



Getting Ready for a “New Normal”



*A helpful guide
for
starting dialysis*



National Kidney
Foundation®

Getting Ready for a “New Normal”: A Helpful Guide for Starting Dialysis

Supported by an educational grant from



Dedication

To all people with chronic kidney disease
and their families, who are about to enter the
unfamiliar world of dialysis.

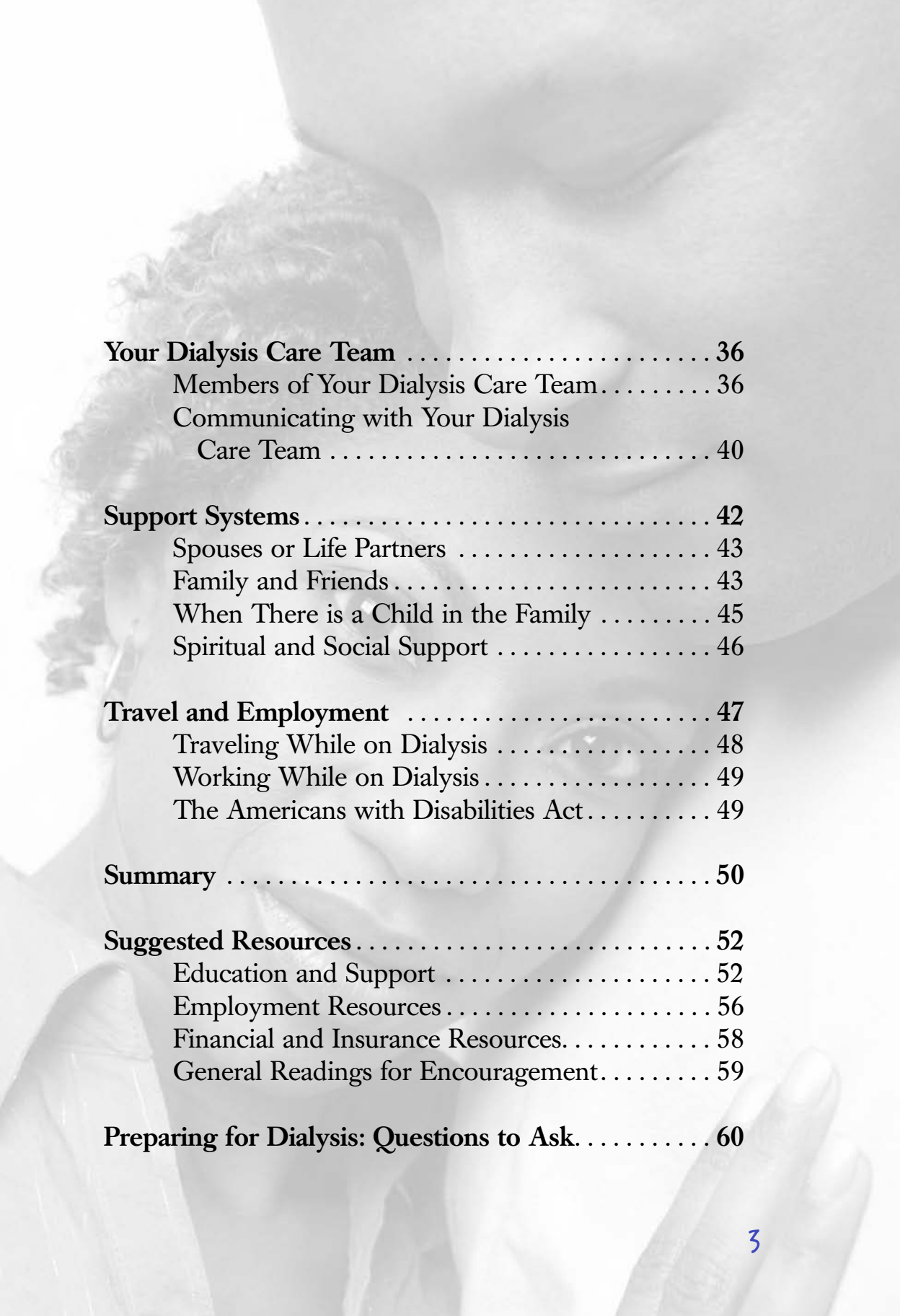
Special thanks to:

Our thanks to the many people
who shared their experiences and innermost thoughts
about starting dialysis.

Charles Corr, PhD, for contributing to this book.

Table of Contents

Introduction	4
Your Kidneys	5
Kidney Failure	6
Treatment Options	8
Choosing No Treatment	8
Dialysis	9
Hemodialysis	10
Vascular Access	10
Self-Care Hemodialysis	13
Home Dialysis	13
Peritoneal Dialysis	15
Emotional Health While Preparing for Dialysis:	
Issues of Loss and Coping	17
The Serenity Prayer	20
Challenges for People Facing Dialysis	22
Physical Health in CKD Stage 4	25
High Blood Pressure	26
Anemia	27
Bone Disease	28
Cardiovascular Disease	29
Diabetes	31
Lab and Other Diagnostic Tests	32



Your Dialysis Care Team	36
Members of Your Dialysis Care Team.....	36
Communicating with Your Dialysis Care Team	40
Support Systems	42
Spouses or Life Partners	43
Family and Friends.....	43
When There is a Child in the Family	45
Spiritual and Social Support	46
Travel and Employment	47
Traveling While on Dialysis	48
Working While on Dialysis.....	49
The Americans with Disabilities Act.....	49
Summary	50
Suggested Resources	52
Education and Support	52
Employment Resources.....	56
Financial and Insurance Resources.....	58
General Readings for Encouragement.....	59
Preparing for Dialysis: Questions to Ask	60

“It is so important that when someone is told they are going on dialysis, they connect with another patient to talk to. The general public knows nothing about dialysis. I know when I was told I needed dialysis, I felt like my world would end. It was so helpful to have someone to encourage me and let me know it would be all right.”

Introduction

This book has been written for you, someone who is about to start dialysis, to help you get ready.

Much of the information in this book comes from people with kidney disease who, like you, are facing the possibility of going on dialysis sometime in the near future. This book offers valuable information and tries to answer your questions about what to expect while preparing for dialysis, with a special look at the emotional issues surrounding this time. Most of all, this book will help you realize that you are not alone. More than 20 million Americans have chronic kidney disease (CKD). Many don't even know it.

People with CKD have had their lives affected by illness and share a history of dealing with kidney disease. Male

and female of every age, and of many different cultural backgrounds and religious affiliations, each one of you is unique. Having kidney disease and choosing to start dialysis affects everyone similarly. You all face uncertainty, loss of your way of life as you know it and have experienced a variety of reactions to what is happening. All of this is on top of the changes in your physical health, which may range from okay to not-so-good, even while the need to replace your kidney function looms large.

