

# Coping Effectively

## A Guide to Living Well With Kidney Failure



National Kidney  
Foundation®

[www.kidney.org](http://www.kidney.org)

**LOVE YOUR  
KIDNEYS**

## National Kidney Foundation's Kidney Disease Outcomes Quality Initiative

The National Kidney Foundation (NKF) has created guidelines for clinical care to improve patient outcomes. The information in this booklet is based on the Kidney Disease Outcomes Quality Initiative (KDOQI™) recommended guidelines for chronic kidney disease (CKD). All KDOQI guidelines have information to help your doctor and health care team in making decisions about your treatment. If you have any questions about these guidelines, you can speak to your doctor or your health care team, or call the NKF at 800.622.9010.

### Stages of Chronic Kidney Disease

In February 2002, the NKF published clinical care guidelines for CKD. Your doctor determines your stage of kidney disease based on whether you have kidney damage (such as protein in the urine) and your estimated glomerular filtration rate (eGFR), which is a measure of your level of kidney function. Treatment is based on your stage of kidney disease (see the table below). Speak to your doctor if you have any questions about your stage of kidney disease or your treatment.

#### Stages of Kidney Disease for Kidney Transplant Recipients

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

\*Your GFR number tells your doctor how much kidney function you have. If chronic kidney disease gets worse, your GFR number becomes lower.

†Transplant

## Introduction

Although many medical advances have been made in treating kidney diseases, people living with CKD face possible kidney failure, and with it, the many challenges involved in treating this condition. This booklet is for those who are affected by kidney disease and are facing the possibility of kidney failure.

### Treatment for Kidney Failure

#### What treatments are available for kidney failure? How do I know which treatment is best for me?

If you have advanced kidney disease and are wondering about treatments for kidney failure, you are not alone. Most people will have concerns about kidney failure and what type of treatment is best.

Three major types of treatment are available: **hemodialysis**, **peritoneal dialysis** and **kidney transplantation**. You also have the right to choose not to start

treatment if you feel the burdens of dialysis would outweigh its benefits to you.

It is important to remember that treatment does not cure kidney failure and that each type of treatment has its pros and cons. You and your family should explore each treatment option with your doctor, transplant surgeon and other health care team members. Each treatment choice has requirements and responsibilities that should be reviewed carefully. You should become educated about health care services and learn as much as possible about the choices available. Your lifestyle, including work, hobbies, time spent with family and friends, studies, etc., can help you decide which treatment is best.



A treatment decision is not always final. Someone who has decided that hemodialysis is the best choice may, at a later time, still consider peritoneal dialysis or a kidney transplant. If you decide that a transplant is the best choice for you, you should be aware that a period of waiting will be necessary for a deceased donor kidney to become available. Waiting time can be less if you have a transplant from a living donor.

Your dialysis care team should tell you about all treatments, even if some are not available at your dialysis center. Another center near your home may offer different treatments for kidney failure.

In certain cases, people may choose not to start any form of treatment, and occasionally someone may choose to stop treatment that has already started. In general, these decisions are based on a patient's medical condition and quality of life. If you are concerned about these issues, you should consult your doctor

or health care team. Those who choose to stop dialysis should do so knowing they will die without treatment.

## Further Reading

For more information about treatment choices, see these National Kidney Foundation publications:

- *Choosing a Treatment for Kidney Failure* (11-10-0352)
- *Kidney Transplant* (11-10-0304)
- *If You Choose Not to Start Dialysis Treatment* (11-10-0330)
- *When Stopping Dialysis Treatment Is Your Choice* (11-10-0331)
- *The “New Normal” Dialysis Series: Getting Ready for a New Normal* (11-10-0306) and *A New Normal: Life on Dialysis—The First 90 Days* (11-10-0307)
- **[www.livingdonors.org](http://www.livingdonors.org)**  
Website for information on living donation

## Is it normal to have fears about beginning treatment for kidney failure?

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, how treatment will affect your personal relationships, and how long you can live with the disease.

The following steps can help you cope with your feelings:

- Before you begin dialysis, visit the dialysis center where you will be treated; this can help make the process less frightening.
- If you're interested in a transplant, ask your doctor for a referral to a transplant center. Set up an appointment to visit with the staff and make a list of questions to ask. Read the NKF's brochure, *Kidney Transplant* (11-10-0304), for more information.
- Talk to others who have been through the same experience.

- Discuss your concerns with the health care team at the dialysis or transplant treatment center.
- Call your local NKF office for information and a list of the programs and services in your community. Visit the NKF website at [www.kidney.org](http://www.kidney.org) or call 800.622.9010 to find your local NKF office.

