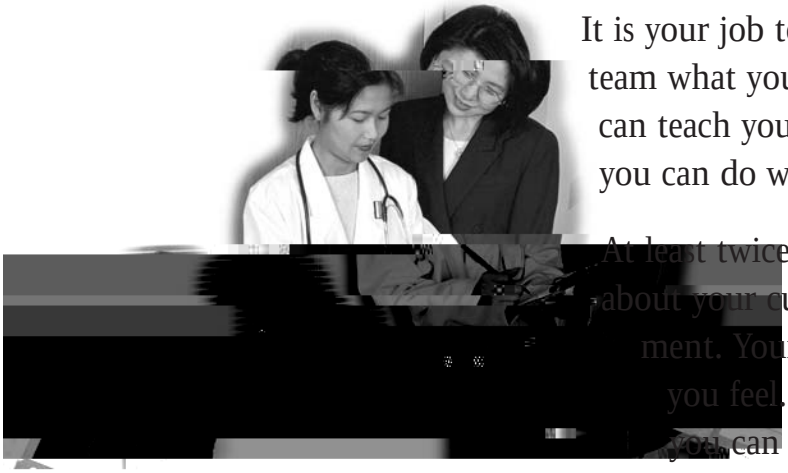
"You have the right to choose ahead of time what you want done in case of such an emergency."

You and Your Health Care Team

You and the people who care for you make up your health care team. Your family or caregiver, doctors, nurses, social workers, dietitians and technicians are all part of the team. Your health care team guides you in choosing and managing your treatment, understanding your insurance options, and planning your diet. Each person on the team plays a role in your care, especially you.

Your Role

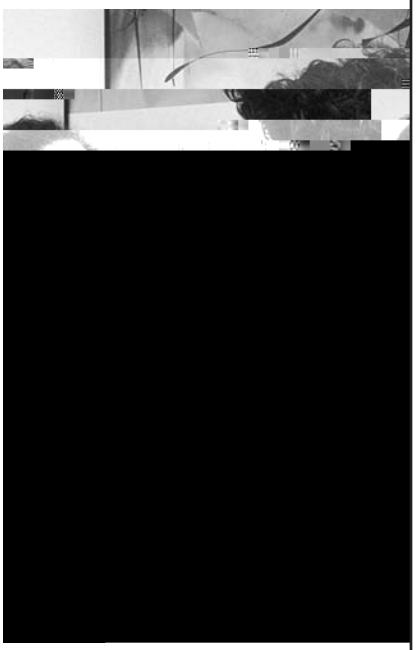
You are the number one person on your health care team. It is your job to take care of your health and to tell the team what you need and how you are feeling. The team can teach you about your health and treatment, but only you can do what is needed to stay healthy.



At least twice a year, your health care team meets to talk about your current care and plan for your future treatment. Your health care team needs to listen to how you feel. You should always go to these meetings so you can participate in making care decisions, understand your treatment, and how you can make it better.

Always feel free to ask questions. There are no dumb questions. If you don't understand an answer, let someone know. You can write down questions you have for your health care team in a notebook. When you go for treatment, take the notebook with you and write down the answers.

"To protect your health, tell your kidney doctor before you make an appointment with your dentist."



Your Dentist

Your dentist cares for your teeth. To protect your health, tell your kidney doctor before you make an appointment with your dentist.

Your Nurse

Nurses coordinate your care. They answer questions about your health, your treatment, and on how to manage your medicines. They can help teach you and your family how to stay healthy. You need to talk with your nurse often about how you are feeling. Nurses can also give dialysis treatments and oversee other staff who help with dialysis treatments. Some nurses also train patients and family members to do home dialysis or to care for themselves in a center.

Your Social Worker

Your social worker can give one-on-one, family, or group counseling to help you cope with your kidney failure, life's stressors, and other issues. Social workers can help answer questions about your insurance, paying for care or medications, and getting to and from your treatments. They can also make referrals to community programs that can help with such things as getting proper foods. Your social worker can also help you find resources for volunteering, job training, or placement. Staying active helps to improve the quality of your life.

