New Life, New Hope: A Book for *Families & Friends* of Renal Patients

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The Life Options Rehabilitation Advisory Council

*and*

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When a loved one’s kidneys fail, you are also affected. You both face life changes because of kidney disease and its treatments. How you adapt to these changes depends on many things. A better understanding of the disease and its treatments can help you make choices which will work best for you.

By learning what you may be facing, you can better understand your own feelings and concerns. You can also help your loved one adapt to treatment successfully and return more quickly to a fulfilling life. That is why the Life Options Rehabilitation Advisory Council (LORAC) and the American Association of Kidney Patients (AAKP) teamed up to write *New Life, New Hope: A Book for Families & Friends of Renal Patients*. The LORAC is a group of health care professionals, patients, business persons, and researchers concerned with helping dialysis patients and their families. AAKP is a national membership organization representing the interests of all kidney patients.

If you are the family member or friend of someone with kidney failure, this booklet will help you learn about dialysis and how it will affect your life. Even if you are not directly involved in day-to-day dialysis care, this booklet will help you understand what people with kidney failure are going through. *New Life, New Hope* will also give you basic information about kidney disease and its treatments, and information to help you talk with members of the health care team.

The information you will find most helpful in this booklet will depend on your own needs and the needs of the patient. You may want to read it cover to cover, or you may choose to skip around or search for the topics that are most important to you right now. Later, you may read this booklet again and look for different information. For example, family members or friends of someone who has just been diagnosed with kidney failure may want to learn:

- How kidneys work
- How the disease affects the kidneys
- What can be done through diet to reduce the side effects of kidney failure
- How the patient’s medical progress will be followed

Families and friends of someone choosing a treatment may be interested in learning:

- What treatments are available
- Where patients can go for treatment
- How much treatment costs (and how Medicare and insurance can help)
- How the treatment will affect day-to-day life
- How to help the patient keep doing valued activities and remain active
When the patient actually begins treatment for kidney failure, it can be an especially challenging time. Families or friends of patients who are starting dialysis may be most interested in:

- How the treatment will make the patient feel
- How to cope with changes in usual roles and routines
- How to live with the special diet and fluid restrictions
- How to help the patient be as independent as possible

Finally, your learning needs may change once the patient has received treatment for several months or years. Your new learning needs may include topics like:

- How to be sure the patient receives enough dialysis
- How to help the patient resume important activities and roles
- How to react to medical crises that may occur
- How to travel or find a new job

We hope you will find what you want to know in this booklet. The patient’s medical team will be another important source of information about what to expect. In addition, a list of educational resources is included at the end of this booklet to help you learn more.

Remember, no matter where your loved one is in the course of kidney failure, you are not alone. There are more than 200,000 people with kidney failure living in the United States. Most of them have family members and friends who are caring and supportive. Some of them share their thoughts and advice in this booklet.

Please note that most of the words in italics are defined in the glossary at the end of this booklet.
Kidney Function

Kidneys are one of the body’s cleaning systems. Like a water filter cleans water, the kidneys filter out the wastes, or toxins, from the blood. These toxins, as well as excess fluid, are stored in the bladder and removed from the body as urine.

Besides removing toxins and fluid, the kidneys maintain important chemical balances (such as calcium, phosphorus, and potassium) and produce several hormones. These hormones regulate bone minerals, blood pressure, and red blood cell production.

As you know, the kidneys do not always work properly. Sometimes an infection or injury causes the kidneys to fail without warning. This is called acute renal failure. “Renal” means relating to the kidneys. Acute renal failure may be reversible and the kidneys may start working again.

Other forms of kidney disease can cause the kidneys to fail permanently. This is called chronic kidney disease. When only 10% to 15% of kidney function is left, patients have kidney failure or end-stage renal disease (ESRD). At this point, a substitute for the damaged kidneys must be used to keep the patient alive. This substitute is either dialysis or kidney transplantation.

When other organs such as the liver or heart fail, the only treatment option is a transplant. However, people whose kidneys fail have two treatment options available—dialysis or a kidney transplant. Either option can help patients live active, productive lives.
The choice of treatment for kidney failure depends on many factors, including lifestyle, ability to adapt to the treatments, and medical condition. All treatment options should be discussed, but some options may not be possible for some patients. The choice of treatment is made by the patient and the nephrologist, a doctor who specializes in kidney disease. Whatever the decision, your loved one will appreciate the support you and other family members and friends can give.

The treatment decision is not always a one-time event. After careful weighing of pros and cons, patients who want to switch to a different treatment can often do so. If a transplant is not successful, the patient may return to one of the dialysis options, or perhaps have another transplant. A lifestyle change, such as a move, a different job, or family matters, may also lead a patient to consider a treatment change.

There are two types of dialysis: hemodialysis and peritoneal dialysis. Hemodialysis is done with a machine and can be in-center (at a dialysis facility) or at home. Peritoneal dialysis may be done with or without the help of a machine. In addition to dialysis and transplantation, some patients choose to have no treatment. Each of these options will be discussed below.

**Hemodialysis**

Hemodialysis is a way to remove toxins and fluid from the blood, using a filter called a *dialyzer*. To circulate the blood through the dialyzer, a surgeon connects an artery and a vein together (usually in the forearm) to create a vascular access with a strong blood flow. When the artery and vein are connected directly, the access is called an *arteriovenous fistula* or *AV fistula*. When the artery and vein are connected with an artificial tube, it is called a *graft* or an *arteriovenous graft*. Sometimes a tube called a *catheter* is inserted into a vein in the neck or chest to allow temporary hemodialysis until the vascular access is ready for use.

