



A “New Normal”:

Life on Dialysis—The First 90 Days



Helpful advice
from people
on dialysis



National Kidney
Foundation™

A “New Normal”: Life on Dialysis—The First 90 Days

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Dedication

To all people with kidney failure,
and their families, who have recently entered the
new and unfamiliar world of dialysis.

Special thanks to:

The many people who shared their experiences
and innermost thoughts about their lives on dialysis.

Charles Corr, PhD, for contributing to this book.

“My friends and family are an emotional support, but in the end, I have to depend on me. It’s my responsibility, my body, my life.”

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Living on dialysis can be challenging. Many issues demand your attention as you develop “new normals” in your life. This booklet can help you learn about what to expect and how to address the issues you might face.

Introduction

You have been living with chronic kidney disease (CKD) for some time. Now your kidneys have failed and you have recently started dialysis treatments. Having to go on dialysis was no doubt difficult for you and your loved ones. However, living with a chronic illness often helps people learn how to cope with new and unfamiliar situations.

This booklet is for new dialysis patients. The information comes from people who have recently started dialysis. Topics covered include adjusting to dialysis, what to expect in the first few months, emotional and physical health while on dialysis, support systems, managing cardiovascular disease and other conditions, lab values, employment, travel, daily living activities and more.

People cope with difficult times differently. The first few weeks are usually the hardest, but as time passes people adjust to new situations in their own ways.

“I was a afraid. Now I am doing fine and am very comfortable doing peritoneal dialysis.”

“I was an emotional mess but I am coping.”

“I felt scared. I feel good about it now.”

“When I originally discovered that my kidneys were bad, I was devastated.... The first time I had dialysis I had a hard time watching my blood leave my body. Now that I have been doing dialysis for 10 months, I am fine with it.

“Dialysis can be hard to cope with, but it’s worth it to have one more day with your family.”

Most of us feel fear and unease, followed by acceptance, and in some cases, positive feelings about the dialysis experience.

What to Expect in the First Few Months

“I don’t enjoy dialysis, but considering the alternative, I accept it.”

Unless someone is on dialysis themselves, or has a friend or loved one on dialysis, the average person knows very little about it.

Although we know dialysis can be a *life-saving* treatment, we may not fully understand that it can also be a *life-changing* experience. For many of us with kidney failure, dialysis greatly improves our quality of life. However, for some of us, it may not, because of the seriousness of our health problems.

Even if your health problems are different from someone else’s, it’s likely that you have many things in common, including an unfamiliar world with new routines, new sets of rules, people you have never met before, a different language, strange machines and many tests.

WHAT IS DIALYSIS AND HOW DOES IT WORK?

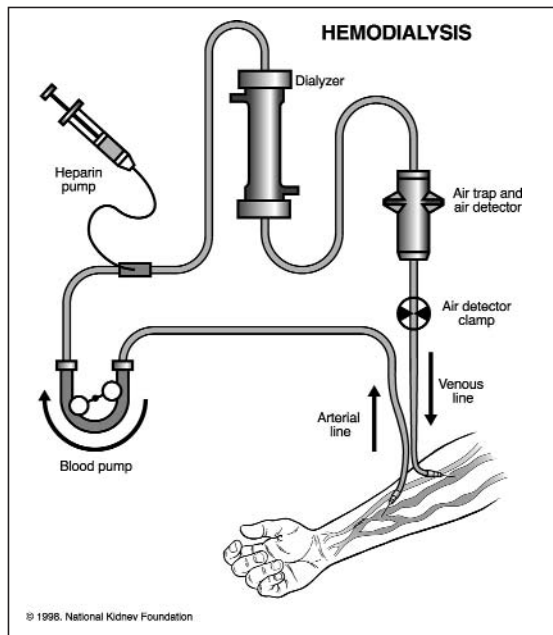
Dialysis is a treatment that does some of the things normally done by healthy kidneys. Dialysis is needed when your kidneys don't work well enough to keep you healthy. Dialysis:

- ❖ removes waste products, salt and extra water to prevent them from building up in the body;
- ❖ helps keep a safe level of certain chemicals in your blood, such as potassium, sodium, bicarbonate, calcium and phosphorous;
- ❖ helps to control blood pressure, and
- ❖ helps in red blood cell production to correct anemia.

There are two types of dialysis: hemodialysis and peritoneal dialysis.

HEMODIALYSIS

In hemodialysis, an artificial kidney (hemodialyzer) is used to remove waste products, extra chemicals and fluid from your blood.

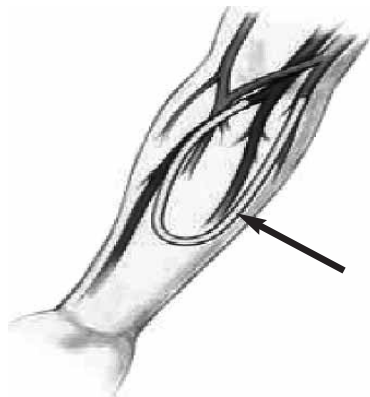


To rapidly remove the blood from your body into the artificial kidney and back, a physician needs to make an access (entrance) into your blood vessels. This is done by minor surgery to an arm or leg. Ideally, an access is made by joining an artery to a vein under the skin to make a bigger blood vessel; this type of access is called a fistula. A fistula is considered the first and best choice for hemodialysis access, because it has the lowest chance of infection.



Fistula

However, if your blood vessels are not adequate for a fistula, the doctor may use a soft plastic tube to join an artery and a vein under your skin. This is called a graft.



Graft

Sometimes an access is made with a thin plastic tube, called a catheter, which is inserted into a large vein in the neck. This type of access is usually temporary, but may be used for long-term treatment only if a fistula or graft cannot be made.