Your Dietitian

Your dietitian's role is to help you understand what kind of foods to eat and how much fluid to drink. This is important because when your kidneys stop working, what you eat or drink can help or hurt how you feel. Your dietitian can teach you how to pick foods that will help keep you healthy, even when you eat out. Your dietitian may also help you understand how your blood test results are affected by your diet.

Your Technician

Most treatment centers have technicians who help care for you. When supervised by nurses, technicians can start and stop your dialysis treatment. They also watch your vital signs during treatment.

Tips for Making Treatment Better

Dialysis or transplant can affect your whole body and how you feel. This section talks about the things you can do to help yourself feel better and to keep your body healthy. To keep your life on track, you need to take charge of your health.

Changes in Mental Health

Life can be stressful, whether or not you have kidney failure. Kidney failure brings a lot of changes in your life. Sometimes these changes can be managed and become part of daily life, and sometimes you may need help dealing with these changes. You can talk with your social worker about ways to help you and your family adjust. Your social worker can also tell you where to get counseling if you need it.

"Dialysis or transplant can affect your whole body and how you feel."

Everyone adjusts to having kidney failure in different ways. If you notice that you often feel uneasy, fearful, tired, irritable, or nervous, it could be anxiety. Other signs of anxiety are a fast heartbeat, heavy sweating, or an upset stomach. If you are sick, you may have these same symptoms. It's important that you talk to your doctor as soon as you can if you are feeling this way, so you can get the help you need.

Mood changes are common in people with kidney failure for a few reasons. Stress can affect a person's mood. Some medicines can cause mood swings. Also uremia (the build up of waste products in the blood) can irritate the body's nervous system and cause mood changes.

"You can talk with your social worker about ways to help you adjust."

Tell your doctor right away if you can't or don't want to eat, have trouble sleeping, have repeated angry outbursts, or lose interest in daily living or in sex. These may be signs of depression. Other signs are feeling sad or angry all the time, using drugs or alcohol to cope, or having thoughts of taking your life. Remember, don't wait to tell your doctor if this is how you are feeling.

Physical Changes

With kidney failure you may see changes in your body. Sometimes your skin may become darker, paler or a little yellow looking. Skin may become dry and flaky. Darker skin may look ashy. It helps to wash and moisturize your skin daily.

The taste in your mouth and smell of your breath may change. This is from the build up of waste products in the body that used to be removed by your kidneys. Following your treatment plan helps remove the waste products that cause this condition. It can also help to gently brush your teeth, gums, and tongue a few times a day.

Changes in Sexual Desire

For both men and women, it's very common that desire for sex may change, as they adjust both physically and emotionally to kidney failure. Men may be unable to have or maintain an erection. Women may be unable to have sexual arousal. This may be due to certain medicines, anemia, or built up wastes in the blood. If you have concerns about these problems, talk to your doctor, nurse, or social worker. You may feel uncomfortable talking about your sex life, but your health care team can't help you if they don't know something is wrong.

Talk with Your Doctors

Before you see your doctor, write down any questions you have. Bring these questions with you to your visit so you can ask your doctor and get answers that you understand.

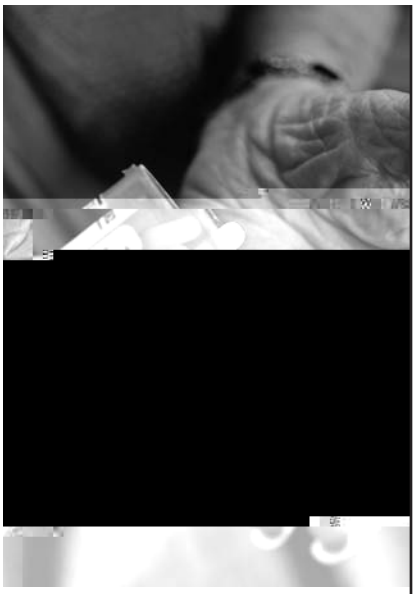
- On a regular basis, talk with your kidney doctor on how your treatment is going and if changes to your treatment plan are needed.
- Every six months, discuss your treatment plans with your kidney doctor and health care team.
- See your family doctor for routine check ups.
- Tell your kidney doctor before you make an appointment with your dentist.
- Take a copy of your health records to any doctor you see. Let all of your doctors know about your treatment and changes in your health.