At each dialysis treatment, needles placed in the vascular access are connected to hollow plastic tubes, or lines, that carry blood to the dialyzer to be cleaned. The
dialysis machine pumps the blood out of the body through the access and through the lines to the dialyzer. The dialyzer filter contains small, hollow fibers. Toxins and extra water in the blood pass through tiny holes in the fibers into dialysate fluid, which is flushed away. The dialysis machine pumps the cleansed blood back into the patient’s access.

At any one time during hemodialysis, only about one cup of blood is outside the person’s body. Alarms and safety devices on the machine, along with the knowledge of the dialysis staff, help make treatments safe. Even so, the machine can be frightening at first. What is that whirring noise? What if the power goes out? You and the patient should ask questions about how the machine and alarms work, and how the center plans for emergencies and natural disasters. This can help you both feel more comfortable with the dialysis machine and the treatments.

Hemodialysis is usually done three times per week. Treatment length is prescribed by the nephrologist. Studies show that patients stay the healthiest when they follow the renal diet, take prescribed medications, and spend the prescribed time on dialysis—often four hours, three times per week.

Because hemodialysis is done only three times each week, hemodialysis patients must control their intake of foods high in sodium (salt), potassium, calcium, and phosphorus. They must also control the amount of liquid they drink. The kidneys no longer remove fluid, and dialysis removes only some. If patients drink too much fluid, the excess can cause swelling of the limbs, or edema. Too much fluid can also cause heart or breathing problems, and make dialysis treatments harder on the patient. The patient’s doctor and dietitian will explain how to help your loved one adjust food choices in relation to blood chemistries.
Making a Case for Home Hemodialysis
For Doug, home hemodialysis provides a sense of control over treatment and the ability to work normal hours. “If you know about your health care and you’re committed to following the treatment prescription, you can plan dialysis around your life instead of planning your life around the dialysis facility schedule.”

Doug says home hemodialysis allows him to feel healthier because he spends dialysis time in the comfort of his home with his wife and daughter or friends, rather than going to a clinic. An added benefit, he says, is eating a hot meal during dialysis. For Doug, home dialysis “brings the family back together rather than pulling them apart.” Doug’s wife, Lori, learned home hemodialysis with Doug and assists him when he needs an extra pair of hands.

Whether dialysis is done at home or in a center, it is important for patients to take an active part in their treatments. Family members and friends can help support them in this task.

Making a Case for In-center Hemodialysis
Brooke, a 21-year-old, prefers to dialyze at the clinic instead of at home. “I think of dialysis as another part-time job,” she says. “It’s just someplace I have to go to three times a week, and I spend my time just vegging out—it’s the only time I ever watch TV. I really like being at home and I don’t want this to be a part of my home life; I don’t want my friends dropping by when I’m dialyzing. I want dialysis to be a separate part of my life.” Other patients prefer in-center dialysis because they like being around other patients during their treatments and having a professional available to assist them.

Today, hemodialysis is the most common method for treating chronic kidney failure. Most hemodialysis patients dialyze at a center in an outpatient clinic or a hospital. Some patients choose to do hemodialysis at home. Both home and in-center hemodialysis have pros and cons for patients to consider.

Peritoneal Dialysis
Another type of dialysis is *peritoneal dialysis*, or PD. PD uses the thin layer of natural tissue around the abdomen’s internal organs, called the *peritoneal membrane*, as a dialysis filter. Toxins and excess water flow from the blood through the peritoneal membrane into *dialysate fluid* that is put into the peritoneum. The time the dialysate spends in the body is called *dwell time*.

To prepare for PD, a surgeon permanently places a tube called a *catheter* into the abdomen to carry dialysate in and out. The dialysate flows slowly into the body through the catheter from a sterile bag. After the waste products have moved into the dialysate (which occurs during dwell time), the fluid is drained from the body through the catheter into an empty bag. The process of draining the used dialysate and putting in fresh dialysate is called an *exchange*. The amount of fluid, dwell time, and number of exchanges per day are prescribed by the nephrologist.

There are several types of peritoneal dialysis. In *continuous ambulatory peritoneal dialysis* (CAPD), the dialysate is drained out and replaced with fresh fluid at least four times each day. Each exchange takes about 20 to 40 minutes. The dialysate stays in the abdomen between exchanges. During the dwell time, often four to six hours, patients can move about and do their usual activities. The ability to do treatments by themselves and choose foods and fluids more freely than hemodialysis patients are benefits that make CAPD an option for many patients.
The daughter of one patient says CAPD was a good choice because her mother does not drive, and would have a hard time getting to the nearest dialysis center. “Peritoneal dialysis gives her a lot more freedom and it is much more private. She does it right at home,” she says.

In continuous cycling peritoneal dialysis (CCPD), the fluid exchange takes place at home overnight while the patient sleeps or is in a resting position. A machine called a cycler fills the peritoneum with dialysate and allows it to stay there for the prescribed dwell time. The machine drains the used dialysate into an empty bag. This method may offer freedom from daytime exchanges and also allows patients to eat a less restrictive diet than hemodialysis patients.

In some cases, a combination of CAPD and CCPD can be used. This can occur when CCPD alone does not remove enough toxins, so some CAPD exchanges may be needed during the day. Some traveling patients do not want to take the cycler machine along on their trips, so they do CAPD exchanges until they return home.