Hemodialysis treatments involve a lot of your time. The time needed for your dialysis depends on:

- ❖ how much fluid weight you gain between treatments
- ❖ how much waste products you have in your body
- ❖ your size (which determines the amount of waste products your cells make)
- ❖ the type of artificial kidney used.

Hemodialysis can be done in a dialysis center, in a hospital's dialysis unit, or at home.

IN-CENTER HEMODIALYSIS

Hemodialysis can be received in a facility that is either part of a hospital (called a dialysis unit), or in an independent dialysis center. A lot of time is spent at the dialysis facility (approximately three times per week for three to four hours each time). It may take some time to get used to this new experience. Hopefully, you had a chance to visit your dialysis center and ask questions before starting treatment. If not, it's never too late to ask questions and express your concerns.

At first, the staff at the dialysis facility, and the other patients, will seem like strangers. The surroundings are new and unfamiliar, and you may experience negative feelings about having to spend so much time at the facility. But, with patience and support from your loved ones and the dialysis team, your sessions will soon become a familiar routine.

“It surprised me that so many people were on dialysis. The staff made me comfortable and the other patients seemed to be okay with the treatment.”

“Coming from home dialysis to a unit was troublesome but they allowed me to continue just as if I was at home.”

HOME HEMODIALYSIS

Hemodialysis can be performed at home. You may do the treatments yourself or you may have someone helping you. Home hemodialysis may help you to fit your treatments into your daily schedule. Studies show that the more a person knows about treatment and the more independent a person is, the better one is likely to do on dialysis.

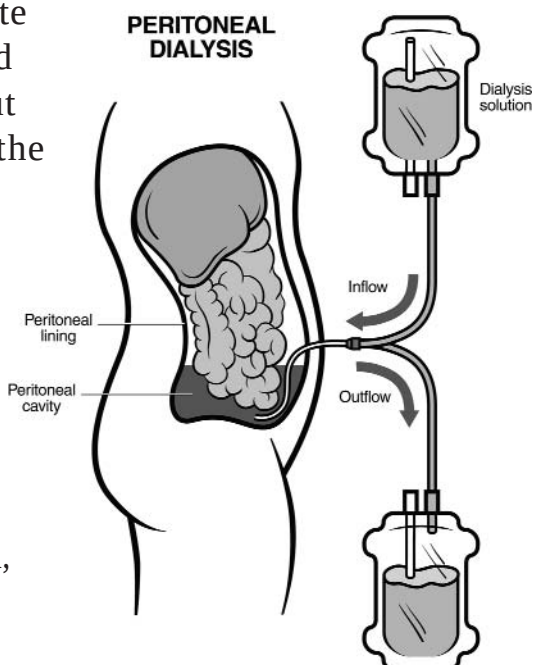
Three types of hemodialysis can be performed at home. They are:

1. **Conventional home hemodialysis:** This is done three times a week for three to four hours or longer each time. You and your care partner are trained to do dialysis safely and to handle any problems that may come up. Training may take 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 partner are trained over several weeks. Because dialysis is 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. In addition, control of certain blood chemicals, such as phosphorus, is much better with daily dialysis.
3. **Nocturnal home hemodialysis:** These are long, slow treatments done at night while sleeping. It may be done six nights a week or every other night, depending on what your doctor prescribes for you. Treatments usually last about six to eight hours. You and your care partner are trained over several weeks. Some centers monitor treatments by sending information from the dialysis machine to a staffed location by telephone modem or the Internet. More hours of dialysis each week helps to remove more waste.

It may also be possible to combine daily and nocturnal home hemodialysis. Whether you can combine treatments depends on your needs, your medical condition and the type of dialysis machine you have. Not every type of home hemodialysis is available at each dialysis program. Your doctor can help decide if home hemodialysis best fits your needs.

PERITONEAL DIALYSIS

In peritoneal dialysis, the blood is cleaned inside the body. The doctor will do a procedure to place a plastic tube, called a catheter, into the abdomen to make an access. Special fluid called dialysate flows through the access catheter into the abdomen (called the peritoneal cavity). The fluid stays in the peritoneal cavity and removes extra fluid and waste products from the blood. After awhile, the dialysate containing the extra fluid and wastes is drained out through the catheter in the abdomen. This helps remove extra fluid and waste products from the blood. Then, new dialysate is placed back into the abdomen to continue the removal process. Each time fluid is removed and replaced, it is called an exchange.



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

Continuous Ambulatory Peritoneal Dialysis (CAPD) is the only type of peritoneal dialysis done without machines. You do this yourself, usually four to 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 four to 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 your peritoneal cavity, you can go about your usual activities at work, school or home.

Continuous Cycling Peritoneal Dialysis (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 exchanges are done throughout the night, while asleep.

Whichever type of dialysis you are on, it is important to get the right level of dialysis. Tests should be done regularly to check the dialysis level you are receiving. Do not hesitate to speak with your doctor and dialysis care team for more information.

PASSING THE TIME DURING DIALYSIS SESSIONS

People receiving hemodialysis at a center spend many hours each week attached to a dialysis machine. It is important that you figure out ways to pass the time, so you do not become bored. Some people like to watch TV and play video games. Others prefer to read and chat with other patients. Some folks listen to music, sleep or play cards. Still others like to use their laptop computer. These sessions can be good opportunities to pass the time in ways you enjoy.

For those doing dialysis at home, you may have the option of dialyzing at night, while asleep. For many, this can be an ideal situation because it eliminates the boredom associated with dialysis that's performed outside the home.

“At first the PD (peritoneal dialysis)ycler was hard to sleep with. Now it is hard to sleep without.”

“When I was on hemodialysis I watched TV. Now I do peritoneal dialysis at home so I can talk to my husband, look out a window or look at catalogs.”



Emotional Health

Dialysis is a life-changing process. Learning how to cope is important.