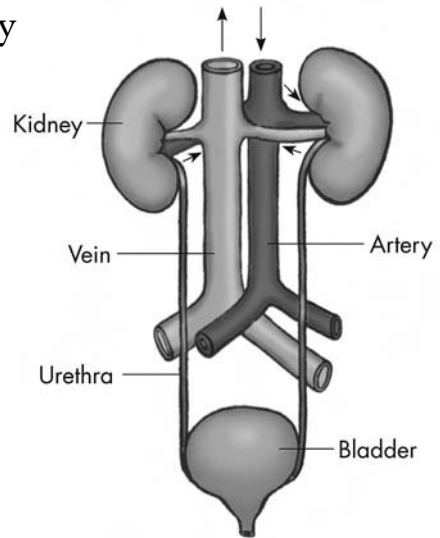
YOUR KIDNEYS

People don't usually think about their kidneys. Generally speaking, the kidneys and how they work are a mystery to many of us. People usually have two kidneys, even though one is all that is needed to live a healthy life. Unlike your heart or lungs, which have more noticeable functions (the heart beats to pump blood; the lungs expand and contract when we breathe in and out), your kidneys perform their important work without being noticed.

The major job of the kidneys is to remove waste products and excess fluid from the body through the urine. The kidneys also produce hormones that affect the function of other organs. For example, a hormone produced by the kidneys called erythropoietin (or EPO) helps the body make red blood cells. Other hormones produced by the kidneys help control blood pressure and how the body uses calcium.

The kidneys are powerful chemical factories that perform the following functions:

- ❖ remove waste products from the body
- ❖ remove drugs from the body
- ❖ balance the body's fluids
- ❖ release hormones that control blood pressure
- ❖ produce a form of vitamin D that promotes strong, healthy bones
- ❖ control the production of red blood cells.



KIDNEY FAILURE

Kidney failure does not happen overnight. In the early stages of kidney disease, there are few, if any, symptoms. Symptoms usually show up late in the process. Kidney failure is the end result of a typically gradual breakdown of kidney function. The most common causes of kidney failure are diabetes and high blood pressure. As your kidneys failed, your blood urea nitrogen (BUN, a substance which comes from the breakdown of protein in the foods you eat) rose, as did the level of creatinine (a measure of kidney function) in your blood. Some of you may also have nausea, vomiting, a loss of appetite, weakness, increasing tiredness, itching, muscle cramps (especially in the legs) and anemia (a low blood count).

The glomerular filtration rate (GFR) is the best test to measure kidney function and figure out the stage of kidney disease. Your doctor can measure your GFR from the results of a blood creatinine test, your age, race and gender. GFR helps your doctor make a care plan for each stage of your kidney disease.

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
3	Moderate decrease in GFR	30 to 59
4	Severe reduction in GFR	15 to 29
5	Kidney failure	Less than 15

**GFR is a number that tells your doctor how much kidney function you have. As chronic kidney disease progresses, GFR decreases.*

TREATMENT OPTIONS

When CKD or some other condition caused your kidneys to stop working properly, kidney failure followed. When this happened, you were faced with having to take steps to replace your kidney function in order to stay alive. Choices for kidney replacement included a kidney transplant or some form of dialysis (hemodialysis or peritoneal dialysis).

If you prefer to have a kidney transplant, you will need to be put on a waiting list to receive a compatible organ from a living or deceased donor. Or, a suitable person must be found (relative, friend, loved one) who is willing to donate one of his or her kidneys. Dialysis—either hemodialysis or peritoneal dialysis—may be required while waiting for a transplant. If a compatible donor organ is not found or if transplant is not possible, dialysis could be required for the rest of your life.

CHOOSING NO TREATMENT

There are some people who choose not to go on dialysis at all or who may prefer to go on dialysis on a trial basis to see how it helps them. Although the decision about dialysis is ultimately yours, it should ideally be based on discussions with your health care provider, family, caregivers and loved ones.



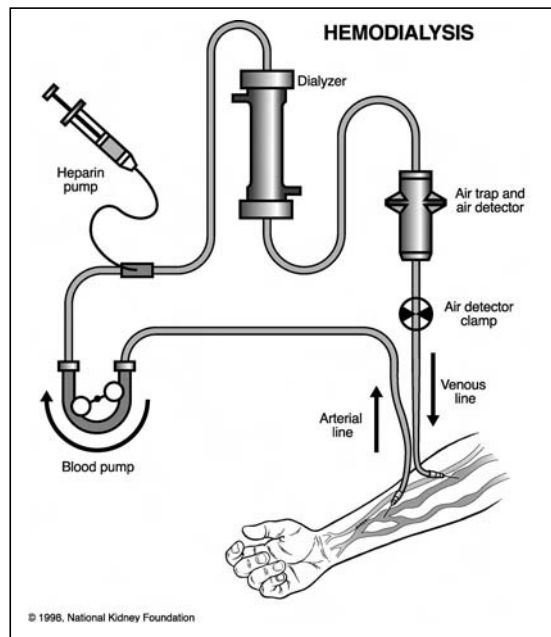
Dialysis

Dialysis (hemodialysis and peritoneal dialysis) is a treatment that does some of the things normally done by healthy kidneys. Dialysis is needed when your own kidneys can no longer take care of your body's needs. Like healthy kidneys, dialysis helps to keep your body in balance. Dialysis does the following:

- ❖ removes waste, salt and extra water to prevent them from building up in the body
- ❖ keeps a safe level of certain chemicals in the blood such as potassium, sodium and bicarbonate.

HEMODIALYSIS

In hemodialysis, an artificial kidney (or simply, a dialyzer) is used to remove waste, extra chemicals and fluid from the blood. To move the blood from your body into the dialyzer, the doctor needs to make a vascular access (entrance) into the blood vessels. This is done by minor surgery to the arm or leg and allows blood to travel through soft tissues to the dialyzer.



VASCULAR ACCESS

For a hemodialysis patient, an access is one of the following:

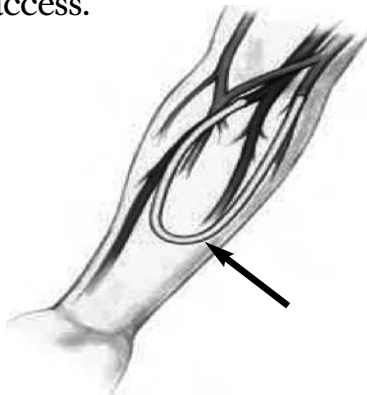
- ❖ An access may be made by joining an artery and a vein under the skin to make a bigger blood vessel called a fistula. A fistula is considered the first choice for dialysis

access because it generally lasts longer and has fewer problems such as infections and clotting. However, some people may not be able to receive a fistula because their blood vessels are not strong enough. Sometimes, it may be possible to switch to a fistula from another type of access. If you do not have a fistula, ask your dialysis care team if a switch would be possible.