Making a Case for Peritoneal Dialysis

When Nancy began dialysis, her son was just seven years old. Blind since her son’s birth, Nancy started hemodialysis in a center. She decided to try peritoneal dialysis because of her need to be independent and her desire to be home to care for her young son. First, she had to convince the dialysis staff that she could learn peritoneal dialysis even though she was blind.

Never a passive participant, Nancy suggested to the home training nurse, “Tell me what I need to do, and I’ll adapt the procedure to me.” Nancy performed peritoneal dialysis safely while caring for her son, working full time, and competing in karaoke contests and archery competitions.
**Transplantation**

A kidney transplant is another treatment option. Patients may be on some form of dialysis for weeks, months, or years before a transplant organ becomes available. A few patients may receive a transplant prior to ever starting dialysis, especially if they have a family member, spouse, or close friend who is able to donate a kidney. A well-functioning transplant is often the treatment preferred by patients who have experienced both dialysis and transplantation. However, transplant patients must have major surgery and take medications daily for the rest of their lives to prevent the body from rejecting the kidney.

When a family member donates a kidney for a transplant, this is called a living-related transplant. An unrelated person may also be able to donate a kidney. This is called a living donor transplant. A cadaveric transplant occurs when a person dies who made it known that he or she wanted to donate organs, and/or the next of kin agrees to donate the organs.

**No Treatment**

One option a person with kidney failure may choose is no therapy. Without treatment, a person with kidney failure will die. When the kidneys are failing, the patient must face the possibility of dying. Some may consider a life on dialysis not worth living. This may be the case for elderly patients with other serious health problems. Others may be on dialysis for years, but because of severe illness or other reasons decide to stop treatment. Encouraging patients to focus on their treatment and rehabilitation often helps them find life more precious even with a serious illness. Therefore, a trial of dialysis may help the patient make the right individual choice.

**Making a Case for No Treatment**

Jim had been on in-center hemodialysis for a while when his health worsened. He could not do the daily volunteer work that made his life meaningful and could no longer climb stairs at his church or home. When Jim and his wife refused nursing home care, Jim’s doctor ordered physical therapy and equipment to help at home. Nothing helped Jim to regain his independence.

Jim talked with the dialysis social worker about his quality of life and options. He was afraid that stopping dialysis was suicide. His social worker encouraged him to talk with his priest. The priest assured Jim this was not the case, which allowed Jim to decide with his wife to stop dialysis. The social worker arranged hospice services and helped Jim complete an advance directive and “do not resuscitate” form. Open communication between Jim and his wife, the priest, and the dialysis center, allowed Jim to die comfortably with dignity at home.

**Medications**

A dialysis or transplant patient may be taking several medications—in a combination of pills, shots, and intravenous medicines—on any given day. Medication prescriptions are often changed as the patient’s condition requires.

It is best for the person with kidney failure to assume full responsibility for taking the pills and following the diet. By learning more about what medications do and why they are important,
you can encourage your loved one to take them consistently, as prescribed. You may ask, “Was it two pills, three times a day or three pills, two times a day?” You are not alone if you become confused. Problems can occur when people who get confused do not ask questions. It is smart to ask.

Along with your loved one, you should ask the doctor, dialysis nurse, or pharmacist questions about a medication’s use. Write down your questions; it will help you remember them. Be sure to follow the doctor’s directions carefully, because dosages may change. Also, dialysis patients should talk with the nephrologist before taking medications prescribed by another doctor. The patient should also ask the nephrologist about any over-the-counter medications, including vitamins, minerals, antacids, herbs, or remedies from health food stores.

**Physical Effects of Dialysis**

Many patients with kidney disease are very ill before they begin dialysis. The body sometimes has trouble adjusting to losing several pounds of fluid and toxins all at once during a hemodialysis session. At first, some patients may have cramps, nausea, vomiting, or dizziness during or just after dialysis. During the last hour of hemodialysis and for a short time after, your loved one may be tired or weak, and not think as clearly as usual.

Diabetics who take insulin may find that their insulin needs change when they start dialysis. They may need to monitor blood sugar more often, even at the dialysis facility. These effects usually lessen over time. Patients learn to make changes to avoid problems, such as getting up slowly to avoid dizziness, or limiting salt and fluids to avoid large weight gains between treatments (which can lead to muscle cramps during hemodialysis).

Many patients look forward to hemodialysis once their bodies adjust to it. They often feel tired and “heavy” before a treatment because of excess fluid and toxins in their bodies. Dialysis can make them feel better. Some patients schedule dialysis in the evening so they can enjoy a full day and go to bed afterwards.

Even though patients may feel better after hemodialysis, many do not enjoy the treatment itself. Inserting the needles used in hemodialysis can be uncomfortable, and dialysis can be boring. That is why some patients want to cut their treatments short. But recent studies show that patients who receive adequate (enough) dialysis are likely to live longer. Increasing dialysis time is one of the best ways to achieve adequate dialysis. Therefore, many nephrologists prescribe longer hemodialysis treatments—four hours or more, three times per week, depending on each patient’s body size and medical condition.
It is just as important for persons on PD to follow the doctor’s prescription. That prescription will include the dialysate composition and volume, and the dwell time of each exchange, to ensure adequate treatment. Peritoneal dialysis patients often have fewer symptoms than hemodialysis patients because the treatments are slow and continuous. However, they must be very careful to use sterile procedures during the dialysis exchange to avoid infection of the catheter area or the peritoneum (a serious condition called peritonitis).
Kidney disease and its treatments affect the emotions as well as the body. Often a person beginning dialysis will go through phases on the way to accepting the new way of life. These feelings are common for loved ones too; they are normal, natural reactions to chronic illness. Others who have kidney disease also experience the same feelings. You, too, can adjust to even the most difficult situation, with information and time.