### Why is it important for me to get the right amount of treatment?

Dialysis treatment removes excess waste and fluid from your blood. When you have enough treatment, your overall health may improve and you may have more energy to cope with the changes in your life. If you don't get the right amount of dialysis, excess waste and fluids remain in your blood, which can make you feel ill. In addition, studies have shown that getting the right amount of dialysis treatment can help you live longer. Your dialysis center will test your blood to make sure enough waste is removed.

More information is available in the NKF's booklets, *Hemodialysis: What You Need to Know* (11-50-0214) and *Peritoneal Dialysis: What You Need to Know* (11-50-0215). The information in these booklets is based on the NKF's Kidney Disease Outcomes Quality Initiative (KDOQI), a program developed to improve patient outcomes.



### What are my rights?

As a dialysis patient, you have certain legal rights. Knowing these rights may help you feel more confident about starting dialysis treatment. Your legal rights include:

- Quality care
- Information you can understand

- Individual treatment
- Privacy and confidentiality
- Services without discrimination
- Kidney transplantation
- Home care
- Self-care treatment
- Emergency care
- Dietary counseling
- Social work services
- Facility management
- Access to a formal complaint process
- Treatment refusal and advance directives
- Medical consultation
- Choosing whether to participate in research programs
- Knowing treatment costs
- Taking part in decisions about your care and types of treatment

## What are my responsibilities?

Understanding and taking charge of responsibilities are the first steps in adjusting to the treatment. You should:

- Apply for funding to cover the cost of treatment.
- Arrange transportation to the dialysis center by car, bus or taxi. The social worker at the center may be able to help by suggesting transportation sources.
- Know and take medication as prescribed. Inform the health care staff if you have any problems taking medicines or lack the funds to buy them.
- Arrive on time for scheduled dialysis treatments and stay for the entire treatment. Cutting treatment time short or missing treatments can cause worsening health.
- Follow the prescribed diet and fluid restrictions and tell the health care staff about any problems you may have in following the diet.
- Make necessary arrangements for dialysis well in advance when traveling.

Learning that dialysis or a transplant is needed can be overwhelming at first, but normal activities can be resumed slowly. Understanding your own needs and taking charge of your health can help you feel more in control of your life.

Don't be afraid to seek assistance from family or friends; they want to help.

### **If you are waiting for a transplant, how can you cope with the stress?**

In deciding to have a transplant, you have made one of the most important decisions of your life. What happens next is one of the more difficult parts of the

process—waiting for a suitably matched, donated kidney to become available.

If you have a potential living donor, your wait may be relatively short. Those awaiting a deceased donor have a longer wait, sometimes up to three years or longer, and there is no way of knowing if and when a suitable kidney will become available. During the waiting period, some people become fearful of the unknown. Here are some suggestions for turning the time delay into a positive experience:

- Discuss your concerns openly with your dialysis care team—doctors, social workers, nurses and dietitians.
- Use the waiting time to learn more about transplants by reading about the surgery and your post-transplant care.
- Ask to talk with people who have had kidney transplants—both successful and unsuccessful.
- If you are unable to work at your former job, ask your social worker about job retraining.



- Consider volunteering your time to a worthwhile cause, such as programs to increase organ donation.
- Be sure to get regular exercise within your abilities.

Your main goals during the wait for a new kidney are to increase your knowledge about transplants and to maintain your physical and emotional health and activities. To make sure everything goes smoothly when the time comes for you to have the transplant, you should:

- Make sure the transplant center has your correct phone number and contact information, and that all blood samples for screening are sent to the tissue-typing lab on time.
- Make necessary family and job arrangements for your time away from home.
- Be prepared to get to the hospital in a timely fashion at any time of day or night when a suitable donor kidney becomes available. For more information, see the

National Kidney Foundation publication, *Waiting for a Transplant* (11-70-0656). Also, see the NKF's website: [www.kidney.org/transplantation](http://www.kidney.org/transplantation)



## How will I pay for my treatments?

Many of the costs associated with hemodialysis, peritoneal dialysis and kidney transplant are covered by:

- Medicare
- Private health insurance
- TRICARE, formerly called CHAMPUS (if you are active in or retired from military service)
- Veterans' benefits
- State medical assistance
- State kidney programs (where available).



The financial counselor or social worker at your dialysis or transplant center can explain insurance coverage to you in more detail.