CHALLENGES ASSOCIATED WITH BEING ON DIALYSIS

Fear and confusion are very common feelings among new dialysis patients. One person even spoke of being “*an emotional mess*,” others felt anxious, frightened or lost. Almost all had to adjust to a variety of new specialists, strange settings, new peers, new technology and new procedures.

A familiar event for those of you who had not been blood donors before was the odd experience of seeing the blood leave your body to go through the dialyzer.

Another challenging issue was needles. Few people like “*being stuck*” even when it is done without pain.

Some of you found that having a lowered sex drive was a problem; others didn’t like being tired or feeling sore.

Some of you felt that dialysis limits your freedom of movement; this was especially true of those who received hemodialysis at a dialysis center or unit several times each week for three hours or more. For those doing peritoneal dialysis at home, concern about being away from home for more than a few hours at a time is common.

Many of you feel it is necessary to limit your travel, either locally or while on vacation. It can be hard to take spontaneous trips and spend extended time away from home or a dialysis center without careful advance planning.

For some of you, working with dialysis team members is challenging. These issues are addressed later in the section on “*Communicating with Your Team.*”

WAYS TO COPE

Almost everyone gets past their initial fears of being on dialysis. Most of you can say that you are now doing fine and are comfortable with dialysis. Some of you were helped early on by talking to professionals and people who were already on dialysis. One man, new to dialysis, said that if other people could do this, so could he. For most of you, a typical comment is: *“Don’t be afraid. It changes your life drastically, but it can be managed.”*

One person who has been on dialysis for four years said, *“the first year is the hardest.”* Another said, *“don’t be scared because it is better in the long run.”* A third person sums up her dialysis experience with, *“It hasn’t changed, but I understand now how things work around there.”*

Becoming more knowledgeable and more experienced—knowing what to expect—often helps a person cope better. One man advises: *“Information is the best way to overcome the fears of dialysis treatment.”* Seeking information and using resources like this booklet can also be helpful.

It is so important to eat right, drink alcohol in moderation, stay active and exercise whenever possible, take medications regularly, and be careful to follow the dialysis procedures properly. As one person advised: *“Following the guidelines makes all the difference; shortcuts don’t work!”*

Those of you who disliked receiving dialysis treatments at a center found it helpful to learn how to take care of your needs on home dialysis. This was especially true for those

who learned to do dialysis at night while we slept. You had more freedom during the day. *“Select the method that is best for you.”* It’s also possible to change doctors or use a different dialysis clinic to get service that best fits your needs.

Switching to peritoneal dialysis helps if you are uncomfortable with needles. But if you prefer hemodialysis over peritoneal dialysis, simply looking away from the needles may be helpful.

If you are concerned about having the freedom to come and go, either locally or on vacation, we recommend planning and arranging in advance. This means arranging for equipment and supplies for peritoneal dialysis or preparing for back-up support at a different hemodialysis unit while traveling.

Choosing your own way, as much as possible, is important for good coping.

Some people who were told that they would feel better on dialysis confirm that it is true. *“I feel physically better and have more appetite now that I am on dialysis.”* Several people believe that their sex drive improved.

“Once you have adjusted to the treatment you can work around it and begin to enjoy life to the fullest.”

Sometimes you feel resigned to what must be:
“I just show up and get it over with.”

*“I do what I have to do. I don’t enjoy dialysis,
but considering the alternative I accept it.”*

Many people said that the best part of their dialysis treatment is *“when I go home”* or *“when it is over.”*

But sometimes you feel more positive.

“Take it one day at a time!”

“Never, never, never give up!”

“Dialysis can be hard to cope with, but it’s worth it to have one more day with your family.”

Some feel fortunate that dialysis is available: *“We are very lucky to live in a country where it is possible to live with kidney failure,”* apparently referring to the federal government’s mandatory insurance coverage for dialysis treatments.

And some of you look forward to a kidney transplant. It is up to each of you to cope in ways that work for you.

DEPRESSION

Up to 60 percent of people on dialysis may experience episodes of depression, according to some studies. If you are struggling with sadness most of the time, speak to a social worker or other mental health provider on your dialysis care team.

QUALITY OF LIFE

What may be a high quality of life for one person may not be for another. The main challenge for most of you is to be realistic about the differences between your “before” dialysis life and your “on” dialysis life.

There will be things you can no longer do, or will find difficult to do, now that you are on dialysis. As one person says, *“I miss the independence of not having to rely on a machine to sustain my life. I have accepted the fact that dialysis is a lifelong treatment and I must modify my lifestyle.”*

Some of us prefer not going on vacations, *“I feel like I don’t want to go on vacations because I don’t want to receive dialysis anywhere but at my center. But that’s my choice [right now] and maybe I’ll change feeling that way.”*

On the other hand, some people say that dialysis helps more than before, *“I probably do more since I’ve been on dialysis because I feel better. I can’t say there is anything that I miss.”*



Physical Health

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’ll have to follow a healthy diet, exercise, and monitor your blood pressure, lab and blood values to stay healthy.

Getting used to the routines of dialysis can be difficult. There is so much to learn and many new experiences to

adjust to in the first few weeks. One important routine is measuring and maintaining your target lab values and blood pressure. You may feel that you don't have time to do this in the beginning. Fortunately, your dialysis care team is there for you. Feel free to ask them for help in managing your time so that you can stay healthy.

What You Can Do to Stay Healthy on Dialysis

- ✓ Come to every dialysis treatment.
- ✓ Stay for the entire dialysis treatment.
- ✓ Follow the prescribed diet as much as possible. This means that you likely will need to avoid drinking too much fluid.
- ✓ Avoid eating too much salt, potassium and phosphorus. Speak to a dietitian about this.
- ✓ Take all of your medications exactly as prescribed.
- ✓ Get regular physical activity.
- ✓ Watch over and manage your stress.
- ✓ Stay close to others. Social support helps.
- ✓ Watch for and seek help with depression.
- ✓ If you smoke, smoke less or consider quitting.