According to one researcher, who has a chronic illness herself, a typical adjustment may include these phases:

- **Crisis**—fear of the unknown
- **Isolation**—pulling back from support
- **Anger and despair**—feelings of “why me?”
- **Reconstruction**—learning new ways to live
- **Intermittent depression**—comparing life now to before the illness
- **Renewal**—rehabilitation

When a person is diagnosed with kidney failure, the situation is a crisis. Even if the kidney failure happened over a long period of time, beginning dialysis is a scary new time. Families will pull together to help the patient adapt to the new routine, but there is so much to learn that it may all seem overwhelming.

**Isolation** can occur when it becomes clear that the kidney failure is permanent—it will not go away. Patients may resent the disease and not want to depend on others. They may feel their lives have been taken over by sickness and people are bored of hearing about it. They may push away family members and friends who want to help them. If you feel this is happening, reassure the patient that he or she is still a valued person. Do something special for fun, if you can, or insist that the patient help you with something important. Participating in usual daily family life is part of feeling useful, needed, and valued.

Once the patient accepts the need for dialysis, you may both go through a period of anger and despair. Your loved one may resent needing dialysis and may be angry, taking it out on friends, family members, and health care professionals. You may feel the same. People with chronic illness often feel a loss of independence and grieve over what is missing in their lives. Dialysis professionals and family members sometimes offer too much help. This can reduce the patient’s self-esteem, pride, and sense of usefulness. Although patients may not talk about dying to family, friends, or health professionals, the diagnosis of kidney failure may also cause them to think about death.
Ask Paul Castro what caused him the most frustration during his first six months of dialysis and the answer comes quickly: the diet.

Ask Paul Castro what helped most in his adjustment to dialysis and the answer also comes easily: his family.

Paul’s kidneys failed rather suddenly due to Berger's disease, a form of primary glomerulonephritis. His wife, Alicia, and children, 13-year-old Christopher and 9-year-old Veronica, went through some scary moments when the condition seemed life-threatening. His first hospitalization was on the cardiac floor, due to heart muscle damage from the kidney failure.

“I didn’t feel sorry for myself,” says Paul. “I was concerned for my wife because her nerves were taking a beating.”

As Paul got better and became more used to the dialysis treatments during a four-week absence from work, his family learned as much as they could about dialysis and how to help Paul.

“In the hospital, I asked the doctor if the kids could visit the dialysis center,” says Paul. “They were very curious about what was happening and this helped them understand.”

The kids are now actively involved in providing support to their dad, helping their mother watch Paul’s diet, and helping him to remember when to take various pills.

While the eating plan has been a challenge to Paul, who was used to eating everything he wanted, Alicia encourages him to adhere to it because it’s important to his health.

“My wife is an angel,” says Paul. “She helps me to no end with the special diet—she does even better than me at sticking to it. And my friends also prepare special allowable meals just for me when they invite us to dinner. They’re great!”

Paul admits he sometimes gets grouchy when he can’t eat what he wants. Alicia’s encouragement to stick with the eating plan can seem like nagging at times, but he still appreciates her efforts. “When my head clears, I know the only reason I’m doing as well as I am is because of her,” says Paul.

Paul, whose active lifestyle includes riding his bike about 10 miles a day and working full-time, lost 50 pounds when his kidneys first failed and he felt too ill to have much of an appetite. While he now needs suspenders to keep his pants up, he knows that making appropriate food choices is an important part of keeping healthy.
“There are other patients at my center who don’t take the diet so seriously,” he says. “But they are usually the ones who aren’t doing so well. Some people aren’t concerned with their well-being, but I want to do everything I can to stay well.”

Six months after starting dialysis, Paul points out at least one blessing that resulted: the ability to spend more time with his family.

“This really has brought us closer together as a family,” he says. “My wife and I... our love just keeps growing. I’m closer with my mother and father, too.”

Before his kidneys failed, Paul was a retail store manager for 12 years, working long hours six days per week. Four weeks after he began dialysis, he was back at work, but with a lighter load—one that allows him to have breakfast with his father after dialysis treatments and to spend more time with his wife and kids.

Thanks to an understanding employer, Paul was able to arrange his schedule to fit in his three-mornings-a-week dialysis sessions. He began working in one of the company’s other stores and is no longer a manager, which allows him to work fewer hours.

“On dialysis days, I felt really well. Then, when I started working again, I got more tired—sometimes I have sleepy days,” says Paul.

Despite feeling tired sometimes, Paul strives to do well at his job and continues to work a five-day-a-week schedule. “I’m trying to do a good job. I don’t want to be ‘dead weight’ to the rest of the crew at work,” he says. “I also want to do well because it was nice of the owner to adjust my schedule—and my insurance through work is helping to cover my dialysis treatments.”

While Paul likes being back at work and is adjusting to his new role, he admits his co-workers were somewhat uncomfortable when he returned.

“They were concerned that my condition was life-threatening and they’d look at me with these sorry eyes,” says Paul. Some even asked him if it was okay to tell other people that he was on dialysis, as if it were something to be hidden.

“I’d tell them it was no big deal. Being on dialysis is nothing to be ashamed of,” he says.

Because of Paul’s work schedule and lack of out-of-country insurance coverage, he wasn’t able to make an annual trip to Mexico with his wife and kids to see family this year. “At first Alicia didn’t want to go without me, but I pushed her to,” says Paul. “I’m OK. I’m pretty self-sufficient. She went, and I think she had a good time. I’m pushing for her to do it again.”