- For more information about Medicare eligibility and coverage, contact Social Security at 800.772.1213; check Medicare's website at **[www.medicare.gov](http://www.medicare.gov)**; or call your local Social Security office for a copy of the handbook explaining Medicare coverage for dialysis and transplant services.
- Many kidney patients may receive help paying for medication through the new Medicare Part D prescription drug benefit. To find out how this may affect you, speak to your social worker. You can find more information at the website: **[www.kidneydrugcoverage.org](http://www.kidneydrugcoverage.org)**
- For information about TRICARE and veterans' benefits, contact your local Veterans Affairs office or check TRICARE's website at **[www.tricare.osd.mil](http://www.tricare.osd.mil)**

- For information about eligibility and benefits under state Medicaid, contact your county welfare department (Department of Social Services).
- For information about paying for medications not covered by Medicare or other health insurance, read your policy carefully and talk with your insurance agent or company benefits counselor about your benefits.
- If you are 65 or older, you may be able to get counseling about health insurance benefits at your local senior citizens' center.
- For information about paying for medications not covered by Medicare or other health insurance, speak to your social worker. Many drug companies have programs to assist individuals who cannot afford to pay for their prescription medications. These websites may also be helpful: **[www.medicare.gov/prescription/home.asp](http://www.medicare.gov/prescription/home.asp)**, **[www.rxassist.org](http://www.rxassist.org)** and **[www.needymeds.org](http://www.needymeds.org)**



### **If you are on dialysis or have had a transplant, how can you cope with changes in medications and diet?**

Taking all your medications and following the diet and fluid recommendations are very important to your success on dialysis or with a transplant. For people on dialysis, eating foods that are not part of your kidney-friendly diet or missing treatments or medications can lead to serious complications, such as bone disease, heart attack, stroke and even death. For transplant recipients, not taking medication as prescribed can lead to rejection of the new kidney.

Remembering to take new medications can be difficult. Medication reminders and pillboxes can help you remember to take all your medications.

Eating less salt, limiting foods high in potassium and phosphorus, and limiting fluids can be frustrating. A dietitian specially trained in nutrition therapy for kidney disease can be very helpful. The dietitian will teach you how you can incorporate small amounts of restricted foods you like into your meal planning and how to flavor foods with spices instead of salt.

### **Returning to Work and Other Activities**

#### **Can I return to previous activities after starting treatment for kidney failure?**

Absolutely! You can return to activities when you are medically stable. Discuss your plans early on with your doctor. When patients and their families return to a more normal routine, they feel much more satisfied with their lives. They also suffer fewer emotional problems, such as depression.

Although the need for worthwhile and stimulating activity is important, you and your family must keep a flexible and patient attitude. The way you feel from day to day will be less predictable than before. Understand that you may no longer be able to tolerate some activities. Giving up those things may feel like a loss. It's best to talk with someone you trust about these feelings.

Family members are encouraged to continue to pursue their own interests and activities. Giving up their time to meet your needs may lead to feelings of resentment and may make you feel like a burden. It can also promote a "sick" role, which is not healthy for you or your family.

### **Can I return to work?**

Yes, with your doctor's permission, you are encouraged to return to work. At first, working in addition to following a complicated medical program can be tiring. You may need extra support and encouragement at home and from your health care team. If you are employed, you may

want to consider taking sick leave or a brief leave of absence instead of giving up your job.

When attempting to return to work, you should keep several things in mind. If you are no longer able to perform your job functions in the same way, talk with your employer about your condition. Answer any questions or concerns the employer may have. The employer should be informed that your doctor considers you medically stable. Your doctor can provide a letter for your employer stating that you are able to work and describing any limitations you may have.

Special needs or accommodations that make it possible for you to do your job, such as a change in your work schedule, should be discussed. If either you or your employer is uncomfortable about your return to work, a trial period may be helpful, after which both of you can evaluate the situation.

In addition, people who receive dialysis in a center or hospital

should request a treatment time that best fits with their work schedule. Many people who work prefer dialyzing at night, because they sleep after dialysis and wake feeling refreshed. Most dialysis centers will make it a priority to schedule employed patients on a convenient shift. If you are a peritoneal dialysis patient, you should ask your employer for a clean, private place to do your dialysis exchanges.

If you receive Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI), the local Division of Vocational Rehabilitation office may assist you in returning to a job or retraining you for another job. For more information on the Social Security Administration's Ticket to Work program and other employment initiatives, go to [www.ssa.gov/work](http://www.ssa.gov/work) or call 800.772.1213. A pamphlet, entitled *Working with Chronic Kidney Disease* (11-10-0501), is available from the NKF.

People facing dialysis treatment or a transplant may worry that their treatment could cause them to lose their job. A law passed in 1990 (the Americans with Disabilities Act) prohibits 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. To order publications, call 800.669.EEOC.



## Can I exercise?

Yes. An exercise program approved by your doctor can increase strength and endurance, prevent fatigue, reduce stress and depression, and increase your overall quality of life.