"Tell your

Take Your Medicine as Prescribed

Medicine is an important part of your treatment. You need to take the medications that all your doctors prescribe. But first, tell your kidney doctor before taking any medicine another doctor prescribes for you. You may need to take medication to

- help your body make red blood cells,
- control your blood pressure,
- replace vitamins and minerals lost during dialysis or from diet restrictions,
- keep your bones strong,
- get rid of phosphorus that builds up when your kidneys are not working,
- replace hormones that your kidneys used to make, or
- treat an infection or other illness you may have.



"Write down all your medications and keep this list with you at all times."

Ask your kidney doctor when, how often, and how best to take your medications. Some medicine should be taken with a meal and some should be taken when your stomach is empty. Also, ask your kidney doctor if you are not sure how much water you should drink when you take your medicines. If you don't want to take a certain medicine, tell your kidney doctor.

Ask your doctor about any side effects and what you should do if you have them. You can also ask your pharmacist these questions. If you can, try to fill your prescriptions at the same place each time. This way your pharmacist can get to know you and the medications you take.

Know the names of your medications, why you are taking them, the dosage, and when and how to take them. Write down all your medications and keep this list with you at all times. If a prescription has passed its expiration date, throw it away. Also, never give your medicine to anyone else.

Beware of Over-the-Counter

Medicines to Avoid

- Baking soda or remedies for heartburn or acid indigestion that bubble. They are high in sodium.
- Antacids with aluminum or magnesium. Aluminum and magnesium can build up in your body and cause problems in your brain.
- Aspirin, unless your kidney doctor tells you to take it. Aspirin can keep your blood from clotting and may cause bleeding.
- Enemas and laxatives because you can become dehydrated or lose needed minerals.
- Vitamins (unless prescribed), food supplements, or salt substitutes. These may be high in potassium or magnesium.
- Any “cure all” remedies, herbs, or over-the-counter medicines that your kidney doctor has not told you are okay.

Talk to your Kidney Doctor Before Starting "Alternative" Treatments

Alternative medicine is a treatment that is used along with, or instead of, traditional care. Common treatments are acupuncture, herbal remedies, chiropractic therapy, and mind-body techniques, among others. Mind-body techniques can be visualization or breathing exercises.

While some people may be helped by alternative treatments, there may be harmful side effects for people with kidney failure. Ask your kidney doctor before starting any alternative treatments. Tell your health care team about any of these kinds of treatments you may be using now.

“Ask your kidney doctor before starting any alternative treatments.”

"You can get a free pneumonia shot as well as a flu shot once a year if you go to a doctor that accepts Medicare."

Get Shots (Vaccinations) to Help Stay Healthy

If you are on dialysis or have a transplant, your body may have trouble fighting off infections and diseases. You need extra protection from the flu, pneumonia, and Hepatitis B. Getting shots can keep you from getting sick or going to the hospital. Shots may even save your life.

You can get a free pneumonia shot, as well as a flu shot once a year if you go to a doctor that accepts Medicare. For a Hepatitis B shot, Medicare pays 80 percent of reasonable cost and you or your other insurance pays the other 20 percent. Often shots are given at the treatment center.

