



LIVING WELL





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Introduction

"Living Well with Kidney Failure" is a video series created by the National Kidney Foundation to help you understand kidney failure and its treatments. There are six videos. Each video has a companion booklet to provide more information and to help you review what you've learned. The six videos and booklets are:



This booklet assumes you already know something about kidney failure and its treatment. It will focus on some of the non-medical issues that you and your family may face as you learn to live with kidney failure and its treatment.

What will I learn?

You'll learn about kidney failure, and what happens when your kidneys don't work. This is discussed in the video and booklet called "What is Kidney Failure?"

You'll learn about other health problems that can happen as a result of having kidney failure, and what you can do about them. These are discussed in the video and booklet called "How Kidney Failure Affects Your Body."

You'll learn about the two basic treatments available—kidney transplant and dialysis. There are two kinds of dialysis: peritoneal dialysis and hemodialysis. Each treatment is discussed in the videos and booklets called "Kidney Transplant," "Peritoneal Dialysis," and "Hemodialysis."

In "Living Well," you'll learn about some of the personal and lifestyle changes you can expect when you have kidney failure, and how you and your loved ones can learn to cope with them.

Finally, you will be introduced to some medical terms and important words that may be new to you. To help you get to know these new words, there's a list of "Words to Know" at the end of each booklet.





Don't be afraid to ask your healthcare team questions.

Who is on my healthcare team?

Nephrologists are doctors specially trained in treating kidney disease and kidney failure. Your nephrologist will give you regular checkups, monitor your health, prescribe medicines, oversee your monthly blood tests, and much more.

Advanced practitioners are also trained in treating kidney disease and kidney failure. They work closely with your nephrologist to give you checkups, medicines, and other medical care.

Nurses work closely with other team members to coordinate all medical aspects of your care.

Dialysis technicians work in dialysis centers. They keep an eye on you and the dialysis machine while you're having treatment. They make sure all is well, and that you are as comfortable as you can be.

Dietitians will be working with you, too, teaching you to eat and drink the right things in the right amounts

Social workers help you with the many personal, non-medical aspects of your treatment, and with the changes in your life that kidney failure may bring.

If you choose to have a kidney transplant:

A team of **transplant specialists** at a transplant center will work with you, too. They will help you decide whether a kidney transplant might be a good treatment choice for you. They are responsible for all medical care related to your transplant, and for doing the transplant operation.



Who is affected by kidney failure?

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

Kidney failure is a lot to handle. It requires lifestyle changes—not only for you, but for your entire family. You and your family may find it helpful to share your concerns and questions with people who offer support. This may include members of your healthcare team, as well as your family, friends, and others you trust.



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 may have trouble adjusting to the changes in their lives that the disease brings.

It's important to understand that the stresses and frustrations of kidney failure are real and at times very difficult for both you and your family. You may feel like your world is caving in. Your family members may feel that way too, especially if the diagnosis was unexpected. 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.

A period of confusion and tension may occur 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 are going to experience many emotions as you learn to live with kidney failure.

You may feel sad, confused, anxious, fearful, angry

— 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 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 the closest family members cannot read your mind, so 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 disease. It can be caused by:

- Waste products. The buildup of waste products in the blood (called "uremia") can be irritating to the nervous system.
- Medications. Some medications may cause moodiness or make you feel depressed.
- The stress caused by chronic illness. This
 includes general irritability, anger, and frustration
 over the problems caused by the illness, and
 feelings of being hopeless and helpless when
 faced with a life-threatening disease.

Your family members and friends may find some of your moods confusing. Talking openly and honestly with them may help. Understanding that irritability and moodiness can be part of having

kidney failure may help your family accept these changes. You may want to discuss different ways for you and your family to relax when tensions are high. Or you may want to consider family counseling.



Who can help?