Many people with kidney failure report being unable to do as much physical activity as before. However, the use of EPO (erythropoietin), a medicine that treats anemia, often improves the energy levels of people who receive dialysis treatment and, as a result, they are better able to start and continue a regular exercise program. People who have successful kidney transplants are often able to tolerate more standard exercise levels.

Before beginning an exercise program, it is important to consult your doctor and remember the difference between “doing” and “overdoing.” An exercise program should be planned to meet your special needs. Exercising with a family member

provides increased safety and companionship. A brochure, entitled *Staying Fit with Chronic Kidney Disease* (11-10-0502), is available from the NKF.

## Can I travel?

Yes. Travel for people with kidney failure requires planning in advance, but it can be done. In fact, the ability to travel can be an important part of living well with kidney disease.

When planning a trip, people on hemodialysis should make arrangements at least six to eight weeks in advance with a dialysis center in the area to be visited, or earlier during popular touring seasons, when dialysis centers may be less able to accommodate unscheduled patients. Friends or family who live in the area can assist you in finding the closest units by calling their local hospital or the National Kidney Foundation. The social worker in your local dialysis center can help make these arrangements, but in general, the initial contact is your responsibility.

You can find information about U.S. dialysis centers at [www.medicare.gov](http://www.medicare.gov) and international dialysis centers at [www.dialysisfinder.com](http://www.dialysisfinder.com) and [www.globaldialysis.com](http://www.globaldialysis.com)

To make the arrangements, the dialysis unit you are visiting will probably request medical information from your “home” center. At the same time, information about your payment method will be requested. Many dialysis centers bill Medicare for the traveling patient. Usually, you will have to pay the 20 percent balance and wait for any insurance reimbursement.



It is important to check with the person who handles the dialysis center’s billing about the amount owed. In many dialysis units, doctors’ fees are separate and may or may not be billed to Medicare and/or other insurance providers.

People on peritoneal dialysis (PD) will need to make plans for back-up medical care if they are going to be out of town for any length of time.

The PD nurse or doctor can provide a referral to a PD program in the area you are visiting and make sure the appropriate records are sent. Financial arrangements should be discussed with both dialysis centers, as the methods of payment for PD services may differ.

If you are on a transplant waiting list, notify the transplant center staff about how they can reach you at all times. You can also change your status to “on hold” until you return.

Make sure to bring enough of your medicines along and carry them onto the plane with you if you are flying. Drugstores in the area in which you are traveling may not have your medicines.

Travel agencies that make reservations for cruises for people on dialysis are available. It is important to reserve in advance because of limited openings. Check with your insurance company about coverage for dialysis on cruises. In most cases Medicare does not cover treatments outside the United States. For more information, see the National Kidney Foundation booklet, *Travel Tips for Kidney Patients* (11-10-0513).

## Physical Appearance, Sexuality and Childbearing

### **What kinds of changes may occur in my physical appearance?**

Changes in physical appearance due to chronic kidney disease vary from person to person. Sometimes your skin may become paler or slightly yellow. Some people may want to use

makeup to change their skin tone. Skin may become dry and flaky and produce an “ashy” appearance on darker skin tones. It is important to bathe daily and keep your skin well-moisturized.

Variations may occur in body weight, due to fluid loss or gain or some transplant medicines. With more severe kidney disease, you may also notice a different taste in your mouth and smell to your breath. This is due to the buildup of waste materials in your body, which would have been removed by your kidneys. Good mouth care can help. Brush your teeth, gums and tongue several times a day. Having dental checkups twice a year is recommended.

In hemodialysis, an access called a “fistula” will be created surgically (usually in the arm) to insert the hemodialysis needles. It will appear as a large vein under the skin. However, the arm access site does not appear as tubes or “plugs” sticking out of your skin. The skin near the site will become tougher due to the scar tissue that forms from the needle insertions.

This is also the case if your access is a “graft” – the man-made material used to join an artery to a nearby vein. A slight vibration, or “thrill,” will be felt over the access site. If blood vessels in your arm can’t be used, a catheter (thin tube) is inserted into a blood vessel in your neck or upper chest. The catheter can be hidden by clothing.

For peritoneal dialysis, a catheter (thin tube) is placed in the abdomen to allow for exchanges of cleansing fluid (dialysate). The external part of the tube will be taped to your abdomen but can be hidden easily with clothing. As with any changes in appearance, you will feel more comfortable once you become used to them.

After a transplant, the anti-rejection drugs can have an effect on physical appearance. This may include temporary puffiness of face and neck, increased hair growth, acne (pimples) and weight gain. Also, there will be a scar on the lower abdomen after the transplant surgery.

