

COPING

Managing Your Kidney Disease



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National Kidney Foundation's Kidney Disease Outcomes Quality Initiative

Did you know that the National Kidney Foundation's Kidney Disease Outcomes Quality Initiative (NKF-KDOQI™) offers guidelines and commentaries that help your doctor and health-care team make important decisions about your medical treatment? The information in this booklet is based on those recommended guidelines

Stages 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
3a	Moderate decrease in GFR	45 to 59
3b	Moderate decrease in GFR	30 to 44
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.

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Dealing with Emotions

Why me?

Anyone can get kidney failure, regardless of who you are, where you live, how old you are, or what type of work you do.

Having kidney failure is a lot to handle. It requires lifestyle changes—not only for you, but for your family, too. This brochure can help you and your loved ones learn how to cope with kidney failure.

How does kidney failure affect patients and their families?

In time, many patients accept the fact that they have kidney failure and will need treatment for the rest of their lives. Others have trouble with all the changes in their lives that the disease brings.

It's important to understand that the stresses and frustrations of kidney failure are real. At times, it may be difficult for both you and your family to cope. You may feel like your world is caving in. Your family members may feel that way too, especially if they haven't faced a major crisis before, or if the diagnosis was not expected. They may feel helpless because they



cannot do anything about your illness. They may be angry that kidney failure has happened to “their” family or friend. They may fear that you may die. They may feel guilty if they did not realize the serious nature of your illness earlier.

A period of confusion and tension may follow as everyone tries to cope with the demands of the illness, the anxiety of treatment, and the disruption of everyday life. You and your family will need time to adjust. Remembering that can help.

Is it normal to feel afraid?

You and your family will have many emotions as you learn to live with kidney failure. You may feel sad, confused, anxious, fearful, angry, or even guilty. At times, your feelings

may shift from disbelief and denial to acceptance or grief.

The goal is to understand, cope with, and even accept your feelings, rather than ignore them or pretend they don't exist. Understanding that other people, like you, share many of your feelings can help. What you're going through is normal. It is part of getting used to your diagnosis, and to living with kidney failure.

It can also be helpful to share your feelings with others, to ask for help, and to tell others what you need. Even your closest family members cannot read your mind. It's important to tell them how you feel.

In addition to loved ones, other people can provide emotional support, including friends, clergy, support groups, chat rooms, professional counselors, and of course, your healthcare team.

Is it normal to have mood swings?

Moodiness is common among people with kidney failure. It can be caused by:

- **Waste products.** The buildup of waste products in the blood (called "uremia"), which can irritate the nervous system.

- **Medicines.** Some medicines may cause moodiness or make you feel depressed.
- **The stress caused by chronic illness.** The problems caused by your illness can make you irritable, angry, frustrated, and much more. Mood swings can come from feeling hopeless or helpless about having a life-threatening disease.

Your family members and friends might feel confused by your moods swings. It may help to talk with them about it openly and honestly. If they understand that being irritable and moody can be part of having kidney failure, they may find it easier to cope. You and your family may want to discuss ways for everyone to relax when tensions are high. Or you may want to consider family counseling.

Who can help me and my family adjust?

Every dialysis unit and transplant center has a clinical social worker on staff who is trained to deal with the non-medical issues that you and your family face. They can answer many of your questions, or direct you to others who can help. Social workers are important members of your healthcare

team. They are there to help make treatment a manageable part of your life.

Inspiration and support can also come from other patients. Ask your social worker about support groups in your area.

If you would like to connect with another patient, the National Kidney Foundation can help. Contact the National Kidney Foundation, and ask about the “Peers Lending Support” Program. Call toll-free **1.855.NKF. PEERS** (1.855.653.7337) or email **nkfpeers@kidney.org**.

When should I seek professional counseling?

Feeling sad or upset on occasion is a normal part of life. However, there are times when you may need help coping with these feelings.

Asking for help is not a sign of weakness, but of your desire to do well. Many people need help with their emotions as they learn to cope with kidney failure.

If you find yourself feeling overly sad, irritable, isolated, overwhelmed, unable to face each day, crying too much, or feeling like you want to give up, you

may have depression. It's important to know that depression is a medical condition. It can be treated. You do not need to suffer from it, or be embarrassed about it. Studies show that 20 to 40% of people with kidney failure may have depression.

Your social worker can help you figure out if what you're feeling is caused by depression, and will help you get treatment for it. Treatment may include medicine, counseling, or other things.