Track Your Dialysis Treatment Progress

As part of your dialysis treatment, you may have lab tests once a month or more often to track your progress. If you know what these tests measure and what your treatment goals are, you will be able to take better care of yourself. Your dietitian can give you tips on how to meet some of your goals by having a proper diet. Recommended lab tests measure: serum creatinine, blood urea nitrogen (BUN), URR, albumin, hematocrit, hemoglobin, TSAT and serum ferritin, parathyroid hormone (PTH), calcium, phosphorus, and potassium. Your Kt/V, blood pressure and weight are also recorded to track your treatment progress.

Blood Urea Nitrogen (BUN)

Urea nitrogen is a waste product in your blood that comes from the breakdown of proteins from the food you eat and from your body's stored protein. Healthy kidneys remove BUN from blood. With kidney failure, your dialysis treatments remove the BUN from your blood. Your BUN level can go up if you don't get enough dialysis or eat too much protein.

URR

URR stands for “Urea Reduction Ratio.” This test measures how much urea was removed from your blood during hemodialysis. Urea is a waste product that builds up in your body when your kidneys stop working. Your blood is tested before and after treatment to see how much cleaner the blood is. URR is shown as a percent. A URR of at least 65 percent shows that your dialysis was okay or adequate.

Kt/V

Kt/V (pronounced “kay tee over vee”) is another measure of how well your dialysis treatment is working. Kt/V applies to people on both hemodialysis and peritoneal dialysis. Kt/V of at least 1.2 is the minimum number you can have for your hemodialysis to be okay or adequate. Adequate dialysis for peritoneal dialysis is a Kt/V of at least 2.1.

To help reach your target Kt/V or URR, don’t miss any treatments. Be on time for your treatment and stay on the dialysis

Hematocrit

Your hematocrit measures the red blood cells that your body makes. A low hematocrit (or low number of red blood cells) may mean you have anemia. Anemia will make you feel tired. To treat anemia, you may need to take extra iron and a hormone called EPO. You will feel less tired and have more energy when your hematocrit reaches about 33 to 36 percent.

Hemoglobin

Hemoglobin lets red blood cells carry oxygen to all the cells in your body. Your hemoglobin level is another way to tell if you have anemia. Your hemoglobin level should be at least 11 to 12.

TSAT and Serum Ferritin

TSAT means transferrin saturation. Both TSAT (active iron) and serum ferritin (stored iron) are tests that measure the iron in your body. Iron is needed to make red blood cells. Your TSAT should be at least 20 percent and not more than 50 percent. Your serum ferritin should be at least 100 and not more than 800. You may need extra iron to reach your target range.

Parathyroid Hormone (PTH)

A poor balance of calcium and phosphorus in your body can lead to high levels of parathyroid hormone (PTH). This can cause bone disease. Ask your doctor and dietitian how your calcium and phosphorus levels can be kept in balance so your PTH level doesn't get too high.

Calcium

Calcium helps make strong bones and teeth. Low blood calcium can cause muscle spasms. Calcium is also needed for blood clotting. To keep the right amount of calcium in your bones, your kidney doctor may recommend taking calcium supplements.

"To keep the right amount of calcium in your bones, your kidney doctor may recommend taking calcium supplements."

Phosphorus

Phosphorus is found in most foods. A high phosphorus level can lead to weak bones and can make your skin itch. Taking a phosphate binder helps control the amount of phosphorus in your blood between dialysis treatments. It acts like a sponge to soak up, or bind, phosphorus while it's in the stomach. When it's bound, phosphorus doesn't get into the blood and is passed out of the body in the stool. Follow your diet and take your phosphate binders with all meals and snacks.

Potassium

Too high or too low a level of potassium in your blood can lead to heart problems and even a heart attack. Follow your diet as to how much food with potassium you should eat. Ask your dietitian about which foods are high or low in potassium.

Blood Pressure

Ask your doctor what your blood pressure should be. List your average pre- and post-dialysis blood pressure each month. If your blood pressure is high, it helps to take the blood pressure medicine that your kidney doctor has told you to take. Following your fluid intake plan and cutting down on salt in your diet will help too. If your doctor tells you that you are overweight, losing weight with exercise will also help lower your blood pressure.