## Can people with chronic kidney disease still enjoy sexual relations?

As with other chronic illnesses, the desire for sexual activity may change with the onset of kidney failure; it varies for every person. Don’t be surprised if your interest in sexual activity is lower. At first, a lot of your energy will be needed for the physical and emotional adjustment to your illness. Erectile dysfunction, a man’s inability to have or maintain an erection, is common in kidney failure. It may be due to other medications, anemia, or a buildup of toxic wastes in the blood that may not be removed entirely by dialysis.

Emotional issues, such as depression, fear of disability or death, or marital problems, can also affect sexual function. Couples who find that their sex lives are changing as a result of one partner’s kidney failure should talk about the problem with a doctor or social worker; many of these problems can be treated.



While some men and women with kidney failure suffer from sexual problems, many transplant recipients become more sexually active and have fewer sexual problems as their new kidney continues to function. For additional information, see the NKF brochure, *Sexuality and Chronic Kidney Disease* (11-10-0504).

### **Can men with chronic kidney disease 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 about possible fertility tests.

### **Can a woman who is on dialysis have a baby?**

Women with kidney failure, whether or not they have begun dialysis, may be advised against becoming pregnant. The rate of complications and the risk to both the developing baby and the mother are high. It is important to consult a doctor for further information and advice,



and to consider birth control. The use of EPO, a special medicine that treats anemia, may increase the chance of becoming pregnant.

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

Yes. A woman who has had a kidney transplant usually has more regular periods and better general health. Therefore, it is easier for her to get pregnant and have a child. However, pregnancy is not recommended for at least one year after the transplant, even with stable kidney function. In some cases, pregnancy may not be recommended because of risk to the mother's life or possible loss of the transplant.

## Dealing With Emotions

### **What can my family and I do about feelings of depression and worry?**

These feelings are very common. One of the most helpful things you can do is talk about them. Feelings are real and need to be shared. You may have been taught that it is “weak” to cry, but many times that is exactly what you need to do.

You and your family will have more difficulty adapting to kidney failure if you hold the sadness and worry inside. Other patients can be a good source of support and inspiration. Ask your treatment team or your local NKF office for the names of patients with whom you can talk.

Talking about your needs is healthy. Even the closest family members cannot read your mind, so tell your family how you feel. With the stress of kidney disease, it is important to keep a sense of warmth and closeness with family and friends. You may feel you are a burden to your family. It is important to realize that kidney

failure did not happen just to you alone—it happened to your family as well.

Sharing your thoughts and feelings freely in an honest, respectful manner can help you and your family and might even bring you closer together. This includes the negative feelings of sadness, anger, fear and resentment. Holding these thoughts and feelings inside can result in emotional distance between family members.

### **How can my family and I deal with the stress of chronic kidney disease?**

It is important to realize that the stresses and frustrations of kidney failure are real, and at times, very difficult. Family members may feel as though their world is caving in, especially if they have not faced a major health crisis before, and the diagnosis was unexpected. They may feel helpless because they cannot do anything about your illness. They may be angry that kidney disease has happened to “their” family. They may fear that you

could die. They may feel guilty if they did not realize the seriousness of your illness, thinking they should have or could have done something to prevent it.

A period of confusion and tension may occur as everyone tries to cope with the demands of the illness, the anxiety of treatment, the disruption of everyday life and the sudden presence of the health care team in your lives. Kidney failure requires changes in lifestyle. Routine chores and activities that demand physical strength may be difficult for you to perform now. Family members or friends may have to take on added responsibilities.

Eventually, family life may return to nearly normal, with treatment becoming more or less routine.



The following steps can help decrease stress:

- Talk to the staff at the dialysis center or transplant clinic.
- Write down questions ahead of time and inform family members about changes in treatment.
- Find out as much as possible about the illness through the National Kidney Foundation, local or national support groups, written materials and educational classes.
- Stay involved in the joys, activities and responsibilities of daily living.
- Find time to exercise at a level to suit your abilities.
- Share your feelings with family or close friends.
- Share your feelings with other patients.
- 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.

- Find time to enjoy the outdoors.
- Arrange your treatment around your previous activities.
- Be patient and set realistic goals in adjusting to all lifestyle changes.

### **Is it normal for people on dialysis to feel upset at times with the staff at the dialysis center?**

Yes. A dialysis center is different from any other health care setting. The unit almost becomes a “second family,” because of the amount of time you spend there. As with family members, it is normal to feel frustrated and angry with your health care team sometimes.

Resentment of being dependent on other people is a common cause for these feelings. Sometimes you may disagree

With the care or treatment you are receiving. It is important that you openly discuss your concerns with the staff. Bottling-

up resentment can affect your treatment, health and emotional adjustment.