People on dialysis are much more likely than the general population to develop heart and blood vessel disease (also called cardiovascular disease). This higher risk is due to kidney disease and other health problems like diabetes and high blood pressure. It is very important that you do what you can to prevent or manage heart and blood vessel problems.

A treatment plan should help you:

1. Get enough dialysis.

Getting enough dialysis is important to help you feel your best. Some special blood tests are done each month to help your doctor decide if you are getting enough.

One test is called Kt/V (pronounced kay tee over vee); the other is the urea reduction ratio (URR). If you are receiving enough dialysis, your Kt/V should be at least 1.2. If URR is used, it should be 65 percent or more.

If your numbers are too low, one possible cause may be that your access is not working properly. Ask your dialysis team to check. Another reason is that you simply need more time on dialysis to get rid of waste products.

2. Keep blood pressure controlled.

High blood pressure can cause kidney disease. It is also a complication of kidney disease. If your blood pressure is not controlled, it can cause heart and blood vessel problems, such as hardening of the arteries and enlargement of the heart (cardiomegaly). Limiting fluid and salt intake will help keep your blood pressure under control.

The target blood pressure for dialysis patients before a dialysis treatment is less than 140/90. The target blood pressure after a dialysis treatment is less than 130/80. A doctor or nurse can check if your blood pressure readings are on target. If you check your own blood pressure at home, you should keep a record of your daily blood pressure readings and show this to your doctor at each visit. For blood pressure readings that are not on target, ask your doctor about what you can do to improve them.

As one person told us when asked about tips on how to achieve target blood pressure measurement, *“I control my blood pressure level by taking my medication as prescribed.”*

The blood pressure pills usually preferred for people with CKD are called angiotensin converting enzyme (ACE) inhibitors or angiotensin receptor blockers (ARBs). Following your doctor’s advice, taking your medications as prescribed, eating right and exercising will go a long way toward achieving a healthy blood pressure.

3. Reduce high cholesterol levels.

High blood levels of fats (also known as lipids) like cholesterol increase your chance of developing heart and blood vessel problems. You will have blood tests to check for total cholesterol and other fats in your blood. If your levels are too high, you may need to follow a low-fat diet and do more exercise. Some patients may also need to take medication (such as a statin) to help lower cholesterol.

4. Follow a healthy diet.

Eating right will help you stay healthy. It is important that you have the right amount of protein, calories, fluids, vitamins and minerals each day. Your dietitian will help plan your meals to make sure you get the proper balance of nutrients.

Your doctor and dietitian may also ask you to reduce your intake of foods that are high in saturated fats and cholesterol, such as eggs, whole milk, most cheese and fried foods. Foods high in potassium and phosphorus also frequently need to be limited, as high blood potassium and phosphorus can be harmful.

Eating foods that are rich in heart-healthy omega-3 fatty acids may be helpful. These include cold-water fish like salmon, albacore tuna, lake trout and sardines, and other foods like flaxseed oil, canola oil and walnuts. For those of you on a protein- or potassium-modified diet, speak to your doctor and dietitian before making any changes in your diet.

5. Treat anemia.

Most people with kidney disease will develop anemia. Anemia means having a low red blood cell count. Red blood cells carry oxygen from your lungs to all parts of your body to give you the energy you need for your daily activities. When you have kidney disease, your kidneys cannot make enough of an important hormone called erythropoietin (EPO). EPO tells your body to make red blood cells. Without enough EPO, your red blood cell count will drop and anemia will develop.

Anemia may make a person feel tired, look pale, have a poor appetite, have trouble sleeping, be short of breath and have a rapid heartbeat. Like high blood pressure, anemia can also lead to a heart problem called left ventricular hypertrophy. Ventricular hypertrophy is a thickening of your heart muscle's main pumping chamber (left ventricle). It happens because the left ventricle gets larger from overwork. Treating anemia helps keep your heart healthy.

Your doctor can tell if you have anemia by measuring your hemoglobin level. Hemoglobin is the part of red blood cells that carries oxygen throughout your body. When you are on dialysis, your hemoglobin is measured on a regular basis to check for anemia.

Anemia can be treated with drugs called erythropoiesis-stimulating agents (ESAs). ESAs act like the natural hormone EPO to help your body make red blood cells. Anemia may also be treated with extra iron. Your body needs iron to make red blood cells, especially if you are receiving ESAs. Without enough iron, your ESA treatment will not work.

The goal of anemia treatment is to keep your hemoglobin level between 11 and 12.

Be sure to speak to your doctor or other members of your dialysis care team about anemia and kidney disease.

6. Keep important minerals—calcium and phosphorus—in balance.

These important minerals can get out of balance when you have CKD. As a result, bones may lose calcium and become weak over time. Some calcium and phosphorus may end up in parts of your body where they do not belong, like your heart and blood vessels. This makes your blood vessels get stiffer and narrower. When this happens, you are at increased risk for a heart attack or stroke.

There are medications to treat the bone and mineral disorders that come with CKD. Speak to your doctor about which medications are right for you.

7. Increase physical activity.

Be sure to ask your doctor about an exercise program that is right for you. Regular exercise helps to:

- ❖ Lower cholesterol
- ❖ Control blood sugar levels if you have diabetes
- ❖ Reduce high blood pressure
- ❖ Lose excess weight
- ❖ Improve the health of your heart and lungs
- ❖ Increase your energy level
- ❖ Improve emotional health.

8. Control blood sugar if you have diabetes.

Diabetes mellitus, or simply diabetes, happens when your body does not make enough insulin or cannot use insulin properly. Insulin is a hormone that controls the amount

of sugar in your blood. A high blood sugar level can cause problems in many parts of your body. Diabetes is the most common cause of kidney failure.