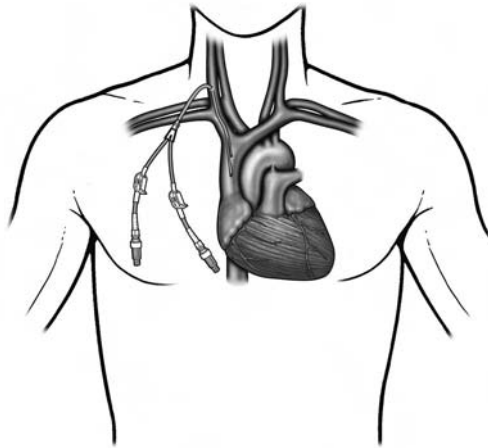
Fistula

- ❖ If the blood vessels are not suitable for a fistula, the doctor may use a soft plastic tube to join an artery and vein in the arm. A graft is considered the second choice for an access.



Graft

- ❖ Occasionally, an access is made by means of a narrow, soft plastic tube that is placed in a large vein, usually in the neck or chest. This is called a catheter. Catheters are generally used as a temporary access, but may sometimes be used for long-term treatment.



Catheter

If your access is a fistula or a graft, your nurse or technician will place two needles into the access at the beginning of each dialysis treatment. These needles are connected to soft tubes that go to the dialysis machine. Your blood goes to the machine through one of the tubes, gets cleaned in the dialyzer, and returns to you through the other tube. If your access is a catheter, it can be connected directly to the dialysis tubes without the use of needles.

Dialysis treatments involve a good deal of time. Usually, each hemodialysis treatment lasts around four hours and is done three times per week. It can be done in a dialysis center or clinic, or it may be performed at home. The time needed for your dialysis depends on:

- ❖ how well your kidneys work
- ❖ how much fluid weight you gain between treatments
- ❖ how much waste you have in your body
- ❖ your body weight
- ❖ the type of artificial kidney used.

SELF-CARE HEMODIALYSIS

In some centers, it is also possible to engage in self-care hemodialysis. Self-care allows you to perform much of your own dialysis, with the staff there simply to help you if needed.

HOME DIALYSIS

In some cases, hemodialysis can be performed at home, where you are the one doing your treatments. At home, you may be better able to fit your treatments into your daily schedule. Studies show that the more you know about your treatments and the more you do on your own, the better you are likely to do on dialysis.

Three types of hemodialysis can be performed at home. They are:

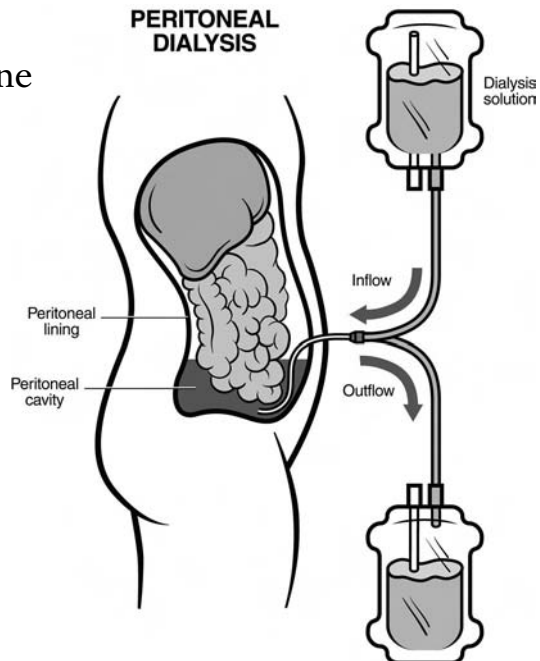
1. **Conventional home hemodialysis:** This is done three times a week for a minimum of three to four hours each time. You and your care partners are trained to do dialysis safely and to handle any problems that may occur. Training may take from several weeks to a few months.
2. **Short daily home hemodialysis:** This is usually done five to seven times a week using machines designed for short daily home treatment. Treatments usually last about two hours each. You and your care partners are trained over several weeks. Because these treatments are done more often, less fluid generally needs to be removed each time. This reduces symptoms like headaches, nausea, cramping and feeling “washed out” after treatment.
3. **Nocturnal home hemodialysis:** Long, slow treatments are done at night while you sleep. This kind of dialysis is done six nights a week or every other night, depending on what the doctor prescribes. More hours of dialysis each week can result in more waste removal. Treatments usually last about six to eight hours. You and your care partners are trained over several weeks. Some centers can monitor your treatments from your dialysis machine through information sent by telephone modem or the Internet to a remote-staffed location.

It is possible to combine daily and nocturnal home hemodialysis. Whether you can combine treatments depends on your needs, medical condition and machine. Whichever treatment option you choose, it is important to know if you are getting the right amount of dialysis. Tests should be done regularly to check the amount of dialysis you receive. For more information, speak with your doctor and your dialysis care team.

PERITONEAL DIALYSIS

In peritoneal dialysis, the blood is cleaned inside your body. The doctor will do surgery to place a catheter into the abdomen (belly) to make an access. During the treatment, the abdominal area (called the peritoneal cavity) is slowly filled with dialysate (dialysis fluid) through the catheter.

The blood stays in the arteries and veins that line the peritoneal cavity. Extra fluid and waste products are drawn out of the blood and into the dialysate.



There are two major kinds of peritoneal dialysis: Continuous Ambulatory Peritoneal Dialysis (CAPD) and Continuous Cycling Peritoneal Dialysis (CCPD).

CAPD is the only type of peritoneal dialysis that is done without machines. You do this yourself, usually four or five times a day at home and/or at work. You put a bag of dialysate (about two quarts) into the peritoneal cavity through the catheter. The dialysate stays there for about four or five hours before it is drained back into the bag and thrown away. This is called an exchange. A new bag of dialysate is used each time you do an exchange. While the dialysate is in the peritoneal cavity, you can go about your usual activities at work, at school or at home.

CCPD is usually done at home using a special machine called a cycler. This is similar to CAPD, except that a number of cycles (exchanges) occur. Each cycle usually lasts 1 1/2 hours and the exchanges are done throughout the night while you sleep.

Many of you have found new freedom and improvement in your quality of life through peritoneal dialysis. As one person stated,

“Hemodialysis controlled me; peritoneal dialysis gave me control and freedom.”

Emotional Health While Preparing for Dialysis: Issues of Loss and Coping

"My main concern was the changes to my lifestyle."

"Before I started, I was nervous. I didn't understand anything."

"When I was told that I may have to go on dialysis, it hurt. I felt so helpless and afraid because I didn't know what to expect."

Nobody knows better than you do the feelings you have about starting dialysis. You are about to enter an unfamiliar world filled with new routines, a new set of rules and people, and strange machines and tests. You may have a lot of questions such as: How will dialysis change my lifestyle? How much time is involved? Will the treatments hurt? How will my family and friends react? How much will treatments cost and are they covered by health insurance? Will I die without these treatments?

You may be scared, anxious, resentful, hopeful, optimistic, happy, angry, sad, all of these or none of these. Although you may know that dialysis can be a *life-saving* treatment, you may not fully understand that it may also be a *life-changing* experience. For many people with kidney failure, dialysis greatly improves their quality of life. However, some people do not see a big improvement, often because they have other serious health problems.