### **When should professional counseling be sought?**

Living with kidney disease and its treatment can be distressing, particularly in the early weeks and months. You and your family may go through a period of grieving as you try to adjust to difficult feelings and make needed changes. You and your family may wonder if you will be able to cope and whether your feelings are “normal.” Many people go through a crisis period at the beginning, but with the support of family, friends, medical staff and other patients, you will eventually adjust to life with kidney disease.

Dialysis units and transplant centers have professionally trained social workers who are available to provide adjustment counseling. Generally, the following may indicate a need for professional help:

- Depression lasting more than two weeks

- Thoughts of suicide
- Loss of appetite or increased appetite
- Too much or too little sleep
- Loss of interest in activities you used to enjoy
- Repeated angry outbursts
- Drug or alcohol abuse
- Inability to make decisions
- Social isolation

Through counseling, you and your family can learn to draw on inner strengths and learn new ways of coping with kidney disease and necessary treatment. If additional professional help is needed beyond what can be given by the social worker at your treatment center, ask for a referral to your local mental health center or private practice counselor (psychiatrist, psychologist or social worker). Remember, asking for help is not a sign of weakness, but of your desire to do well.



## Is it normal to have mood swings?

Moodiness is common among people with kidney disease. It is often thought to be a result of the following factors:

- Uremia, or the buildup of waste products in the blood, can irritate the nervous system, causing an increase in irritability.
- Some medications may cause moodiness or make you feel depressed.
- The stress caused by chronic illness accounts for a wide range of feelings and moods. This includes general irritability, anger and frustration over the problems caused by the illness, and feeling hopeless and helpless when faced with a life-threatening disease.

## How can my partner handle these changes?

Someone whose husband, wife or partner has always been easygoing and pleasant may find these mood changes upsetting. If a new medication was added, or if a medication was increased before the change in mood occurred, notify the doctor.

Understanding that irritability and moodiness may be part of the experience of kidney disease can help your partner to accept these changes. It may be helpful to talk openly and honestly or remind the patient that this behavior affects others. It also is important to discuss ways to relax when tensions are high. Having a friend or family member to talk to can be helpful to the partner.

## When Young Adults Have Kidney Disease

### How can teenagers with kidney failure handle fears about what friends and schoolmates will think of them?

Teenagers are concerned about how to tell their friends about their condition and how their friends will react. Often, schoolmates will notice the graft or fistula in the patient's arm and ask about it. Friends may wonder why the teen patient has to go to the hospital or clinic several times a week. Sometimes teenagers may have some knowledge about dialysis and transplants; they may have seen TV programs about kidney failure or transplants and be aware and supportive.

Teenagers who have difficulty telling others about their medical problem may not have worked out their own feelings about the illness. Talking with the school counselor or social worker in the dialysis center or transplant clinic may help them work through these feelings. Also, talking to



other teenagers with kidney disease about how they deal with things may help. The key is feeling secure and comfortable with themselves; then telling other people becomes easier.

### **Do many teenagers with chronic kidney disease feel that their plans for the future are over?**

Yes. Most teenagers (and even adults) who have kidney failure feel this way. Having kidney disease affects an individual's life, but the future is far from over. Starting dialysis treatments or having a transplant, following a special diet and taking medicines are big changes. A kidney transplant may make extra medical visits necessary.

Most young people worry about being able to continue with school, earn a living, get married or have meaningful relationships. However, many teenagers with kidney failure have gone on to complete school and start successful careers. Talking to the social worker at the dialysis center or transplant clinic about these concerns may be helpful. Other teenagers with kidney failure may be willing to discuss how they cope with setbacks.

Summer camp is a great place to meet other young people with kidney failure. The NKF or a social worker can provide information about the many summer camps throughout the country available for teenagers with kidney disease.

Another publication available from the NKF is written specifically for teenagers: *It's Just a Part of My Life: A Guide for Young Adults with Chronic Kidney Disease* (11-10-1901).

## Can a youngster with kidney failure safely take part in active sports?

A youngster who is feeling well and enjoys active sports does not want to feel overly protected. Parents may find it difficult to know how far to let their child venture. Talking this over with the doctor will help parents learn whether they are making a decision from a medical or emotional standpoint. Often a doctor's advice will be based on the type of physical activity (e.g., horseback riding, football).

Controlling a child too much may make the child angry, rebellious and resentful. It is important to try to keep a healthy balance between common sense and concern over the child's health and well-being. As time passes and the parents see that their child continues to feel better, they may feel more comfortable with their decisions.

## Family Issues

### How can a parent handle having to make difficult medical decisions for a child who has CKD?

Parents do not have to make decisions about medical care alone. A team of health care professionals is there to help make these decisions based on the most up-to-date information. The choices are not always easy, and no one can predict the future.