In the "Living Well with Kidney Failure" videos, you learned about the healthcare team that works with you and your family at dialysis or

transplant centers. Social workers are important members of that team, trained to deal with the non-medical issues facing you and your family. They can answer many of your questions, or direct you to others who can help. Social workers meet regularly with all members of your healthcare team. They are dedicated to helping you make treatment a manageable part of your life.

Your social worker can also help if you are feeling overly sad, irritable, unable to face each day, or feeling like you want to give up. Studies show that 20 to 40 percent of people with kidney failure may have depression.

It's important to know that depression is a medical condition, and it can be treated. There's no need for you to suffer from it or be embarrassed about it. 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.

What else should I understand about my emotions?

It's important to understand that your emotions and your physical health are connected. This means that having 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, staying socially active, and so much more.



Can people with kidney failure have healthy relationships?

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



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.

Hormones, nerves, energy levels, medicines—all these can affect your sexuality if you have kidney failure. But there are 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.

How important is social activity?

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

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!

Try doing things you enjoy that also give social support, like walking clubs, volunteer work, babysitting, or even taking classes. Your social worker can help you find groups and activities to join. Activities like hobbies, clubs, community action groups, sports, and spirituality can have a positive effect on your health.

Working part-time or full-time is also possible talk to your social worker about resources for employment or going back to school if that is a goal.

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.



How can I keep a healthy outlook?

You may find that a positive attitude helps. Setting reasonable goals for yourself, being flexible and allowing for mistakes, or even having a sense of humor and spending time with people who make you laugh is important. All these things can help you stay positive.

How important is exercise?

Physical activity will give you energy, reduce stress, and help you stay more independent. It has also been shown to improve depression and overall mood. Physical activity should not be confused with heavy exercise. Any form of body movement helps — walking, gardening, dancing, babysitting, 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. Always check with your healthcare provider before beginning any new physical activity.



Why should I stay informed?

The more you learn about kidney failure, the better you will be able to make healthy choices about your treatment.

Because you have kidney failure, you'll need to learn more about a lot of things that affect your health. The more you know, the more you'll understand why something is part of your treatment. As a result, you'll be more likely to follow your treatment plan faithfully. You'll be better prepared for the many choices you'll have to make in the months and years ahead.

Don't be afraid to ask your healthcare team questions, especially if you don't understand something. You will be receiving a lot of new information as you live your life with kidney failure. Your healthcare team is there to help you learn and understand.



How can the National Kidney Foundation help?

The National Kidney Foundation has many helpful programs and informative brochures related to coping with kidney failure.

If you would like to request a brochure, participate in a program, or ask a question, visit the NKF website at www.kidney.org, or call the National Kidney Foundation at 1.855.NKF.Cares (1.855.653.2273).



Social workers are dedicated to helping you make treatment a manageable part of your life.

Review

It's important to understand that the stresses and frustrations of kidney failure are real, and at times very difficult. It can be helpful to remember that what you're going through is normal. The following steps can also 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.



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.

True or False

- Having kidney failure requires lifestyle changes for both you and your family. T
- 2. Your emotions do not affect your physical health. T F
- It is common for people with kidney failure to have mood swings. T F
- 4. A social worker is a member of your healthcare team who is trained to help you deal with non-medical issues facing you and your family. T F
- 5. It is better to ignore or suppress "bad" emotions (like sadness, anger, fear, and guilt) than talk openly about them. T F
- 6. There is little or no health benefit from physical activity, unless it's heavy exercise that makes you sweat. T F
- Reducing stress is your responsibility alone. It is not part of your treatment plan. T
- Depression is a medical condition and it can be treated. T F
- 9. Staying socially active and doing things you enjoy can have a positive effect on your physical health. T F
- 10. People with kidney failure can have healthy marriages and meaningful relationships. T

Words to Know

advanced Members of your healthcare team who work closely with your nephrologist to give you regular checkups, medicines, and other medical care. Advanced practitioners include nurse practitioners, physician assistants, and clinical nurse specialists.