While Paul appreciates Alicia’s help, he knows she needs to have her own life as well. She took a two-week leave of absence from her job with an airline company to help Paul while his fistula healed. After that, she was back at work full-time.

“She likes her job and I know she missed it,” says Paul. “It’s good because it takes her mind off other things.”
Reconstruction is a time of adjustment to a changed situation. For example, patients who want to continue all their old activities may find that some things must wait—at least temporarily—or take a little longer than they used to. Some changes in daily routine may be needed with a chronic illness, but the changes may not be permanent. At times when the patient is feeling strong and healthy, he or she can take on the world. At other times, such as after a surgery, the patient may need to lighten the load a bit.

Intermittent (on and off) depression is a common response to a chronic illness. Sometimes even when things are going well (but especially on a bad day), something will remind the patient of how much easier life once seemed, without the need for many medications, doctor visits, a modified diet, or regular dialysis treatments. You may feel the same way. Do not be surprised if your loved one’s illness makes you feel low on some days, too. This is normal. Intermittent depression is also called “situational depression” because it is triggered by the situation being faced. Clinical depression—which includes symptoms like changes in sleep patterns and appetite, loss of pleasure in usual activities, feeling sad, and loss of energy—is a more serious problem. Both types of depression can be treated. If you suspect that you or your loved one has intermittent or clinical depression, be sure to talk to your social worker.

Renewal is the stage where you and the patient realize that even though life after kidney failure is different, it is still good to be alive. Rehabilitation, which you will read more about later in this booklet, is a way to help patients and their loved ones reach renewal. By learning, talking with each other, and following the treatment plan, you and your loved one can successfully face the challenge of kidney failure.

Your Role in Your Loved One’s Rehabilitation

By providing encouragement and support, family members and friends play a key role in the patient’s rehabilitation. Rehabilitation means more than restoring health. It also means returning to work, hobbies, and activities that make a person feel useful and fulfilled. It includes becoming more physically fit and learning about living with dialysis.

Before rehabilitation can work, certain factors must be in place. As a person without kidney failure, you know you are not at your best when you are “under the weather.” Now try to imagine having the flu for a month, or a year, or longer. This is how patients with kidney failure may feel if they do not get adequate dialysis, or if they are tired because of anemia, or weak due to poor nutrition. Although at first it may seem overwhelming, learning about kidney disease and beginning treatment as soon as possible can improve patients’ chances of living a healthy, active life.
**Getting Enough Dialysis**

Adequate dialysis makes a world of difference in how patients feel and how long they live. If dialysis is not removing enough fluid and toxins—because it is not done often enough, long enough, or with the right equipment and methods—your loved one will not feel as well. A formula called Kt/V or URR is used to measure adequacy. Kt/V should be at least 1.2 or URR at least 66% for adequate dialysis. Both you and the patient can help ensure adequate dialysis by following the treatment prescription and telling the renal professionals when there is a problem. Healthy kidneys work 24 hours a day, 7 days a week, and dialysis replaces only a small part of their function. It is important to come to hemodialysis treatments on time and stay for the whole treatment to get adequate dialysis. Peritoneal dialysis patients should use as much dialysate as the doctor prescribes, and let it dwell for the prescribed time. Weekly Kt/V for peritoneal dialysis patients should be at least 2.0. Patients who cut corners on their dialysis are only cutting corners on their own lives.

**Eating Healthy Foods**

Following the recommended eating plan, even though it is a big change, is important for feeling well and avoiding complications. Over time, poor nutrition can lead to illness, hospitalization, and even death. Loss of appetite or a “funny” taste in the mouth can make some patients stop eating. It is important to talk about these kinds of problems with the dietitian. There are solutions you can learn.

Patients with kidney failure can eat out at friends’ homes or restaurants—they just need to learn how to make wise food choices. The renal dietitian can also help your family understand how the patient must adjust food choices to maintain good blood chemistry levels. They can help the patient find new recipes and understand how to read food labels at the grocery store.

It may seem like a huge task to plan meals for someone with kidney failure, but there are many good sources of information to make it easier. *Living Well on Dialysis* is a very nice, free cookbook with recipes analyzed for people with kidney failure and combined kidney failure and diabetes. Dialysis centers can get copies from Amgen Professional Sales Representatives. Amgen is also the source for a free Southwest Cookbook for People on Dialysis with TexMex style recipes. More cookbook sources are in the Resources section on page 48 of this booklet.

It is important to be able to continue to have foods and family celebrations that give meaning to your life. Talk to your dietitian before special occasions and ask for help planning meals that will be enjoyable and healthy for your loved one. Cookbooks and reference books can be helpful, but the most useful
knowledge is how to include foods that are traditional in your family, whether you see them in cookbooks or not. That is where the dietitian can help.

**Controlling Anemia**
Anemia, a shortage of red blood cells, is common with kidney failure. Anemia causes patients to look pale, be more tired than usual, and feel cold when others are comfortable. With fewer red blood cells to carry oxygen to the body’s tissues, patients may have muscle weakness, impotence, and trouble thinking clearly. EPOGEN® (Epoetin alfa) helps control anemia for those on dialysis. Iron supplements help the EPOGEN to work. Hematocrit, or red blood cell count, is a measure of anemia. In a new set of evidence-based guidelines for the care of anemia in patients with ESRD, the National Kidney Foundation’s—Dialysis Outcomes Quality Initiative (NKF-DOQI™)—recommends a hematocrit between 33% and 36%.