Here are some thoughts expressed by people upon first learning they needed to start dialysis:

“I don’t want to do it. I don’t have time. My life will change. There must be a pill I can take. Will I actually feel better? Will I still be independent?”

“Thoughts of dying first prevailed and still do, but I’m strong mentally and spiritually. Both my doctors say I’m very alert, active and attentive. I’m in good mental health at 83 years of age and pretty spry.”

“My family is ‘concerned’ about how to cope with dialysis.”

“Logically, I understand I have a problem, but my symptoms are deceiving. I live life ‘go, go, go.’ How can I be this sick? It’s like it’s not really happening to me, but a doctor said it is. I don’t think it’s denial. I’m smart. I understand.”

“I had disbelief and anger toward previous doctors who did not see the problem. I reached out for further information and looked into the possibility of slowing this problem with diet.”

For many of you, the need to go on dialysis came as a surprise. Many of you were not aware that you had kidney disease until symptoms occurred in the late stages. Even for those of you who knew, you may have thought the need for dialysis was far-off in the future. The news that the time had arrived may have come as a shock for some of you.

THE SERENITY PRAYER

Many of you who have faced losses and challenges in your lives have found comfort in *The Serenity Prayer*. You may know its familiar lines. (Sifton E. *The Serenity Prayer: Faith and Politics in Times of Peace and War*. New York, NY: Norton; 2003.)

*God, give us grace
to accept with serenity
the things that cannot be changed,
courage to change the things
that should be changed,
and the wisdom to distinguish
the one from the other.*

Some psychologists who write about coping make the same suggestions as the *Serenity Prayer*. What they have to say may be good guidelines as you face dialysis for the first time. Their view is that a person's coping skills can involve one or more of three approaches:

- ❖ First, when the prayer asks for *wisdom*, psychologists encourage you to use what they call *appraisal-focused coping*. This type of coping looks at different ways to understand things that are stressful in your life. An example of this is to think of dialysis not so much as a burden, but as a way to improve and extend the quality of your life. One person summed it up nicely by saying,

“I was in shock and couldn’t believe that someone as young as I was had to go on dialysis. I didn’t even know what it was at first. My feelings changed as I went to dialysis and realized that I dialyzed to live and not the other way around. I coped by using family, friends and my faith.”

- ❖ Second, when the prayer asks for *courage*, psychologists encourage you to use *problem-focused coping*. This type of coping looks at what you can do to change the situation. By gathering information about different types of dialysis, a person can make a well-informed decision about the best type of treatment for him or her.
- ❖ Third, when the prayer asks for *serenity*, psychologists encourage you to use *reaction-focused coping*. When you cannot change the world around you, two things that always remain within your control are your own feelings about and reactions to what is happening to you. Some use humor to help deal with stress. Others have accepted the need for dialysis as a fact that cannot be changed and as something that is better than harsh alternatives. One person told us,

“Whenever it happens, then let it be. There’s nothing more that I can do or change.”

CHALLENGES FOR PEOPLE FACING DIALYSIS

“I wish I’d been more aware of the changes I felt just prior to starting dialysis.”

These are some of the issues you may be facing:

Some of your **physical challenges** may include:

- ❖ a lack of energy and a need for rest
- ❖ problems with large fluid intake and frequent urination
- ❖ gastrointestinal upset and gas, hemorrhoids
- ❖ joint flare-ups
- ❖ the need to get an access to your blood for dialysis.

Some of your **psychological challenges** may include:

- ❖ shock and denial
- ❖ feeling healthy and not wanting to be a patient, or always having felt ill and being without any quality of life
- ❖ fear and concerns for safety
- ❖ nervousness and anxiety about not understanding what is happening or not understanding labs and medications
- ❖ concerns about exactly when dialysis would start

- ❖ feeling angry at a previous doctor who had not diagnosed the condition earlier
- ❖ wondering if dialysis could be avoided by taking a pill, changing a diet or keeping blood pressure under control
- ❖ worrying about being in pain, being at the mercy of someone else, being a “number” and feeling like an invalid
- ❖ concern about whether the need to go on dialysis is somehow one’s own fault or responsibility.

Some of your **social challenges** may include:

- ❖ concerns that you won’t have time to start dialysis and that it will affect how you care for children/grandchildren
- ❖ transportation to see doctors or to the dialysis center
- ❖ limited or no insurance
- ❖ other financial issues
- ❖ issues related to living alone or with other people
- ❖ getting to know and rely on new health care providers
- ❖ unsure of which hospital or which specialists will be involved in your care
- ❖ condescending, distant care providers.

Some of your **spiritual/existential challenges** may include:

- ❖ thoughts of dying
- ❖ feeling like your life and dreams are over, that life has been turned upside down.

It is important to learn how to deal with these issues. For example, following an exercise program and a healthy diet, and discussing problems with doctors and other health care providers, including mental health specialists, social workers and others, can go a long way toward addressing physical and emotional challenges.

Getting used to dialysis is often difficult and requires patience and physical and emotional strength. However, with a positive yet realistic attitude, the understanding that dialysis may possibly save your life and help from other individuals in the same situation, dialysis will become a “new normal” in your life. One thing is for certain: Starting dialysis will profoundly change your life and that of your family, friends and loved ones.

“If I could tell newly diagnosed patients one thing about dialysis, I’d tell them to keep up with their dialysis treatments because it is important to get rid of the toxins in the body...”

Try to visit with others on dialysis to see how they have learned to cope. Talking with your health care team members, especially your social worker, about any problems you are having is also a good thing to do. Some dialysis clinics or communities have support groups you can attend.



Physical Health in CKD Stage 4

Regardless of what brought you to the point of kidney failure and the need for dialysis, you need to manage your physical health on a regular basis. Whether you have high blood pressure, diabetes, heart disease, anemia, bone disease or some other condition, going on dialysis will not make these conditions “go away.” Staying healthy and strong will help you cope with the stress of dialysis. You should follow a healthy diet, exercise and check your blood pressure, lab and blood values.

HIGH BLOOD PRESSURE

Blood pressure is the force of blood against the walls of the arteries as it circulates in the body. High blood pressure occurs when blood vessels become narrow or stiff, forcing the heart to pump harder to push blood through the body. When the force of the blood against the artery walls becomes too high, you are said to have high blood pressure, or hypertension. High blood pressure is both a cause and complication of CKD.

Blood pressure is measured as two numbers—a top number (called the systolic pressure) and a bottom number (called the diastolic pressure). A diagnosis of high blood pressure is not made on just one high reading, but must be checked on two or more visits to a doctor or clinic. In general, for adults 18 and older, blood pressure that stays at 140/90 or more is considered high. However, for people with diabetes or CKD, a blood pressure of 130/80 or more is considered high.

Controlling blood pressure will help the dialysis process work better and more efficiently. As one person stated,

“Aggressive blood pressure and anemia control is important to prevent heart disease in patients with any stage of CKD.”