Is it normal for people on dialysis to feel upset sometimes with the staff at a dialysis center?

Yes. A dialysis center is different from any other healthcare setting. It can feel like a "second family" because you spend so much time there. It is normal to feel frustrated and angry with them sometimes. It is important that you discuss your feelings openly with the staff. Keeping your feelings bottled up inside can affect your treatment, health, and emotional adjustment.

Is it normal to feel anxious while waiting for a kidney transplant?

Waiting for a suitable kidney can be stressful. If you have a living donor, your wait for a transplant should be

fairly short. If you are waiting for a kidney from someone who has died, you may have to wait a long time—even years. Using this time to learn as much as you can about a kidney transplant can help. Talk to others who have had a transplant, and discuss your concerns openly with your healthcare team. The more you learn, the less afraid you'll feel.

What else should I understand about my emotions?

It's important to understand that your emotions and physical health are connected. A healthy emotional life will help you to live longer and feel better.

Your “emotional health” means many things—how you cope, how you live, what you do to stay involved in the world around you, and how you relate to others. It's more than feelings or emotions. It means having a sense of purpose, experiencing laughter, having hope, keeping active, and so much more.

Set reasonable goals for yourself. Be flexible. Allow for mistakes. Try to keep a positive attitude. Spend time with people who make you laugh. All these things can help you stay healthy.



Your Family and Relationships

Can people with kidney disease still enjoy sex?

Many people think that sexuality refers only to sexual intercourse. But sexuality includes many things, like touching, hugging, or kissing. It includes how you feel about yourself, how well you communicate, and how willing you are to be close to someone else.

There are many things that can affect your sexuality if you have kidney failure—hormones, nerves, energy levels, even medicine. But there are also things you and your healthcare team can do to deal with these changes. Don't be afraid to ask questions or get help from a healthcare professional.

It's important to remember that people with kidney failure can have healthy marriages and meaningful relationships. They can fall in love, care for families, and even be sexual. Staying intimate with those you love is important. It's something everyone needs.

What if I lose interest in sex?

Your interest in sex may change when you have kidney failure. At first, you may have less interest in sex. This can happen because you need a lot of energy to cope with the physical and emotional changes brought on by your illness. In time, your interest may return to normal.

Some men may find it more difficult to have or keep an erection. This is very common with kidney failure. It can result from the side effects of medicine, having a buildup of toxic wastes in the blood that may not be fully removed by dialysis, or other things. Many of these problems can be treated. Don't be afraid to ask questions or get help from a healthcare professional.

Emotions can also affect sexual functioning. This includes stress, depression, nerves, fear of disability

or death, marriage problems, and much more. Couples who find that their sex lives are changing should talk to their doctor or social worker. Many of these problems can be treated.

People with a kidney transplant usually have fewer sexual problems related to kidney disease. After the transplant, sexual functioning should return to normal.

Can men with kidney failure still father children?

Yes. Men on dialysis or those who have had a kidney transplant can father children. If you've been trying to father a child for a year or more without success, talk with your doctor.

Can a woman with kidney failure have a baby?

Some changes in your body make it hard to get pregnant. For example, most women on dialysis have anemia (a low red blood cell count) and hormone changes. This may keep them from having regular periods.

Women with kidney failure are usually advised against becoming pregnant. The rate of problems is very high. The risk to the mother and developing baby are also high. If you are thinking

of becoming pregnant, talk to your healthcare professional. If you become pregnant, you will need close medical supervision, changes in medicine, and more dialysis to have a healthy baby.

Can a woman who has had a transplant have a baby?

Yes. If you have a kidney transplant, you are likely to have regular periods and good general health. Therefore, getting pregnant and having a child is possible. But you should not become pregnant for at least one year after your transplant, even with stable kidney function. In some cases, pregnancy may not be recommended. This may be because there is a high risk to your life or possible loss of the transplant. Talk with your healthcare professional if you have a transplant and are thinking about getting pregnant.

Adjusting to a New Lifestyle

How important is social activity?

Being involved in the world around you and staying close to others is very important. Social support is something we all need, but it's especially important for someone with a chronic illness.

It may be helpful to find activities you enjoy that also provide social support, like walking clubs, volunteer work, babysitting, or even taking classes. Your social worker can help you find groups and activities to join. Participating in hobbies, clubs, community action groups, sports, and spirituality can have a positive effect on your health.