**Stepping Stones to Rehabilitation: The “5 E’s”**
When medical needs are met, your loved one is more likely to be interested and able to benefit from a rehabilitation program. Starting a rehabilitation program can be the turning point on a return to a fulfilling life—with a little help from the “5 E’s”:

- Encouragement
- Education
- Exercise
- Employment
- Evaluation

**Encouragement**
You play a large role in the encouragement “E.” Research shows that if families believe a patient will do well, the patient will believe it too. Talking openly about kidney disease, having a positive attitude, and believing things will work will
show your loved one that life is still worth living—made more precious because of the relationship you share.

You might be surprised to find out how much some patients can do with a little encouragement. Dialysis patients work in blue-collar and white-collar businesses. They are teachers, doctors, lawyers, truck drivers, computer programmers and analysts, managers, food service workers, and sales persons. They are homemakers and volunteers. They enjoy weight lifting, dancing, bowling, swimming, bicycling, golfing, karate, and other exercise. They do woodworking, sewing, traveling, and other hobbies. With the right attitude and support from family and friends, they can do just about anything they did before their kidneys failed.

**Education**

Research shows that education can reduce fear and help the patient feel more in control, making successful rehabilitation more likely. By learning about kidney disease and treatment, you can help your loved one make healthy decisions.

By learning more, you can also take a more active role in treatment. For example, you can learn about nutritional needs of hemodialysis and peritoneal dialysis patients—they are not the same. You can learn how to build a nutritious “dialysis-friendly” diet into your life. If available, you both can go through training to do home hemodialysis. You can also take first aid classes and cardiopulmonary resuscitation (CPR), which may help you feel more in control and less afraid.

**Exercise**

Researchers have found that exercise has many of the same benefits for kidney patients as it does for everyone else. Exercise can lower blood pressure and cholesterol, make muscles and bones stronger, help make more red blood cells, reduce depression, and improve sleep. If your loved one liked a sport or activity before kidney failure, encourage him or her to try it again. Nephrologists can refer dialysis patients to a physical therapist for an evaluation and specially designed exercise programs. Medicare and private insurance often pay for this.

Lower cost programs are available. A fitness center may offer a reduced rate for people with disabilities or people who exercise during off-peak hours. A local mall may open early for walkers, eliminating bad weather as a reason not to exercise. Be creative!

Exercise can be an enjoyable activity that you can do, too. People on dialysis are not the only ones who benefit from exercise. The Surgeon General of the United States recently warned that most Americans do not get enough exercise.
When Phil is asked why he hasn’t retired yet, he replies matter-of-factly, “Oh, I couldn’t retire. I’d die.” At 82, Phil is president of a paving and landscaping company, among other ventures. Though two sons and two nephews now help run the company Phil and his brother started in 1928, Phil keeps an office in one of the company’s two head- quarters and reports to work nearly every day.

For the last two years, Phil has also devoted some of his time to the local hospital’s dialysis unit, helping fellow patients. Phil has accepted dialysis as a necessary part of his life and doesn’t let it keep him from doing anything he did before his kidneys failed. He recently returned from a 21-day Caribbean cruise with his wife of nearly 60 years, Rosella. The trip was arranged by a company specializing in cruises for dialysis patients.

“I think some dialysis patients should have a different attitude,” says Phil. “If you want to be sick, you’ll be sick. Your body will adjust to whatever your mind tells it—attitude is a big factor in how you feel. Prayer and a strong faith in God also help me cope.” Phil and Rosella have been members of St. Matthew’s Lutheran Church since 1942.

Phil’s message for other dialysis patients is that there is life with dialysis. “Our Lord has given us each day of life to be savored. We can’t change the past and we can’t predict the future. We just have this day to enjoy. That’s why we call this the present.”
and this is harmful to their health. Now is the time to make a healthy lifestyle change together. Ask the dialysis staff about activities and exercises you can do together. Arrange family outings, evening walks, a bike trip, or other activities that give the patient—and you—time to have fun and get healthy exercise. Start slowly and build up gradually. If you get tired, rest a little and take the time to talk or enjoy your surroundings. Many patients say they never took the time to “stop and smell the roses” until they got kidney disease and realized how precious life is.

**Employment, School, and Volunteer Activity**

Encourage working patients to keep their jobs whenever possible. Encourage students to stay in school. When people first begin dialysis, they may feel too sick from kidney failure and the new treatment to work or study. A short leave of absence from work may allow adults time to get used to the treatment. Children need to know that needing dialysis does not mean they can skip school and avoid classwork and homework.

It is important not to make any sudden, major decisions about work or school at this time. Both of you should wait to make any major decisions until after the patient has adjusted to dialysis treatments and regained strength.

Patients and families have certain rights protected by laws passed by Congress: the Rehabilitation Act, the Americans with Disabilities Act, and the Family and Medical Leave Act. Your social worker will help you understand legal rights and other employment issues and help you work through insurance questions and other financial challenges. The booklets *Employment: A Guide to Work, Insurance, and Finance for People on Dialysis* and *Americans with Disabilities: Your Rights in the Workplace* listed in the Resources section of this booklet have more information.

**Evaluation**

Evaluation is an important part of rehabilitation. As the patient begins rehabilitation, watch for changes. Does he or she feel better after a few weeks of exercising? Do you notice a change in attitude after you offer support in a stressful situation? By watching the patient’s progress, you can make small changes when needed.