Another person shared this,

*“Blood pressure was my biggest problem.
A different way of eating and exercise has it
under great control now.”*

ANEMIA

Anemia is a serious condition that affects 3.4 million Americans. Anemia occurs when the body’s red blood cells are in short supply. Red blood cells are important because they carry oxygen from the lungs to all the organs and tissues, providing energy for daily activities.

Many people with anemia have a variety of symptoms. However, anemia is not always found because it is hidden by other chronic conditions such as cancer, diabetes, kidney disease or HIV/AIDS. Even people who know they have kidney disease often do not realize they have anemia until years after their kidney disease has been diagnosed. The common symptoms of anemia include:

- ❖ extreme fatigue
- ❖ rapid heart beat
- ❖ shortness of breath
- ❖ mental confusion or loss of concentration
- ❖ dizziness or fainting
- ❖ difficulty sleeping.

The kidneys make an important hormone called erythropoietin (EPO), which helps the body make red blood cells. When the kidneys are damaged they make less EPO, causing a shortage of red blood cells, or anemia. Treating anemia in CKD involves increasing red blood cell production, allowing more oxygen to move throughout the body. This has a positive effect on both energy level and quality of life.

BONE DISEASE

Many people think of bones as simple, hard objects like wood or metal, but bones are a living, changing part of the human body. Old bone layers are constantly being broken down and new bone is being built. Bones are made of cells, fibers, blood vessels, nerves and large amounts of minerals, mostly calcium and phosphorus. For bones to stay strong and healthy, calcium and phosphorus must stay in balance. Problems occur when these two key minerals get out of balance. This happens with kidney disease.

Bones can be affected in the early stages of kidney disease. Most people do not have any symptoms at these stages of CKD. Even though no symptoms are felt, bone disease still needs to be treated. Itching may be a sign that your phosphorus levels are too high. With more advanced bone disease, there may be other symptoms, including bone pain, muscle weakness, fractures and joint pain.

Your doctor will check your blood levels of calcium, phosphorus and parathyroid hormone (PTH) in order to

tell whether you have bone disease and what kind of treatment may be needed.

CARDIOVASCULAR DISEASE

Cardiovascular disease (CVD) means there are problems with the heart and blood vessels throughout the body, including the brain, lungs and legs. Over time, the blood vessels that bring blood to the heart and brain can become blocked from a buildup of cells, fat and cholesterol. This lowers blood flow to the heart and brain, and can cause heart attacks and strokes.

Dialysis patients are much more likely than others to have CVD. This higher risk is related to kidney disease and other health problems such as diabetes and high blood pressure. For this reason, it's very important for people preparing for dialysis and those currently on dialysis to follow the steps to help prevent heart and blood vessel problems. If these problems occur, patients need to follow their treatment plan carefully to avoid complications like heart attacks and strokes.

Before starting dialysis, all patients should be checked for signs of CVD, as well as for risk factors of CVD such as smoking, high fat diet, lack of exercise, high cholesterol (a type of fat in your blood), high blood pressure and a family history of CVD.

To check how well your heart is working, you should have:

- ❖ An electrocardiogram (ECG or EKG) when you first start dialysis, and then once a year after that. This test checks the electrical activity of your heart.
- ❖ An echocardiogram (ECHO) when you first start dialysis. This test uses ultrasound to examine the heart, and to diagnose abnormalities and disease.

If the results of these tests are not normal, you may also need to have:

- ❖ A stress echocardiogram (a type of echocardiogram that requires exercise, usually on a treadmill) or a nuclear imaging test. These are done to check for a blocked artery.
- ❖ An angiogram (x-ray of the heart or arteries) to find a blocked area and help plan treatment.

Here are some steps you can take to prevent CVD:

- ❖ Speak to the doctor. The doctor and other members of your dialysis care team will work with you to develop a care plan that meets your needs.
- ❖ Keep blood pressure controlled. Follow treatment plans carefully in order to control high blood pressure.
- ❖ Reduce high cholesterol levels.
- ❖ Follow a heart-healthy diet.
- ❖ Increase physical activity.

- ❖ Treat anemia.
- ❖ Keep important minerals—calcium and phosphorus—in balance.
- ❖ Speak to the doctor about taking aspirin to prevent heart attacks.
- ❖ Reduce high homocysteine levels. (Homocysteine is an amino acid. High levels of homocysteine in the blood may raise the chance of having heart and blood vessel problems.)
- ❖ If you smoke, consider quitting.
- ❖ Maintain emotional health.
- ❖ If you have diabetes, check your blood sugar as often as the doctor tells you to. Follow your treatment plans of medications, diet and exercise.

DIABETES

Diabetes mellitus, usually called diabetes, is the number one cause of kidney failure. It is a disease in which the body does not make enough insulin or cannot use normal amounts of insulin properly. Insulin is a hormone that controls the amount of sugar in the blood. A high blood sugar level can cause problems in many parts of the body.

With diabetes, the small blood vessels in the body are damaged. When the blood vessels in the kidneys are damaged, the kidneys cannot clean blood properly. The body will hold on to more water and salt than it should, which can result in weight gain and ankle swelling.

There may be protein in the urine, a possible sign of kidney disease. Also, waste materials will build up in the blood.

About 30 percent of people with type 1 (juvenile onset) diabetes and 10 to 40 percent of those with type 2 (adult onset) diabetes will eventually have kidney failure.

Diabetes may also cause damage to nerves in the body. This can cause difficulty in emptying urine from the bladder. The pressure resulting from a full bladder can injure the kidneys. Also, if urine remains in the bladder for a long time, you can develop an infection from the rapid growth of bacteria in urine.

LAB AND OTHER DIAGNOSTIC TESTS

“I began monitoring my lab results at GFR 45 and got a lab log from NKF. I’m on top of this disease 100 percent. I’m learning everything I can.”

Because you have had to keep on top of your health through the years, you have become all too familiar with the world of blood tests and clinical laboratories.

Knowing your lab values, checking your blood pressure, and doing cardiovascular tests and blood work on a regular basis are ongoing tasks that must be continued in order to stay healthy. This means knowing what the targets are for each test and discussing with your health care team how to reach the targets. Changing your behaviors (diet, exercise, smoking and stress) will go a long way toward reaching target lab values and test results.

Checking your lab values while on dialysis is one way to know if dialysis is working correctly. In addition, regularly checking your heart and blood pressure is important so that doctors and other health care providers can know how your health is doing.

Among the lab values that may be checked regularly are:

Albumin-to-creatinine ratio: The albumin-to-creatinine ratio estimates the amount of protein (albumin) found in the urine in a day and avoids the need to collect a 24-hour urine sample. A measurement of greater than 30 mg/g is considered positive.

Hemoglobin: A hemoglobin test is done to check for anemia, or low red blood cell count. There are many reasons why the hemoglobin level can be low. Individuals with advanced kidney disease and poor kidney function can have anemia. The goal of anemia treatment is to keep your hemoglobin level between 11 and 12.