Parents always wonder whether they are doing the right thing. Parents must take comfort in trying to make the best decisions possible along with the health care team members. It may be helpful to talk issues over with other parents of children with CKD.

### How can the parents of a child who has kidney disease handle discipline?

All parents worry about how best to raise their children. Disciplining a child who has kidney failure is not an easy task for parents. Although parents feel worried and protective, they must



consider the child's development, and think in terms of trying to maintain as normal a home environment as possible.

When a child has a chronic illness, discipline becomes an even more difficult issue. Giving in to a child's every whim or not expecting the child to have any responsibilities in the home can often create short-term and long-term problems.

Children need limits, even though they may argue and become angry. Parents who give in all the time may be creating a demanding, spoiled and undisciplined child. Other children in the family will notice and be affected by how the child with kidney failure is treated.

Talking with other parents who are in a similar situation is helpful. Becoming involved in a parent support group might help lessen anxieties and concerns. One of the most important things parents should remember is that they are doing the best they can.

## **How should parents talk to their child about the death of a close friend in the dialysis center?**

Most people are naturally uncomfortable in this situation. Talk with the social worker and nurse at the unit to see how they handled telling other children. Parents should not deny the event for fear of making their child more afraid or unhappy. Although the child may not mention the death, it has not been forgotten; the child may be waiting for you to start the discussion.

Generally, children can express their feelings when given the chance. It is important to allow enough time to pass and realize that more than one discussion is generally needed. Parents should be aware of their own feelings about this loss. Anyone involved with the child who died will feel upset and will need to talk.

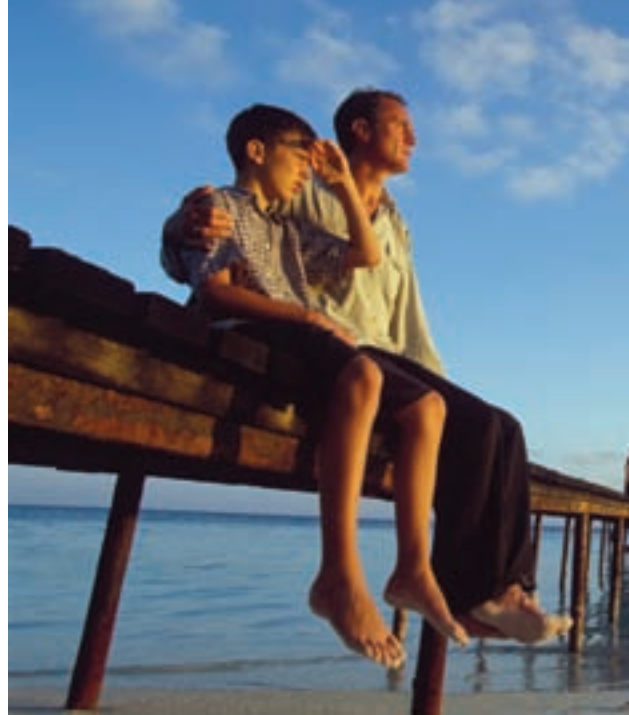
Communication should be kept open with your child and the staff. You and your child may need to talk with the social

worker if your child's sadness or fear becomes difficult for you to handle alone. If you are concerned about how your own child is doing medically, you should seek assurance from your doctor.

### **How should parents explain kidney disease to young children?**

A parent's kidney disease can affect his or her children's lives. Discussing the illness and treatment openly with the children, at a level they can understand, can help prevent them from developing fears and misconceptions. Children may dwell on "terrible" things they have done or said and blame themselves for their parent's illness, which can cause problems in the future.

Often, children may behave differently after the parent is diagnosed with kidney failure. Sometimes, they begin to act like "little adults" or "perfect angels." Other times, they begin to misbehave and have problems



in school. These are ways children cope with a parent's illness and their fears about that illness.

A parent who feels unable to talk to the child should speak with the social worker at the dialysis center or transplant clinic. The social worker may be able to help both parent and child learn how to talk openly about the treatment and fears related to it. The social worker may refer the family to a family therapist or the child to a child therapist.

## **Can the responsibility of helping a parent who has chronic kidney disease be harmful for a young child or teenager?**

Although children or teenagers may be glad to help a parent who is learning to adjust to life with a chronic illness (and sometimes with an associated disability), this may cause problems in the future. The youngster may feel responsible for the parent, leading to a reversal of the usual parent-child roles. When the parent has problems, the child may feel he or she is at fault.