Target Weight or Dry Weight

Your target weight is what your kidney doctor thinks your weight would be if you didn't have kidney failure. Your target weight is when your body has the right amount of water—not too much and not too little. Because your kidneys have stopped working, most of the fluids you drink will stay in your body. When your body holds fluid, you gain weight. If you are losing weight without even trying, talk to your dietitian to make sure you are eating right to stay healthy. With hemodialysis, you are weighed before and after each treatment to see how close you are to your target weight. If you are on PD, you need to weigh yourself each day.

"If your doctor tells you that you are overweight, losing weight with exercise will also help lower your blood pressure."

"Don't drink more fluid or eat more salt than you can have in your diet."

Average Daily Weight Gain

Too much fluid weight gain between treatments can cause swelling, a weakened heart muscle, shortness of breath, or high blood pressure. It can also make your dialysis treatment uncomfortable. Follow your fluid and salt intake closely. Don't drink more fluid or eat more salt than you can have in your diet. Otherwise, you may gain too much fluid weight between dialysis treatments.

Tips for Living with Kidney Failure

"Planning meals around your treatment times helps make the treatments work better."

Follow your Diet and Fluid Intake Plan

When you eat or drink anything, your body uses what it needs for fuel. But the body can't use all that you eat or drink. When your kidneys were working, they cleaned the body of many waste products. Now that your kidneys don't work, waste products stay and build up in your body. Treatment helps rid your body of these wastes, but it can't clean your body of them all. That is why following your diet and fluid intake plan as close as possible is so important.

Your dietitian can teach you how to plan your diet and pick healthy foods, even when you are eating out. You can also ask your dietitian if he or she can help you change your favorite recipes to fit your diet needs. Eating and drinking what your dietitian suggests, not only helps you feel better, it makes your treatments more comfortable. Planning meals around your treatment times helps make the treatments work better. If you need help getting the proper foods, ask your social worker about programs in your community.

Make an Exercise Plan

Exercise is one of the best things you can do for yourself. It can help you feel better and can

- give you more energy,
- make your muscles stronger,
- make your joints more flexible,
- help control your blood pressure,
- lower your chance of a heart attack,
- help you fight depression, and
- make it easier to do the things you do every day.

Talk to your health care team before you start any exercise program. Your health care team will know you are ready when

- you are getting enough dialysis,
- you have stable blood pressure,
- you are free from infections or other illnesses that need care,
- you are following your diet closely,
- you are taking the medications prescribed by your doctor, and
- you have stable glucose control, if you have diabetes.

Your health care team can help you make an exercise plan. You will be more likely to stick to your plan if you set realistic goals, keep track of how often you exercise, and reward yourself when you do well. Being on dialysis may make you feel tired and not up to exercising. Even so, try to stay active. Try to find something that you like to do. Exercising with a friend can make exercise more fun.

"Exercise is one of the best things you can do for yourself. It can help make you feel better."

Doing any exercise comes with some risks, so exercise safely. Don't try to do more than your body will let you. Avoid exercise if you have a fever, missed a dialysis treatment, or have a new illness that hasn't been treated.

Stop exercising and call your health care team if you feel tired or have

- shortness of breath,
- chest pains or pressure,
- irregular heartbeats,
- nausea,
- leg cramps,
- dizziness or feel lightheaded,
- pain or pressure in your neck or jaw, or
- blurry vision.

"You may need to talk about how to balance work with your dialysis or transplant center schedule."

Going Back to Work

If you go back to work, Medicare still pays for dialysis or transplant services. In time, many people with kidney failure return to school or work or even start new jobs. Talk to your social worker about work options or about how to get training in new skills.

Whether you keep the same job or find a new one, you may need to talk to your boss about changing the amount of hours or days you work based on how well you feel. You may also need to talk about how to balance work with your dialysis or transplant center schedule.