Talk with your loved one about setting goals. Think together about a way to chart progress to see small changes that might otherwise be overlooked. On the other hand, if one exercise is not working, ask the doctor or nurse to suggest others. Be on the lookout for new products or programs to solve tricky problems. Or talk to other patients and families to see what worked for them.
Ted was the first person Laurie ever knew who was on dialysis. When they began dating, she had some doubts about the relationship because she didn’t understand what dialysis was about and was afraid Ted might die, even though he seemed healthy and active. She was honest with Ted about her fears, and he tried to explain dialysis. They continued to spend time together, and she often visited him during hemodialysis at the clinic. Soon, they were in love and discussing marriage.

Before Ted popped the question, however, he arranged for Laurie and himself to meet with his nephrologist. Laurie talked about her fears and asked questions. At the suggestion of their pastor, they also met with a marriage counselor. “Getting all the information I could from professionals dispelled a lot of fear,” says Laurie. “The doctors, social worker, and nurses helped me understand dialysis and transplant issues.”

Choices have always meant a lot to Laurie and Ted—initially as they planned their life together and now as they adapt to daily situations. Because dialysis means the difference between life and death, many people feel trapped and powerless. But with the right attitude, Laurie explains, this isn’t necessarily the case. “You can choose to find what choices you do have,” says Laurie. “We’ve learned to ask a lot of questions and educate ourselves so we take a proactive role in Ted’s care.”

A year after they were married, Ted and Laurie chose home hemodialysis. They went through training to operate the dialysis machine together. They like the control and flexibility this treatment offers. Laurie is now more comfortable about the treatment and her role in helping Ted get on and off dialysis and monitoring his vital signs. But she admits that balancing her teaching career, home life, social life, and dialysis can sometimes be tiring.

“Your circumstances can make you bitter or they can make you better,” says Laurie. “We chose to be better.” Laurie credits her husband’s positive attitude and their strong, mutual religious faith for her positive outlook on life. “When I’m exhausted or at my wit’s end, or when there’s a bump in the road, my faith gets me through,” Laurie says.
Building on Your Relationship

Your loved one’s need for dialysis will probably change your relationship in some ways. However, you both need to understand that kidney failure means only that the kidneys do not work. Your loved one is otherwise still the same person he or she was. If your relationship was healthy before dialysis, it still can be. If your relationship was shaky before dialysis, the dialysis social worker may be able to help you get back on the right track. Some patients and family members may wish to see a psychologist or psychiatrist recommended by the social worker. Nothing is more important than a loving relationship, which can be preserved and grown, even with kidney failure.

Finding the Balance

Many family members try to find a balance between certain feelings and situations. Sometimes people have two different feelings at the same time. For example, you may feel sorry for your loved one because of all the new changes—dialysis, food choices, medications—but at the same time, resent being forced to make changes you were not ready to make. One day you may feel completely committed, taking on the world on his or her behalf (even if you were not asked). Other days you feel you cannot go on any longer and want nothing to do with the patient or kidney disease. Sometimes you are more than willing to share your time and energy. Other times, you may feel like you are sacrificing yourself and your needs. You may be cross or angry at the patient and later feel guilty. These are normal, understandable feelings and part of what those who care go through to reach acceptance. Before dialysis you probably had some of these feelings, and you worked through them.

Your loved one may be struggling too. He or she may be used to being independent and not want to be ill. Sometimes he or she feels uncomfortable asking for help and other times asks for too much. Your support and understanding will be essential, but this does not mean you should take on all the patient’s responsibilities. Talking honestly and compassionately with your partner is key.

Another common problem is finding the answer to the question, “How can I help my loved one feel independent, but still follow the treatment plan?” Do you 1) yell at someone who drinks too much water or 2) watch every bite of food? Or do you say nothing and let the patient suffer the consequences? If you are too involved, you will smother independence and make your loved one resent you. On the other hand, if you totally ignore these behaviors, he or she may feel unloved and neglected. Remember, we are all human. Do you always eat what you should? Of course not. Flexibility and compassion are important.
When helping someone follow diet and exercise guidelines, there is a fine line between reminding and nagging. No one wants to be told what to do. Even though your loved one knows the doctor’s advice is important, it is also important to be in control. Offer gentle reminders or try to find solutions to problem areas, but do not get angry, naggy, or pushy. Ask what you can do that would be helpful while respecting your loved one. Remember, it is the patient’s job to take care of his or her health.

The important thing to remember is that it is natural to have conflicting feelings sometimes. Conflicting feelings are a part of life even when health is not an issue. The key to coping with these feelings is finding a balance you and the people you care about can live with.

Talking about how you feel now will help you avoid built-up anger and resentment later. You may be able to reach a solution that will make you both feel comfortable. The dialysis social worker can help you both sort out conflicting feelings, or may refer you to another therapist or counselor who can help.

**Possible Lifestyle Changes**

Most patients and their family members agree they faced many lifestyle changes when dialysis began. At every phase, from kidney failure to diagnosis to rehabilitation, families have to deal with many issues, including possible changes in home life, social life, financial status, sex life, and spirituality.

Adjusting to life changes caused by a chronic, life-threatening illness, like kidney disease, takes time. Once you can accept that change will happen, you will be better able to give and accept the support you need. You may also find that changes that once seemed like losses now seem like gains—such as a closer family and greater appreciation of life.

**Home Life**

Besides making dialysis part of the normal family schedule, family members may make other changes. For example, you may take on tasks the patient used to do, like taking out the trash, mowing the lawn, picking up the children, or shoveling snow. Often, these role changes are only temporary until the patient is feeling well enough to do these chores again.