Lipid Panel: This group of tests is used to find out your risk of heart disease, and includes the measurement of cholesterol and triglycerides.

Estimated Glomerular Filtration Rate (eGFR): This test is used to find out your level of kidney function. Serum (blood) creatinine, age, race and gender are needed in order to provide this measurement. A GFR of below 30 requires the attention of a kidney disease specialist (nephrologist). A GFR below 15 means kidney failure.

Calcium, Phosphorus, PTH: Calcium, phosphorus and PTH tests are done to check bone health, which may be related to kidney disease and/or other problems. The following blood tests are done if eGFR is below 60:

- A. **Calcium** –tests for amount of calcium in the blood. Normal range in adults is 8.5–10.3 mEq/dL and best level is 9.4.
- B. **Phosphorus**–tests for levels of phosphorus in the blood. Normal range in adults is 2.5–4.5 and best level is 3.5.
- C. **PTH**–tests for amount of parathyroid hormone in the blood.

Target levels are different for people on dialysis than for people with other stages of kidney disease. If you have diabetes, the following lab tests may be checked:

Blood Glucose: Blood glucose is the amount of sugar in the blood. A drop of blood placed on a glucose monitor is used to check glucose level. A normal range in adults is

70–115 mg/dL. A test called hemoglobin A1c may also be done to check average blood sugar level.

Microalbuminuria: The microalbuminuria level tells if a small amount of protein (albumin) is present in the urine. Protein is usually not found in the urine. Raised levels of albumin in the urine may mean kidney disease is present. The test is positive if albumin is found in the range of 30–300 mg/24-hour sample.

Here are some thoughts about checking lab values from someone with kidney failure,

“I’m clueless on my labs. I would love if everything was explained to me. The why’s—how everything is working against me. Even my meds—what do they do? Why are they important?”

Your Dialysis Care Team

“My team is very open and helpful to me. All questions were answered and all concerns were addressed.”

Your dialysis care team will be made up of people who specialize in the care and support of dialysis patients, and you are your team’s most important member. It is important for you to know everything about your diagnosis and treatment. If you will be receiving care in the dialysis unit of a hospital or in a dialysis center, you will become familiar with the names and faces of people on your team. People on home dialysis will not see the whole team on a regular basis, but they are still there for you if you have questions or concerns.

MEMBERS OF YOUR DIALYSIS CARE TEAM

The team leaders in many clinics are doctors called **nephrologists** or, to use an easier term, **kidney doctors**. They have special training in treating kidney disease, and are responsible for your care during dialysis treatments. Nephrologists may also take care of patients before and after a kidney transplant.

Nephrology nurses are licensed RN and LPN nurses who specialize in the care of patients with kidney failure. They are responsible for checking patients, making sure that medications and treatments are given correctly and directing the dialysis process on a daily basis. The RN also runs the nursing services and home programs that train patients and their care partners to do self-dialysis, including home hemodialysis, CAPD and CCPD. All Medicare-certified facilities must have a full-time RN on staff who is experienced in dialysis.

Advanced practice nurses, nurse practitioners and clinical specialists with graduate nursing degrees work with the doctors in caring for kidney patients, both in medical offices and in the dialysis unit.

Renal dietitians have specialized degrees in dietetics and must meet certain education requirements to be registered dietitians (RDs). They know what foods are right for you and they can help you plan your meals. Following a diet is an important part of your care, both before and after starting dialysis. Renal dietitians can help you plan a diet to meet your needs.

Nephrology social workers are required to have a master's degree in social work and be licensed or certified. At least one master's-trained social worker must be available in the dialysis unit. Social workers can provide counseling to help you and your family cope with kidney disease and the changes in your family, home, workplace and community. They can help you plan treatments to fit

your lifestyle, and they find sources of emotional support if you need it. They also find services provided by government and community agencies to meet your needs and help you and your family get these services when necessary. Social workers can help you improve your quality of life.

There are two kinds of technicians in dialysis centers: **patient care technicians (PCTs)**, also known as dialysis technicians, and **biomedical technicians**. Both work under the guidance of the nephrology nurse or nephrologist.

PCTs perform your dialysis treatments. In many dialysis centers, they are responsible for starting and ending each treatment, and for watching you before, during and after treatments. PCTs complete a training program and some states require that they have state or national certification.

Biomedical technicians help maintain dialysis machines and water quality in dialysis centers. They order dialysis supplies and process dialyzers (artificial kidneys) to use again.

If you are scheduled to start hemodialysis, another group of health professionals will be involved in your care:

The **vascular access surgeon** will do surgery on your arm, leg, neck or upper chest to make an access (entrance) into your blood vessels. This is done so that your blood can enter the dialysis machine. As discussed earlier in this book, the ideal access is made by joining an artery to a

vein under the skin to make a bigger blood vessel called a fistula. A fistula is considered the first and best choice for hemodialysis access. The other access choices are a graft or catheter.

The **radiologist** will do special x-ray tests called vein mapping to help plan the access surgery. The radiologist may also place a catheter, repair a fistula that is not working properly and remove blood clots from an access. In some centers, a kidney doctor who has special training in radiology may do these procedures.

The **access coordinator**, who may be a nurse or other health professional, will review the history of your accesses, plan treatment, follow up to make sure you get the correct treatment and enter the information in your records.

The **secretary/unit clerks** are often the first people you will meet when coming to the dialysis center. They can direct you to the correct health care team member to answer your questions.

Most dialysis centers have **billing personnel** who can answer questions about insurance coverage and billing or payment.

COMMUNICATING WITH YOUR DIALYSIS CARE TEAM

“My team was very open and helpful to me. All questions were answered and all concerns were addressed.”

Knowing what to expect in the days leading up to dialysis, and about dialysis itself, can help you and your loved ones better prepare for the experience.

Your dialysis care team is responsible for answering your questions about kidney failure and dialysis choices. Don't be afraid to ask them whatever questions you have. It is part of their job to lend support and answer your questions. Remember that sometimes it's what you don't know that causes you the most concern.

If possible, plan to visit the dialysis center and meet the dialysis care team before starting dialysis. Most dialysis centers offer some form of pre-dialysis education where people who are about to start dialysis can meet with members of the center's staff, tour the center, talk with a patient on dialysis and get first-hand information about

both hemodialysis and peritoneal dialysis. Check with your center to see if they offer pre-dialysis education visits.

It may help to prepare a list of questions to ask during your visit and before starting treatment. The answers to your questions may help you to feel more confident and reassured about starting dialysis. (See *Preparing for Dialysis* at the end of this booklet.)

“I would love it if a potential dialysis or transplant patient could be paired with someone living the experience. It would be helpful to me, therapeutic to them and some of the burden would be lifted off of the doctor.”

“My VA [Veterans Administration] doctors are great when I ask them questions concerning the dialysis routine.”