With diabetes, the small blood vessels in the body become damaged. This can lead to hardening of the arteries and increase chances of heart attack and stroke. When the blood vessels in the kidneys are damaged, your kidneys cannot clean your blood properly. When your kidneys are not working well, water and salt build up, leading to weight gain and ankle swelling. Protein is in your urine, and waste materials build up in your blood.

Diabetes also may damage your nervous system. This can cause difficulty in emptying your bladder. The pressure resulting from a full bladder can back up and injure the kidneys in people not yet on dialysis. Diabetes can also affect the nerves in your legs, causing numbness and pain, called neuropathy.

To help keep your blood sugar under control, check it as often as your doctor tells you. Be sure to follow your diabetes treatment plan.

9. Maintain emotional health.

At times, you may feel depressed, angry or upset. Although these feelings are normal, they can make it harder to follow your treatment plan and return to a normal routine. Negative feelings may also increase your chance of getting heart disease or making it worse. It is important to get treatment if you have these feelings.

Talk to a dialysis social worker or doctor to find out if counseling and/or medications may be helpful.

10. Stop smoking!

If you are a smoker, ask your doctor about a program to help you quit. Smoking raises the risk of getting cancer, breathing problems, high blood pressure, heart and blood vessel disease, and many other diseases. It is a major risk factor for heart attack and stroke. Smoking can interfere with medicines used to treat high blood pressure. Uncontrolled or poorly controlled high blood pressure is a leading cause of kidney disease. Smoking slows the blood flow to vital organs like the kidneys and can worsen already existing kidney disease.

LAB TESTS

Because you have had to keep an eye on your health throughout the years, many of you are all too familiar with the world of blood tests and clinical laboratories. Having blood work done on a regular basis must be continued in order to stay healthy. You'll need to know what the targets are for each test. Discuss with your health care team how to reach the targets. Changing your behavior (diet, exercise, quitting smoking and reducing stress) will go a long way toward reaching target lab values and test results and will help you gain control over your health.

In addition, regularly checking your blood pressure is important. You will also need to have some tests done to check your heart.

Albumin-to-creatinine ratio: Albumin is a type of protein. Albuminuria means that the kidney has some damage and is starting to “spill” albumin into the urine. It can be measured by a specific urine test, either on a single urine sample using an albumin-specific dipstick, or by a more precise urine test called albumin-to-creatinine ratio. Sometimes a 24-hour urine collection may be done to measure albuminuria. Any doctor can test for albuminuria. Routine urine analysis does not detect albuminuria. A measurement of greater than 30 (mg/g) is considered positive. Two positive tests for albumin in the urine over several weeks is a first sign of diabetic kidney disease. This test helps doctors identify early signs of kidney disease, particularly in diabetics.

Blood Glucose: Blood glucose is the amount of sugar in the blood. This test is one way to check for diabetes. A drop of blood placed on a glucose monitor is used to measure the glucose in your blood. A normal range in adults is 70–115 mg/dL. A test called hemoglobin A1C may also be done to check if your blood sugar is under control. This is checked every three months, and an optimal level for a diabetic is less than seven percent.

Calcium, Phosphorus, Parathyroid Hormone (PTH): Calcium, phosphorus and PTH tests are done to measure bone health. They should be done if your eGFR is below 60.

Calcium and phosphorus are two minerals important for healthy bones. Diseased kidneys are unable to remove phosphorus from the blood as well as they should. Too much phosphorus in your blood may lead to loss of calcium from your bones. This may cause your bones to become weak and to break easily.

Phosphorus comes from many foods in your diet. By eating fewer high phosphorus foods, you can lower the amount of phosphorus in your blood, which lessens calcium loss from your bones and deposits of calcium and phosphorus in your blood vessels. Your doctor may order a medicine called a phosphate binder to keep your body from absorbing phosphorus from foods. This medicine should be taken with your meals as your doctor orders.

- ❖ **Calcium**—tests for the level of calcium in the blood. The target range in dialysis patients is between 8.4 and 9.5.
- ❖ **Phosphorus**—tests for levels of phosphorus in the blood. The target range in dialysis patients is between 3.5 and 5.5.
- ❖ **PTH**—tests for levels of parathyroid hormone in the blood. Parathyroid hormone is released by the parathyroid glands to help control calcium and phosphorus levels in your blood. High levels of PTH may cause bone disease. The target range in dialysis patients is between 150 and 300.

Target levels are different for people with kidney failure than for those with other stages of kidney disease.

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 to get eGFR. A GFR below 30 requires the attention of a kidney disease specialist (nephrologist). A GFR below 15 means you have kidney failure, and it's time to start dialysis.

Hemoglobin: A hemoglobin test is done to check if you have anemia, or low red blood cell count. If your hemoglobin is lower than the normal range (12 in women and 14 in men), it is likely you have anemia. Treatment with ESAs is started when your hemoglobin is less than 11. If you have kidney disease and are being treated for anemia, your hemoglobin should be between 11 and 12.

Kt/V: The main test used to measure your dialysis dose is called Kt/V (pronounced 'kay tee over vee'). Checking Kt/V is one way to know if you are getting enough dialysis. Another test used by some centers is called urea reduction ration (URR). For people receiving hemodialysis, the minimum target for Kt/V is 1.2 and URR, 65 percent, but the best level of Kt/V is 1.4 and UPR, 70 percent. For those on PD, weekly Kt/V should be at least 1.7, although some doctors feel that the best weekly Kt/V is more than 2.0.

Lipid Panel: High blood levels of fats (lipids) like cholesterol and triglycerides increase your chance of developing heart and blood vessel problems. You may need to have blood tests (a lipid panel) to check for total cholesterol

and other fats in your blood. Target values for blood lipids are:

- ❖ Total cholesterol should be less than 200.
- ❖ HDL cholesterol should be 40 or higher.
- ❖ LDL cholesterol should be less than 100.
- ❖ Triglyceride level should be less than 150.