depressionA serious medical condition that can be treated. Symptoms include feelings of hopelessness, sadness, inability to sleep, loss of appetite, crying, inability to think

clearly, or wanting to give up.

dialysis A process that filters waste products and extra fluid from your blood when your

kidneys are no longer doing their job.

dialysis center A place in the hospital or community where dialysis treatments are given to

kidney patients.

dialysis machine

A special machine that uses an artificial kidney to filter waste products and extra

fluid from your blood.

dialysis technician A member of your healthcare team who is specially trained to take care of the

dialysis machine and other equipment at the dialysis center.

dialyzer The artificial kidney that's part of the dialysis machine, which cleans your blood of

waste products and extra fluid. The dialyzer is a filter for your blood.

dietitian The member of your healthcare team who will help you plan what to eat and drink to help you feel your best.

healthcare team All the people responsible for planning your care and helping you cope with kidney failure. Your healthcare team may include a nephrologist, advanced practitioner, nurse, dialysis technician, dietitian, social worker, transplant coordinator, and transplant surgeon. You, too, are an important member of your healthcare team.

hemodialysis One of the basic forms of dialysis treatment. In hemodialysis, your blood is cleaned of waste products and extra fluid through a dialysis machine.

hormones Chemicals produced by different glands and organs—including the kidneys to trigger certain responses in your body.

kidney disease The loss of some or all of your kidney function. Kidney disease can result from conditions such as high blood pressure, diabetes, heredity, or injury to the kidneys.

The stage of kidney disease at which treatment with either dialysis or a kidney kidney failure transplant is needed to stay alive.

kidney transplant One of the basic forms of treating kidney failure. In transplantation, a kidney from a living donor or from someone who has recently died is surgically placed into a patient's body to do the work that diseased kidneys can no longer do.

nephrologist

A member of your healthcare team who is a doctor specially trained in treating kidney disease and kidney failure.

A member of your healthcare team who is a nurse specially trained to care for nurse

kidney patients, and to perform and monitor dialysis treatments.

nurse practitioner A member of your healthcare team who works closely with your doctor to give you

regular checkups, medicines, and other medical care.

peritoneal dialysis One of the basic forms of dialysis treatment. In peritoneal dialysis, a solution called

dialysate flows through a catheter into your abdominal cavity, where it removes

waste products and extra fluids from your body, and then is drained out.

A member of your healthcare team who works closely with your doctor to give you physician assistant

regular checkups, medicines, and other medical care.

A member of your healthcare team who is specially trained to help you cope with social worker

the non-medical problems you may have, such as the stress of a serious illness.

transplant A member of your healthcare team who is responsible for many parts of the coordinator

transplant process. The transplant coordinator is usually a registered nurse with

special training in kidney transplantation.

transplant physician A member of your healthcare team who will be responsible for much of your

transplant care. He or she may also be a nephrologist.

A member of your healthcare team who will perform the transplant operation, transplant surgeon

should you choose transplantation as your treatment option.

The People on My Healthcare Team

Nephrologist
Advanced practitioner
Nurse
Dialysis technician
Dietitian
Social worker
Transplant coordinator
Transplant surgeon
Transplant physician
Important telephone numbers

Questions for My Healthcare Team

Support provided by:













Acknowledgments

The National Kidney Foundation is grateful to the patients, clinicians, dialysis units, and transplant centers that helped make this program possible.

About the National Kidney Foundation



The National Kidney Foundation (NKF) is a team member working behind the scenes. The NKF offers programs like "Living Well with Kidney Failure" so that you and your family can learn about kidney disease and kidney failure.

NKF also supports patient and community services, research, professional education, organ donation, and public information programs.

This is one of six videos and booklets in this program. If you have questions, ask any member of your healthcare team, or call the National Kidney Foundation at **1.855.NKF.CARES** (1.855.653.2273) www.kidney.org



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