Support Systems

Having people to turn to for support can be a great help while preparing to start dialysis. Among those who can be a part of your support system include:

- ❖ Family and friends
- ❖ People who are waiting to go on dialysis
- ❖ A spouse or significant other
- ❖ Mentors and co-workers
- ❖ Social, religious and spiritual groups.

SPOUSES OR LIFE PARTNERS

If you have a spouse or life partner, you have both been through a lot during your battle with kidney disease. Try to be patient with yourself and your spouse or partner, and understand that the two of you are doing the best you can to cope with the changes that are taking place. The physical changes that go along with your illness can bring up difficult feelings. It helps to talk to your partner about how you feel and what you need. Some of us seek help from a social worker, member of the clergy, psychotherapist, psychologist or other mental health professional as we face these uncertain times.

FAMILY AND FRIENDS

People respond in different ways when they are first told about the need for dialysis. The same is true for family members, friends and co-workers. They will wonder about how dialysis will change your life, their lives and future plans, even if they don't always talk about these feelings.

Family members and friends who are informed about dialysis and who understand its importance in your life are likely to be those to whom you can turn for help. The professionals who provide your dialysis care will help teach you about dialysis. Some members of your family and friends will become “key people” in supporting you and helping you prepare for your new life.

Dialysis will take up much of your time and energy. Family members and friends will need to respect your new focus and understand that you may have less time and energy available to share with them. Often, family members and friends may need to help out with tasks at work or in the home, as well as with transportation to doctor's offices, hospitals or clinics.

Don't be afraid to ask some family members and friends to be your advocates and supporters. These people can help you adjust to dialysis. For example, they may go with you to doctor's appointments or to meetings with the staff at the dialysis center. During such times, they can serve as your "eyes and ears" to watch and listen to what you are being told, to discuss the main points with you and to go over key lessons.

It's a question of balancing what you can do for yourself and what family members and friends can do to support you in these new experiences. Don't be afraid to ask people for help and to show them how to help. Those who love you and who are your true friends may not know what to do at first, but they will welcome your advice. No one who cares about you would feel comfortable just standing around not knowing what to do for you.

Dialysis introduces you to new specialists and to new technologies. Some people may find all of this a little strange at first and perhaps even a little scary, but most people are able to accept change. You, your family members and your friends can adjust to these new situations and experiences. After all, you are still the same person—the

father or mother, grandparent, friend, son or daughter—that you have always been. Opportunities to make stronger and deeper relationships may come from dialysis. Take advantage of them.

Here are some comments from people like you:

“Family members were afraid just like me, and told me to pray about it and find out all I could about the disease and dialysis treatment.”

“Get your family, spouse and children behind you. Keep them informed, even on bad things.”

These comments remind us that friends and family may become helpers and should be kept informed as we face dialysis.

WHEN THERE IS A CHILD IN THE FAMILY

It is important for the children in your family to be told what is going on in language they can understand. Children may not always understand about your need for dialysis, but they almost always are sensitive to the emotional energy within a family and a home. If dialysis is not talked about, young imaginations can take over. Reality—no matter how difficult it may seem at any given moment—is easier to handle than the fears of imagination. Expressing your concerns about starting dialysis in an

honest way and allowing children to express their own reactions can help. Sharing problems and reactions in a caring way can make the concerns easier to manage.

Children feel like they are an important part of the family when they are given ways to help. When they are shown in a loving and caring way how dialysis is likely to affect you, your family and them, they will often be open to making necessary changes – especially if they can look forward to some special treats or rewards for doing so.

At the same time, we must be careful not to place too many burdens on children. They still need to be kids. Be careful not to overload them with worries and concerns. They need time for school and play – the main jobs of childhood. Above all, let children know they are loved and will continue to be taken care of, even though family members may be sick, upset or tired. Serving as a positive role model for the children in your family will help everything go much more smoothly in their lives and in yours.

SPIRITUAL AND SOCIAL SUPPORT

Many of us are helped by spiritual sources when times are hard. There may be days when the uncertainty of illness makes life seem very challenging. Faith may help some of you find moments of hope and peace in each day. Houses of worship can offer emotional support and practical help to those of you who are facing uncertain times.

Travel and Employment

“Kidney disease has no impact on my life. I don’t notice I even have a condition. I may have less energy, but I still go out everyday. I feel good. People think I look good [not sick].”

Managing your kidney disease and starting dialysis can affect if and where you choose to travel, and your type of employment. Many of you are able to keep your disease under control without much impact on your lives. Others, however, find it difficult to lead a normal life with CKD.

“I walk 40 blocks daily and I do my daily chores.”

“Sometimes I am sick and need rest, but 90 percent of the time I feel great.”

Regardless of the type of dialysis you plan to start, you can expect that many hours of dialysis will be needed each week in order to stay alive. This fact will have a big impact on your daily activities.

TRAVELING WHILE ON DIALYSIS

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

Many dialysis centers have a staff member who is experienced in arranging dialysis treatments away from home (transient dialysis). Some centers will help patients in making their own arrangements. Ask your social worker or primary nurse if there is such a person at your center.

People on home hemodialysis can travel as well, but they may want to make plans for in-center treatments while traveling. People who wish to continue doing their own treatment while traveling should check with their dialysis care team about whether they can do home dialysis away from home. Some people travel with their machines, supplies and portable water treatment equipment.

Traveling is often easier for people on peritoneal dialysis because they are not dependent on the availability of a dialysis unit. People on peritoneal dialysis still need to plan ahead and arrange for back-up medical care for their trips. Typically, this would mean contacting a dialysis center in the area where they will be traveling, and asking if the center would be available should a problem arise. The center may request a copy of medical records in advance. You should always carry a copy of your records with you.

WORKING WHILE ON DIALYSIS

Many people on dialysis can go back to work after they have gotten used to dialysis. However, if your job requires a lot of physical labor (heavy lifting, digging, etc.), you may need to look for a different job.

You will need to work out your dialysis schedule with your employer. Many employers will be flexible about your need for dialysis. Try to explain about dialysis as best as you can, and discuss ways you can either make up the time lost from work or make other work arrangements. If dialysis interferes with your job to a great extent, you may have to look for a different job.

THE AMERICANS WITH DISABILITIES ACT

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



Summary

When you are about to start dialysis, it is important to learn as much as possible about all options, and ask questions. Still, the idea of starting dialysis is upsetting for many people. One person expressed concern for safety and worry over reactions of family and friends. Someone else seemed immediately accepting of the idea of having to start dialysis and said,

“You gotta do what you gotta do. It’s my responsibility, my body, my life.”

To be sure, no one wants to start dialysis, but now that you find yourself in the position of needing it, try to stay positive, look to others for help and support, and know that you are not alone. The new and unfamiliar experience of dialysis will soon become a “new normal” in your life.