Don't forget that you are also a valuable friend and partner to others. Remember that your loved ones may need your support as well. On days that you feel well, ask what you can do for them.

If you are feeling isolated or alone, talk to your social worker. There are support groups, patient mentors, and outreach services designed for people like you!

Can I work or go to school?

Many people with kidney failure work or go to school full-time or part-time. Many people who start dialysis or have a transplant want to return to work or school quickly. It helps them feel better, and get their lives back to normal. Some people take a little time off to start dialysis, while others take a longer leave of absence to get used to

dialysis or to recover from surgery. You should talk to your doctor about when you will be able to return to work or school.

At first, working or going to school in addition to your treatment schedule can be tiring. You may need support and encouragement at home, and from your healthcare team. If you are thinking of giving up your job or education, you may want to consider taking sick leave or a brief leave of absence instead.

Discuss your condition openly with your employer or school administrator if you think it will affect your ability to do the job, or to finish your degree. Answer any questions or concerns they might have. Talk about any special needs you might have. For example, you might need to start work earlier in the day in order to go to dialysis.

As you return to work or school, you should keep several things in mind:

- **If you are on peritoneal dialysis** and need to do an exchange during the day, you will need to ask your employer or school administrator for a clean, private place to do your exchange. A letter from your doctor may be requested. This letter should state that you

are medically stable to return to work or school, and describe any limitations you may have.

- **If you dialyze in a clinic**, talk to your dialysis team about changing your dialysis schedule to better meet your needs. Most dialysis clinics will try to schedule a convenient shift for patients who are employed or in school. You may also wish to consider home dialysis options. This will give you more flexibility in your schedule.

If you receive Social Security Disability Insurance (SSDI) or Social Security Income (SSI), the local Division of Vocational Rehabilitation Office may assist you in returning to a job or retraining you for a new job. For more information on the Social Security Administration's Ticket to Work program and other employment initiatives, go to **www.ssa.gov/work** or call **800.772.1213**.

People facing dialysis treatment or a transplant may worry that their treatment could cause them to lose their job. The Americans with Disabilities Act is a law that was passed in 1990 that does not allow discrimination because of disabilities. If you are concerned about

discrimination, contact an attorney, the Equal Employment Opportunity Commission (EEOC) or the Department of Labor. For information about filing a claim, call toll-free **800.669.4000**.



Can I travel?

Yes, most people can travel safely and get dialysis treatments while away from home. Of course, you should always talk to your doctor before planning to travel. Most doctors encourage travel if your health is stable. If you like to travel, it may give a big boost to your spirits and sense of well-being.

It's important to remember to bring enough of your medicines. Also, check with your insurance company about coverage. Medicare covers 80% of dialysis treatments in the United States. But in most cases, it does not cover dialysis treatments outside the United States.

When planning a trip:

- **If you are on hemodialysis:**
You should make plans with a dialysis clinic in the area you wish to visit at least six to eight weeks in advance. You may need to plan even further in advance during popular tourist seasons. This is because some dialysis clinics may be full and less able to take in unscheduled patients. You can find information about dialysis centers in the U.S. at **www.dialysisfacilitycompare.gov**. Many dialysis centers have a staff member who can arrange for dialysis treatments away from home, or help you make your own arrangements.
- **If you are on peritoneal dialysis:**
You will need to make plans for back-up medical care if you are going to be out of town for any length of time. Your nurse or doctor can give you a referral to a peritoneal dialysis program in the area you wish to visit, and make sure the right records are sent.
- **If you are on a transplant waiting list:** Tell the staff how they can reach you at all times. If you are traveling somewhere you cannot be reached, you can change your status to “on hold” until you return.

Can I exercise?

Yes. Physical activity will give you energy, reduce stress, and help you stay more independent. It can also improve depression and overall mood. It's important to talk to your healthcare professional before you begin an exercise program. You may have new limitations due to your dialysis access or protecting your transplanted kidney.

Physical activity should not be confused with heavy exercise. If your ability to exercise is less than it was before, do not be discouraged. Any form of body movement helps—walking, gardening, dancing, even grocery shopping. The key is finding something you enjoy. Your energy will increase with activity, and, in time, you'll be able to do more.

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 develop a nutrition plan that helps you continue to enjoy your favorite foods and be

as healthy as possible. Following your nutrition plan is important. It will help you be more successful at living with dialysis or a kidney transplant.