If your levels are too high, you may need to follow a low-fat diet and exercise more. Some people may also need to take pills (such as a statin) to help lower cholesterol.

OTHER DIAGNOSTIC TESTS

People on dialysis should have regular diagnostic tests to check for heart and blood vessel disease:

- ❖ An electrocardiogram (EKG) is typically done when you first start dialysis and then once a year after that. An EKG checks the heart's electrical activity.
- ❖ An echocardiogram (ECHO) may be done when you first start dialysis. This test uses ultrasound to examine the heart and to diagnose abnormalities and disease.

If the results of your EKG and ECHO are not normal, you may also need to have:

- ❖ A stress echocardiogram. This is a type of echocardiogram that requires exercise, usually on a treadmill, to check for a blocked artery.

- ❖ A stress nuclear imaging test. This is also done to check for a blocked artery.
- ❖ An angiogram. This is an x-ray of the heart or arteries, used to locate blocked arteries and possibly open them up with a balloon and stent (a tube used to keep an artery open).

Support Systems

“My friends and family are an emotional support, but in the end, I have to depend on me. It’s my responsibility, my body, my life.”

Having people to turn to for advice and support can be a great help when you are on dialysis. The professionals on your care team can provide information and guidance about a wide variety of matters. Other people, too, can be an important part of your support system:

- ❖ A spouse or significant other
- ❖ People who are already on dialysis
- ❖ Other family members and friends
- ❖ Mentors and co-workers
- ❖ Mental health professionals.

Social, religious and spiritual organizations, and the National Kidney Foundation, or other patient advocacy group may also be sources of support.

YOUR SPOUSE OR LIFE PARTNER

You have most likely been through a lot with your spouse or life partner during your bout with kidney disease. This is a difficult time for everyone. Try to be patient as you work together with your partner to cope with the life changes and the dialysis-related challenges you are now facing. A spouse or life partner can learn how to help you do what you need to do and can be very helpful as you cope with all the changes from kidney failure and dialysis. Even just having someone to talk to about how you feel and what you need from day to day is so important. This person may also help in other ways like driving you to the dialysis clinic or planning and arranging for receiving dialysis while on vacation.

PEOPLE WHO ARE ALREADY ON DIALYSIS

People already on dialysis, especially those who have been on dialysis for some time, have developed a certain amount of practical experience. You'll meet them at a dialysis clinic or maybe at your kidney doctor's office. Learning from people in a similar situation to yours can be very helpful, especially when you are just beginning dialysis and feel afraid or confused by the new situations and challenges.

Of course, not everyone who is on dialysis will be in a position to assist you. Listen carefully, know yourself, compare suggestions from different people on dialysis and choose people who offer good advice for you. A social worker on your dialysis care team may be able to put you

in touch with someone who might offer helpful advice and support.

FAMILY MEMBERS, FRIENDS AND CO-WORKERS

People respond in different ways when first told about kidney failure and dialysis. The same is true for family members, friends and co-workers. Every one of them will have questions about how kidney failure and dialysis will affect their families. They will wonder about your life, their lives and future plans, even if they don't always bring these concerns out into the open. Help them face these issues directly, just as you have, so that you won't find yourself in the same situation of one person on dialysis who said, *"My friends seem to treat me with kid gloves."*

It is important to understand that some family members, friends, and co-workers will be more helpful than others, partly because of who they are and partly because of other demands in their lives. A lot depends on your relationships before you went on dialysis. Family members, friends and co-workers who were open about their needs and yours, and who have shared information and feelings, are likely to continue to do so when you are on dialysis. Relationships that were less positive may present problems that will need to be addressed.

Those who know about dialysis and understand its importance in your life are likely to be people you can turn to for help. The professionals who provide your dialysis services understand this. They will be willing to

help you learn about dialysis. Some family members and friends will become “key people” in supporting you as you begin dialysis.

It is clear that dialysis requires a new focus in your life. There will no doubt be some changes in your everyday routines. Dialysis will take up a big part of your time and energy. Family members, friends, and co-workers will need to understand that dialysis needs to be a main focus in your life. You will likely have less time and energy to share with them. Often, these individuals will want to help out with tasks at work or in the home, and with things like arranging time off from your job or providing transportation to doctors’ offices, hospitals, or clinics.

It’s a question of balancing between what you can do for yourself and what family members, friends, and co-workers can do to support you in your dialysis-related experiences. Don’t be afraid to ask others to 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 to help you.

Dialysis introduces you to new specialists and to new technologies. You may find this a little strange at first and perhaps even a little scary. However, most people are able to adapt to change. You, along with your family members, friends and co-workers, can adjust to these new situations and experiences. After all, you are much more than just a

“dialysis patient.” You are still the same person—father or mother, grandparent, son or daughter, friend or co-worker—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 can about the disease and dialysis treatment.”

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

These comments point out the importance of getting the help of friends and co-workers as you face the challenges of dialysis. Co-workers, in particular, may be able to help you adapt your work responsibilities to your dialysis needs. Helpers can also come from communities of faith or support groups and other social organizations to which you may belong.

SPIRITUAL SUPPORT

Many people draw courage and hope from spiritual sources when times are difficult. There may be days when the uncertainty of illness makes life seem very hard. For

some of you, faith can be an aid and comfort in helping you find moments of hope and peace in each day.

Houses of worship can provide social support to dialysis patients and their families. Many of these institutions have also provided emotional support and practical assistance to those facing uncertain times.