Suggested Resources

EDUCATION AND SUPPORT

National Kidney Foundation

The National Kidney Foundation (NKF) offers valuable support for you and other members of your health care team. In addition to supporting research to find a cure for kidney diseases, the foundation is a resource in the community for information about kidney disease and its treatment, as well as diet and rehabilitation. The foundation has local affiliates throughout the country that offer a

wide variety of programs and services for patients who have kidney disease. Check your local telephone directory for the office nearest you or call toll-free: [800.622.9010](tel:800.622.9010).

You may also visit our Web site: www.kidney.org

Patient and Family Council

Founded in 1995 by the National Kidney Foundation, the Patient and Family Council (PFC) is dedicated to issues affecting people with kidney disease and their families. The PFC provides an avenue for patients to express their concerns and identify problems so that the foundation can help address these concerns in an effective way. The PFC acts as a liaison between the NKF and the kidney community, and as a voice within the NKF on patient issues.

Membership in the Patient and Family Council is free and open to individuals with kidney disease, their families and friends, health care professionals or anyone who is interested in issues related to kidney disease.

“People Like Us”

To strengthen and unify the voices of the more than 20 million people with chronic kidney disease (CKD), the National Kidney Foundation established “People Like Us.” Through “People Like Us,” individuals with CKD, donors, transplant recipients, family members and loved ones are empowered, educated and encouraged to be strong and active advocates on public policy and other issues related to their health care. Made up of three constituent councils—The Patient and Family Council, the transAction Council,

and the National Donor Family Council – “People Like Us” enables kidney patients, donors and recipients to participate in the public policy process and decision-making with their health care team to choose the best treatment options for their health and well-being.

For more information, or to join “People Like Us,” visit www.nkfpeoplelikeus.org or call the National Kidney Foundation at **800.622.9010**.

NKF Brochures

Diabetes and Chronic Kidney Disease

(11-10-0209, en Español 11-10-0242)

Dialysis Patient’s Bill of Rights and Responsibilities

(11-65-1639)

Hemodialysis

(11-10-0301)

Hemodialysis Catheters: How to Keep Yours Working Well

(11-10-0302, en Español 11-10-0305)

Home Hemodialysis

(11-10-0329)

Nutrition and Hemodialysis

(11-50-0136)

Nutrition and Peritoneal Dialysis

(11-50-0140)

Peritoneal Dialysis: What You Need to Know

(11-50-0215, en Español 11-50-0221)

Taking Control: Money Matters for People with Chronic Kidney Disease

(01-10-0250)

Waiting For a Transplant

(11-70-0656)

What You Should Know About Medicare Prescription Drug Coverage (Part D) If You Are Undergoing In-Center Hemodialysis

(01-10-0231)

What You Should Know About Medicare Prescription Drug Coverage (Part D) If You Are Undergoing Home Hemodialysis or Peritoneal Dialysis

(01-10-0232)

A to Z Guide

Brochures and other resources are available on the NKF Web site. To access these, visit the A to Z Guide by going to **www.kidney.org/KLS**

Dialysis: Choosing Not to Start

(To see this publication, go to **www.kidney.org/atoz**

In the left-hand column click on Dialysis, then click on

Dialysis: Choosing Not To Start.)

EMPLOYMENT RESOURCES

Ticket to Work

The Ticket to Work and Self-Sufficiency Program is an employment program for people with disabilities who are interested in going to work. For further information call **866.968.7842** or visit their Web site:

www.yourtickettowork.com

The following organizations may help answer questions about dialysis and employment:

Equal Employment Opportunity Commission (EEOC)

The EEOC's primary mission is to end employment discrimination at the workplace. If you believe you are being discriminated against at work because you have kidney failure and are receiving dialysis, the EEOC may be able to help. For further information call **800.669.4000** (**800.669.6820**–TTY, for hearing impaired), or visit their Web site: **www.eeoc.gov**

Job Accommodation Network (JAN) of the U.S. Department of Labor

JAN's mission is to help workers with disabilities to find and keep jobs by providing employers, employment providers, people with disabilities, their family members and other interested parties with information on job accommodations, self-employment and small business opportunities and related subjects. For further information call **800.526.7234** (**877.781.9403**–TTY, for hearing impaired), or visit their Web site: **<http://janweb.icdi.wvu.edu>**

The following organizations may help answer questions about dialysis and disability:

National Council on Disability (NCD)

NCD's overall purpose is to support and advance policies that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability. For further information call [202.272.2004](tel:202.272.2004) ([202.272.2074](tel:202.272.2074) – TTY, for hearing impaired), or visit their Web site: www.ncd.gov

National Rehabilitation Information Center (NARIC)

NARIC provides information services and document delivery to the disability and rehabilitation communities across the United States. They have an extensive online library of information on disability services. For further information call [800.346.2742](tel:800.346.2742) ([301.459.5984](tel:301.459.5984) – TTY, for hearing impaired), or visit their Web site: www.naric.com

FINANCIAL AND INSURANCE RESOURCES

State Pharmaceutical Assistance Programs

A number of states have programs with specific financial eligibility guidelines that offer assistance to people with disabilities or senior citizens with outpatient medications. Contact your local Department of Social Services or Medicaid office to see if any programs are available in your state.

The Centers for Medicare and Medicaid Services (CMS)

The federal government subsidizes most dialysis treatment through the Medicare program. For further information, contact the Centers for Medicare and Medicaid Services (CMS) at [800.633.4227](tel:800.633.4227) ([877.486.2048](tel:877.486.2048) – TTY, for hearing impaired).

State Kidney Programs

Many states have programs that offer assistance for kidney transplant and dialysis patients with outpatient medications and other expenses. To find out if your state has such a program, contact the National Organization for State Kidney Programs in Missouri at [800.733.7345](tel:800.733.7345).

Veterans Administration

If you are a veteran treated by a VA physician and meet income and other eligibility criteria, you may be eligible for low-cost prescriptions and follow-up care. Call [877.222.8387](tel:877.222.8387) for further information.

GENERAL READINGS FOR ENCOURAGEMENT

Corr Charles, Corr Donna. *Death and Dying, Life and Living*. 5th ed. Belmont, CA: Thomson Wadsworth; 2006.

Kushner, H. *When Bad Things Happen to Good People*. New York, NY: Avon Books; 1981.

Sifton, E. *The Serenity Prayer: Faith and Politics in Time of Peace and War*. New York, NY: Norton; 2003.

Preparing for Dialysis

Some Questions to Ask When Visiting Your Dialysis Center

Name, address and phone number of your dialysis facility:

Primary contact person:

What can I expect during a typical dialysis session?

How much time is involved in dialysis?

Are dialysis treatments painful?

What can I do during treatments to pass the time?

Does the center support self-care?

How will I feel after dialysis?

Are treatments covered by insurance?

What are the chances that I will die without treatment?

Other Questions:

“It is so important that when someone is told they are going on dialysis, they connect with another patient to talk to. I know when I was told, I felt like my world would end. It was so helpful to have someone to encourage me and let me know it would be all right.”



National Kidney
Foundation™

30 East 33rd Street
New York, NY 10016
800.622.9010
www.kidney.org

Supported by an educational grant from **AMGEN**®