In growing up, a child must learn to separate from the parent. This becomes a difficult task in situations where the parent has a chronic illness, because the child may feel he or she is shirking the duty to help. In some cases, the child may rebel against the illness entirely, causing severe family problems.

Rather than overburden a child, the parent should seek help from a friend or community agency.

Public health and social welfare agencies, as well as local health agencies, may be able to provide help with personal care and housework. This allows the child to grow up normally, with the parent still in charge and in the parent role.

## **What is the best way to help an elderly parent who has chronic kidney disease?**

The experience of having an older parent with a chronic illness can be difficult. A person who has been independent may find it difficult to accept declining health. However, some people stay independent while on dialysis, and their adult children may offer help before it is needed.

In many families, a slow role-reversal occurs as aging parents become more ill and dependent. Treating elderly loved ones with dignity and respect, while at the same time taking more responsibility for their care, requires a delicate balance of patience, sensitivity and honesty.

Often, one of the adult children becomes the primary caregiver of the parents, which can be a burden if the other siblings are not helping with at least some aspects of care. Having everyone in the family talk about what is happening can be helpful.

The ideal solution is when the family pools all its resources, rather than one person carrying the load. Joint planning for everyday needs, such as cooking, cleaning, transportation and paying bills, helps ensure a wise use of family resources. A social worker may help facilitate a family meeting, if family members have a hard time talking together.

Adult children can help by going to meetings at the dialysis center, learning about kidney disease and its treatment and allowing the parent to talk freely about concerns. They can also help the parent cope with the confusing number of agencies, interviews and medical regimens. They should encourage the parent to

continue with as many of their usual activities as possible, such as attending religious services, senior citizen programs, hobbies, travel and visiting with family and friends.

### **What should the family do if the patient is not following medication and diet guidelines?**

Families often confuse love with taking care of the patient. Even with the best of intentions, they can keep the patient in the “sick/dependent” role by taking too much responsibility for the patient’s behavior. Generally, patients have a greater feeling of self-worth when they take control of their own behavior. The following suggestions can help avoid this problem:

- Family and staff need to realize that the patient has the illness as well as control over intake of food, fluids and medication. No one else can assume this control.
- In many cases, the patient will begin to follow the treatment plan if the family clearly states

their concerns and limits of responsibility, then “backs off.”

- A good caregiver is a loving, open person. However, struggles with the patient over diet, fluids and medicines are often mixed with needs for power and control, and feeling responsible and “better than” the patient. This, in turn, makes the patient angry and even less cooperative.
- Family members need to make sure that they are not making it more difficult for the patient to stick to the treatment by offering food or fluids not included in the diet.

## What other resources are available?

The NKF has many helpful materials and programs. Contact your local NKF office or call the national toll-free number, 800.622.9010, for more information. Also, visit our website at [www.kidney.org](http://www.kidney.org)

You may be interested in becoming a member of the NKF’s Patient and Family Council. Membership is free. Call 800.622.9010 for information and to receive an application.

Learn more about NKF’s People Like Us (PLU) advocacy program. People Like Us is a group of people, including those with chronic kidney disease, organ donors and transplant recipients. For more information, please visit our website, [www.NKFpeoplelikeus.org](http://www.NKFpeoplelikeus.org); e-mail us at [peoplelikeus@kidney.org](mailto:peoplelikeus@kidney.org); or call us at 800.622.9010.

**Questions for my  
Health Care Team**

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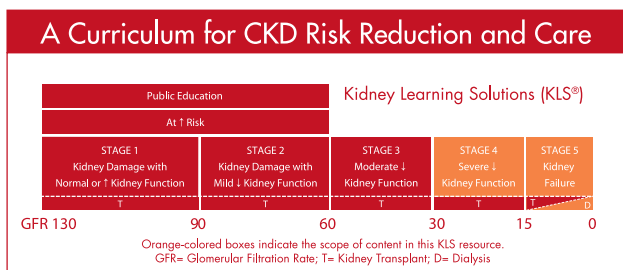
# National Kidney Foundation

The National Kidney Foundation (NKF) is dedicated to preventing kidney diseases, improving the health and well-being of individuals and families affected by these diseases and increasing the availability of all organs for transplantation.

With local offices nationwide, the NKF provides early detection screenings and other vital patient and community services. The Foundation conducts extensive public and professional education, advocates for patients through legislative action, promotes organ donation and supports kidney research to identify new treatments.

In 2009, NKF launched a ground-breaking, multifaceted collaborative initiative to **"END THE WAIT!"** for a kidney transplant in the United States in 10 years by using proven strategies to eliminate barriers to donation and institute best practices across the country.

The NKF relies on individual and corporate donations, foundation and government grants, and membership and special events to support its range of programs, services and initiatives.



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