WHEN THERE IS A CHILD IN THE FAMILY

Children who have a parent or close family member on dialysis will naturally have questions. Some children will ask a lot of questions. Other children are quieter, shyer about asking questions and sometimes afraid of the answers. Keep the lines of communication open. 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 kidney failure and dialysis, but they usually can pick up on the emotional signal within a family and home. If dialysis is not talked about, young imaginations can take over. Children might feel unnecessary fear or anxiety. Reality—no matter how difficult it may seem at any given moment—is usually easier to handle than the fears of imagination. Expressing your feelings and other reactions about dialysis in an honest way and allowing your children to express their own reactions is the best way you can help them. Sharing problems and feelings in a caring manner almost always helps make problems easier to handle.

Children feel like they are an important part of the family when they can be shown ways to help. When they are shown in a loving way how dialysis is affecting 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, it's important not to place too many burdens on your children. They still need to be kids. Don't overload them with worries and obligations. They need time for school and play—the main jobs of childhood. Above all, let your children know they are loved and will continue to be taken care of, even though you may be sick, upset or tired. Serving as a positive role model for the children in your family will help everything go more smoothly in their lives and in yours.

For extra help to meet your child's need for information about kidney disease and treatment or to help your child cope with your kidney failure and dialysis, talk with a social worker.

Communicating with Your Dialysis Care Team

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

Each member of your dialysis care team is a person who is likely to have specific strengths and weaknesses. Some may be better at technical skills, like inserting needles, while others may be especially good at person-to-person contacts. For example, even though a dialysis patient noted his respect for the different skills of the members of his care team, he also added, “*there is considerable variation in their respective abilities to insert needles, pain-wise.*” And he added that, “*I would like unquestioned authority to select the nurse to treat me each morning.*”

Ideally, every member of your dialysis care team will show the highest level of both professional and personal skill as they care for you. Still, it is wise to be realistic in what you can expect from the members of your team and to guide your contacts with them accordingly.

Knowing what to expect as you rely on your dialysis care team over time and as you choose among the available dialysis procedures can help you make your experiences go as smoothly as possible.

Your dialysis care team is responsible for answering questions about kidney failure, dialysis choices, procedures and treatments. Don't hesitate to ask any questions. It is part of their job to lend support and address your concerns. Keep in mind that sometimes it's what you don't know that causes you the most concern.

Try to ask questions and express your anxieties in a clear and respectful manner. That will encourage the dialysis team to respond in a similar way. It also doesn't hurt to praise team members when they provide high quality care.

“I was trained to do peritoneal dialysis by someone on the staff at the Renal Center. She was very thorough and very patient and kind. She made sure I could handle it before I did it on my own.”

“Ask all the questions you have until you feel comfortable with dialysis.”

Giving praise to the team member who is providing good care is a good idea. Pointing out valid concerns in a helpful manner is also a good idea.

It may help to prepare a list of questions or concerns prior to meeting with a member of your care team. Sometimes, it can help to discuss these issues with your spouse, family member or other key person—someone who can go with you when meeting members of your dialysis care team. Your key person can also remind you of things you want to discuss or help explain responses from a health care team member.

Sometimes it helps to get practical answers to your questions from others who are also on dialysis.

“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 the doctor.”

“My VA [Veteran’s Administration] doctors are great when I’ve asked them questions concerning the dialysis routine.”



Employment, Travel and Activities of Daily Living

No matter what type of dialysis you are on, it will require many hours of your time each week. This will have a big effect on your daily activities. Still, most people are able to do many of the same things they enjoyed before being on dialysis. Consider these experiences:

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

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).”

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

CAN I TRAVEL WHILE ON DIALYSIS?

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

“I have the bags sent to where I am going. I call three weeks ahead of time.”

“We have continued to do all that we can to retain a normal lifestyle. Trips are shorter but you can adapt.”

“During my first year, my center made the arrangements for my travel and dialysis to visit my children out of town.”

Many dialysis centers have a staff member who can arrange for dialysis treatments away from home (transient dialysis). Some centers will help patients make their own arrangements. Ask your social worker or primary nurse if you can receive help in planning travel.

You or your patient travel coordinator may need to contact more than one center in order to find one that can provide dialysis for you. It's best to check with the center upon arrival at your destination to confirm your appointment. If possible, you may want to visit the center and meet the staff so you feel comfortable. Before visiting, make an appointment with the social worker or nurse manager of the dialysis center you plan to visit.

Home hemodialysis patients can travel as well, but they may want to arrange for in-center treatments while traveling. Patients who wish to continue doing their own hemodialysis treatment while traveling should check with their dialysis care team about whether they can do home dialysis away from home. Traveling is often easier for patients on peritoneal dialysis because they do not need to go to a dialysis unit. However, they still need to plan ahead and arrange for back-up medical care, just like people on hemodialysis. Typically, this would mean contacting a dialysis center in the area where you will be and asking if they would be available should a problem arise. The center may ask for a copy of your medical records beforehand. You should always carry a copy of your records with you.

There are even cruises that specialize in dialysis, with dialysis staff and doctors to monitor your treatments.

Check with your insurance carrier to make sure that it pays for your dialysis while traveling.

CAN I CONTINUE TO WORK WHILE ON DIALYSIS?

Many people on dialysis can go back to work after they have gotten used to dialysis, but if your job requires a lot of physical labor (heavy lifting, digging, etc.), you may need to find a different job. Be careful not to rush into too many changes at once. Some people quit their jobs before they start dialysis. Then once they begin to feel better, they wish they had not stopped working. A social worker can help with decisions about employment choices.

You will need to work out your dialysis schedule with your employer. Many employers are understanding and flexible around your need for dialysis. Try to explain to your employer as best you can about the process. Ask if there are ways you can make up any time lost from work, or make other work arrangements. If dialysis interferes with your job duties to a great extent, you may have to consider a different job.

It is important that you 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. A social worker can provide more information.



Children on Dialysis

Kidney failure is not limited to one age group. A baby can be born with kidneys that don't work well and need dialysis from the day of birth. Other children may develop kidney failure during some part of their childhood. Just as adults face the emotions we have talked about, so do children.