- **If you are on dialysis:** You will need to eat less salt, avoid foods high in potassium and phosphorus, and limit fluids. If you have other health problems, such as diabetes or heart issues, you may have other restrictions as well.
- **If you have a kidney transplant:** Some medicines may interact with certain foods. You may need to change your diet to prevent this. If you have other health problems, such as diabetes, poor nutrition, or weight gain, you may need to make other changes as well. Otherwise, you may not have many food restrictions. Remember, good nutrition and a healthy weight will help to keep your new kidney working as long as possible.



Your Finances and Insurance

How will I pay for my treatments?

Many of the costs for 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 **800.772.1213** and making an appointment to enroll. Before signing up, your dialysis clinic or transplant center must complete a form and have it signed by your doctor. This form confirms that you have started dialysis or have a kidney transplant.

Does Medicare pay for home hemodialysis and peritoneal dialysis?

The federal government's Medicare program covers 80% of the cost of home hemodialysis and peritoneal dialysis, 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 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. There are many other sources of coverage that can help pay for what Medicare does not cover, including:

- State programs such as Medicaid and high-risk insurance pools
- TRICARE (if you are active in or retired from military service)
- Veterans' benefits
- Employer health insurance, private health insurance, COBRA
- Medigap (Medicare supplemental health insurance)
- State kidney programs (where available)

To learn more about these options:

- Medicare: Contact Social Security at **800.772.1213** or check Medicare's website at **www.medicare.gov**. You can also ask for a free copy of a handbook explaining Medicare coverage for dialysis and transplant services.

- State Medicaid: Contact your state's welfare department (Department of Social Services) or visit **www.medicaid.gov**.
- TRICARE and veterans' benefits: Contact your local Veterans Affairs office or check TRICARE's Web site at **www.tricare.mil**.
- Employer or private health insurance: Read your policy carefully and talk with your insurance agent or company benefits counselor.
- If you are 65 or older, you may be able to get counseling about health insurance benefits at your local senior citizens' center.

Talk with your social worker if you are having difficulty paying for your medications. Many drug companies have programs to help people who cannot afford to pay for their prescription medications.



Review

It's important to understand that the stresses and frustrations of kidney failure are very real, and at times very difficult. The following steps may help:

- Discuss your concerns with your healthcare team. Write down questions ahead of time. Remember, you're an important member of the team, and taking an interest in your own care will help you live better and longer.
- Share your feelings with family, close friends, fellow patients, and others you trust. Allow them the opportunity to share their feelings with you. Together you can learn how to help each other.
- Seek help from the social worker at the dialysis center or transplant clinic, or from an outside counselor if family or personal problems need further attention.
- Stay close to others. Having healthy relationships with others is important for everyone, and it's especially important for someone with a chronic illness.
- Keep involved in the pleasures, activities, and responsibilities of daily living.

- Follow an exercise program approved by your doctor.
- Try not to focus on your problems, but instead, on the good things that may be happening in your life.
- Be patient and set realistic goals.
- Get involved in your own care by finding out as much as possible about kidney failure and its treatment. Your treatment center, healthcare team, and the National Kidney Foundation can help.



Learn more

Becoming an educated patient is very important to being healthy. You can learn more about the subjects discussed in this booklet by reading any of the pamphlets listed below. Call NKF Cares Patient Help Line toll-free at **1.855.NKF.CARES** (1.855.653.2273) or email **nkfcares@kidney.org** to request a copy.

- *Choosing a Treatment for Kidney Failure*
- *Getting Ready for a “New Normal”:
A Helpful Guide for Starting Dialysis*
- *Kidney Transplant*
- *Nutrition and Kidney Failure: Are You Getting What You Need?*
- *Staying Fit with Chronic Kidney Disease*
- *Sexuality and Chronic Kidney Disease*
- *Taking Control: Money Matters for People with Chronic Kidney Disease*
- *Travel Tips: A Guide for Kidney Patients*
- *Working with Kidney Disease: Rehabilitation and Employment*

And learn more at **www.kidney.org**

The **National Kidney Foundation** is the leading organization in the U.S. dedicated to the awareness, prevention, and treatment of kidney disease for hundreds of thousands of healthcare professionals, millions of patients and their families, and tens of millions of Americans at risk.

Help fight kidney disease.

Learn more at **www.kidney.org**



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Awareness. Prevention. Treatment.