According to the Family and Medical Leave Act (FMLA), if you can't do your job for a period of time because of kidney failure, you can take up to 12 weeks of unpaid leave. This law also says if a family member (husband, wife, parent, or child) needs to take care of a person who has a serious health condition, such as kidney failure, he or she may also be able to take unpaid leave.

Plan Ahead for Travel

Kidney failure doesn't mean you have to give up traveling. You can still get the care and treatment you need while you are away, but you need to plan at least one month in advance, if not longer. If you are going to a popular place for a vacation, you may want to plan as far as three months ahead. Your transient coordinator (social worker) can help you arrange your travel plans with a center near your destination. Your social worker will send your health and treatment information to the new center. Before you travel, find out the following from your transient coordinator:

- If the center is Medicare-approved and has the space and time to treat you.
- How much treatment costs, if there are any other fees, when payment is due, and what payment options will the center accept.
- Where the center is located.

If you are on PD, call your supplier to arrange for your supplies to be sent ahead of time to your destination. By doing so, you will not have to carry extra suitcases filled with your supplies. Just in case, you may want to take one or two extra dialysate bags and needed supplies with you. People who use a cycler for CCPD can also have the machine delivered to where they are going.

How to File a Complaint

As you learn to live with kidney failure, you may have to deal with some problems along the way. In dealing with any problems that may come up, it's best if you and your health care team can talk in a calm way about what's happening and not let feelings build up.

If you have a problem with your dialysis treatments or transplant services that you haven't been able to resolve, you can file a com-

Filing Options

1. Talk to a member of your health care team

or

2. Call your ESRD Network

or

3. Call your State Survey Agency

- I need to treat other patients and staff as I would like to be treated, with respect.
- I need to pay my bills on time. If this is hard for me, I can ask about making a payment plan.
- I need to tell my health care team if I refuse any treatment or medicine that my doctor has ordered for me.
- I need to tell my health care team if I don't understand my medical condition or treatment plan.
- I need to be on time for my treatments or when I see my doctor.
- I need to tell the staff at the center if I know that I'm going to be late or miss a treatment or visit with my doctor.
- I need to tell my health care team if I have medical problems, am going to the dentist, am being treated by another doctor, or have recently been to the hospital.
- I need to follow the rules of the center.
- I need to get to and from the center for my treatments. I can talk with my social worker if I need help doing this. M

Additional Kidney Failure Resources

American Association of Kidney Patients
Phone: 1-800-749-2257
Web site: www.aakp.org

American Kidney Fund
Phone: 1-800-638-8299
Web site: www.akfinc.org

The Coalition on Donation
Phone: 804-782-4920
Web site: www.shareyourlife.org

Forum of ESRD Networks
Phone: 804-794-2586
Web site: www.esrdnetworks.org

Centers for Medicare & Medicaid Services (CMS)
Phone: 1-800-633-4227
TTY users call: 1-877-486-2048
Web site: www.medicare.gov
(Dialysis Facility Compare)

Life Options Rehabilitation Program
Phone: 1-800-468-7777
Web site: www.lifeoptions.org

National Kidney Foundation
Phone: 1-800-622-9010
Web site: www.kidney.org

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)
Phone: 301-496-4000
Web site: www.niddk.nih.gov

National Kidney & Urologic Diseases Info Clearinghouse
Phone: 1-800-860-8747
Web site:
www.niddk.nih.gov/health/kidney/nkudic.htm

Polycystic Kidney Research Foundation
Phone: 1-800-753-2873
Web site: www.pkdcure.org

Social Security Administration (SSA)
Phone: 1-800-772-1213
Web site: www.socialsecurity.gov

Transplant Recipients International Org (TRIO)
Phone: 1-800-874-6386
Web site: www.trioweb.org

United Network for Organ Sharing
Phone: 1-888-894-6361
Web site: www.unos.org
or www.patients.unos.org

The Nephron Info Center
Web site: www.nephron.com

The Whole World of Nephrology
Web site: www.nephroworld.com

Note: At the time of printing, phone numbers listed were correct.

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