When a child has kidney failure and receives dialysis treatments or a transplant, it's easy to overprotect them. We think our children have already suffered so much that we, understandably, want to make sure that nothing bad ever happens to them.

However, in order to grow and mature, children need to feel enough freedom to experiment, explore and stretch their abilities. If you are too protective, your child may come to resent you rather than thank you.

If your child wants to try an activity or sport that you have concerns about, talk to the doctor before deciding. It may turn out that your child can participate and gain confidence and self-esteem in doing so. On the other hand, the doctor may say the activity is not appropriate. In that case, you would at least have a medical expert backing you up when you say no.

KIDNEY FAILURE AND YOUR CHILD'S GROWTH AND DEVELOPMENT

How your child's growth and development are affected by kidney failure depends on the child's age when kidney failure occurs. In general, young children with CKD tend to be smaller than other children, and they may take longer to develop sexually. Also, children on dialysis tend to grow slower than those with a kidney transplant.

If kidney failure occurs in the teenage years, sexual development may slow down or even stop. For example, a teenage girl may not have a menstrual period. Delayed sexual development can be upsetting or even depressing for a teenager. He or she may feel different from friends and lose confidence and self-esteem.

If you are the parent of a child with kidney failure, try to be sensitive to issues involving sexuality—especially during the teenage years. Try not to protect your child from the challenges and adventures of growing up. Teenagers need to be free to explore physical, emotional and sexual issues in order to grow into healthy adults. And when they are ready for it, they need to be informed about pregnancy and birth control.

Needing to go on dialysis can be very depressing for teenagers with kidney failure. Just when their friends are beginning to make real plans for the future, they may be feeling like *their* future is over. They may also fear that if their friends find out about their condition, they'll reject them. And to a teenager, losing friends can seem worse than death.

It's important to help your teenager understand that while kidney failure does change their life, it doesn't mean that life is not worth living. By sticking to the dialysis treatments, medication and diet prescribed for them, teenagers with kidney disease can and do achieve wonderful things. They are able to finish school, attend college and move forward into satisfying careers. Others get married and raise children. And most are able to keep their old friends and make new ones.

In addition to a social worker, most pediatric dialysis and transplant programs have a child life specialist who can help a child or teen talk about his or her concerns, fears and feelings. It may also help to have your child talk to

other teenagers who are on the same type of dialysis. Teenagers can learn a lot about coping from their friends, and they will be helped by the social contact.

Another good way to help a child look beyond the limits of his or her condition is to find a summer camp that offers special programs for kidney patients. A camp can be a great place for a teen to socialize and regain confidence and optimism. The National Kidney Foundation offers a publication called "*Summer Camps Directory*." To obtain a copy, call NKF at **800.622.9010**. The directory can also be obtained online at **www.kidney.org**

Summary

“Accept that dialysis treatment is a permanent process. Once you have adjusted to the treatment you can work around it and begin to enjoy life to the fullest.”

“Learn all that you can and stick to the rules. With proper diet, dialysis treatments and fluid intake, you can remain healthy and live a pretty normal life.”

When you are new to dialysis, it is important to learn as much as possible about all options for treatment and ask questions.

To be sure, no one wants to be on dialysis, but since you are, try to stay positive, look to others for help and support, and know that you are not alone. The new and unfamiliar world of dialysis will soon become a “new normal” in your life.



Suggested Resources

EDUCATION AND SUPPORT

National Kidney Foundation

The National Kidney Foundation (NKF) is a valuable resource for people on dialysis and members of their 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, diet and rehabilitation. The foundation has local affiliates throughout the country that offer a

wide variety of programs, services and information for people affected by kidney disease. Check your local telephone directory for the office nearest you or call toll free: **800.622.9010**. Visit our Web site: **www.kidney.org**

“People Like Us”

To strengthen and unify the voices of the more than 20 million people with chronic kidney disease (CKD), the NKF 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 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 NKF at **800.622.9010**.

Patient and Family Council

Founded in 1995 by the NKF, the Patient and Family Council 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 Council 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.

NKF Fact Sheets

www.kidney.org/kidneydisease/fs/index.cfm

“Emergency Meal Planning”

“Hemodialysis Catheters: How to Keep Yours Working Well”

“Home Hemodialysis”

“Take Steps to Keep Your Heart Healthy on Dialysis”

NKF Brochures

Dialysis Patient’s Bill of Rights and Responsibilities

(11-65-1639)

Hemodialysis

(11-10-0301)

Home Hemodialysis

(11-10-0329)

Nutrition and Hemodialysis

(11-50-0136)

Nutrition and Peritoneal Dialysis

(11-50-0140)

Taking Control: Money Matters for People with Chronic Kidney Disease

(01-10-0250)

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 your questions about dialysis and employment:

Equal Employment Opportunity Commission (EEOC)

800.669.4000; 800.669.6820 (TTY for hearing impaired)

www.eeoc.gov

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

800.526.7234; 877.781.9403 (TTY, for hearing impaired)

<http://janweb.icdi.wvu.edu>

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

National Council on Disability (NCD)

202.272.2004; 202.272.2074 (TTY)

www.ncd.gov

National Rehabilitation Information Center (NARIC)

800.346.2742; 301.459.5984 (TTY)

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; 877.486.2048** (TTY).

For more information, the Social Security Administration publishes document #HCFA-10128, *“The Medicare Coverage of Kidney Dialysis and Kidney Transplant Services.”* To order a copy, call: **800.772.1213**.

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** for further information.

GENERAL READINGS OF 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.

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“When I originally discovered that
my kidneys were bad, I was devastated....

The first time I had dialysis

I had a hard time watching my blood
leave my body. Now that I have been doing
dialysis for 10 months, I am fine with it.”



National Kidney
Foundation™

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

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