When this occurs, family members may simply trade some chores. For example, Don now goes to hemodialysis after work, so Mary takes the kids to choir practice. While Don is on dialysis, he balances the checkbook and pays bills, tasks Mary used to do. This kind of give-and-take can ensure you do not feel overburdened and resent the patient. It can also help the patient contribute to the family. Other times, a different solution is needed. For example, yard work Bob
did may be too hard for his wife to do. They may decide to hire someone to do the work or ask their grown son to help.

You may be helping the patient remember medications and choose foods. The meal plan may not be new to you if kidney disease was diagnosed some time ago, but managing a renal diet can be a difficult change for everyone.

Also, remind yourself that you are not the only one affected by changes at home. Dialysis can affect children and even pets. It is important to remember that even though a dialysis patient may need a lot of attention, other family members need to know you love and appreciate them, too. Finally, remember to take care of yourself as well. You, too, need to eat right, get enough sleep, and exercise to remain healthy.

**Social Life**

Sometimes other friends, family, and strangers do not understand the patient’s situation. As you learn more about kidney disease and its treatments, you will be able to tell them and answer their questions. Do not be too surprised if some friends do not invite the patient to certain events, or if some relatives shy away. They may feel uncomfortable with illness and this is their way of coping with their fear. There is not much you can do except try to give them the facts and hope they will understand. When appropriate, you may let them know you are enjoying life, since you have adjusted to kidney failure.

“We do not shun it—we talk about it,” says the wife of one dialysis patient. “Today, most people know someone on dialysis, so they accept it now more than 15 or 20 years ago.” However, she does notice strangers looking at the needle puncture scars on her husband’s arm, and she believes they must think he is a drug user. She knows they are wrong and reminds herself that dialysis is not a bad thing or something to cause shame.

If you turn down one invitation, friends may think the patient cannot go to any events. They may not understand that there was a conflict with dialysis time or that the patient did not feel well that day. If you explain and assure your friends that you both hope to make it next time, you can let them know you want to stay in touch.

Some patients find they make a new group of friends who understand their situation. Through the dialysis center, support groups, and organizations such as the American Association of Kidney Patients and the National Kidney Foundation, you and your family may meet other patients and family members. These people really understand what you are going through. They can help you join enjoyable activities or projects to help other patients.
These new friends will not replace your former friends and loved ones—they just expand the circle. They can also help you find answers for problems you may be having.

**Financial Status**

Financial Status

When someone needs dialysis, one of the first things they think about is cost and whether insurance will cover treatment. Health insurance and Medicare generally will not pay all costs related to treatment. For example, outpatient medication costs are not covered by Medicare or by some health insurance. Transportation costs may not be covered, except for ambulances (Medicaid may pay for some medications and transportation). Medical expenses can be tax deductible, but they also reduce income. The dialysis social worker can help answer financial questions and point you in the right direction for help.

Another concern a new dialysis patient often has is whether he or she can continue to work. Patients *can and do* continue to work, depending on their type of work, but it requires some planning. Your loved one will need to talk with the dialysis facility about work hours, responsibilities, and hemodialysis treatment times after work. With the patient’s permission, the doctor, nurse, or social worker can talk with the employer to answer questions about dialysis. The dietitian can help the patient plan to pack healthy lunches or make wise choices from cafeteria or vending machines. Your loved one may request “accommodations,” such as flexible hours, transfer to a less strenuous job, or a place and time to do a CAPD exchange. It is important to talk with the dialysis team as soon as possible before problems arise. They can discuss options for treatment and scheduling to help working patients keep working.

**Sex Life**

Sex Life

If you are the spouse or partner of a dialysis patient, you may or may not notice a change in your sex life. In some cases, your partner’s interest in sex and ability to have intercourse can be affected by physical and psychological causes.

Physical problems including low energy, poor circulation, hormone problems, inadequate dialysis, and even drug side-effects can reduce sexual interest or performance. If you or your loved one have concerns, have a medical evaluation of sexual problems. Sometimes a medication change or more dialysis helps. If men have erection problems and do not respond to medication changes or more dialysis, they may want to discuss their options with a urologist. Focusing on all aspects of sexuality—such as attentively talking and holding one another, caressing, foreplay, or even a gentle massage after a stressful day can improve your sex life. Trying different sexual positions that require less energy can help, too.
Sexual problems can also have a psychological basis. Someone who feels worthless, unattractive (perhaps due to the dialysis access), or useless may lose interest in sex. Men may begin to have problems getting or keeping an erection. Sexual problems can become worse if either of you becomes upset. Tension, stress, and anxiety are likely to interfere with sexual function. Once relationship issues are resolved, your sex life often returns to normal.

Physical changes related to kidney failure make it less likely that a woman will become pregnant, although it does happen. Pregnancy after transplant occurs more often. Men on dialysis can father children; however, sperm counts often decrease after months or years on dialysis. Consult with a gynecologist or urologist if you need to clarify fertility and family planning concerns.

Not being able to have children can cause disappointment and a sense of loss for some young couples. However, some couples who want children adopt, and others find ways to have children in their lives by becoming a special aunt or uncle, or volunteering with children.

If you have concerns about sexual relations, talk with the social worker. He or she can offer counseling or refer you to a therapist who specializes in these problems.

**Spirituality**

Chronic illness and major life changes can affect the way you feel spiritually. Some people who were never very religious discover new faith when faced with kidney disease and dialysis, while others do not. Some do not let kidney disease affect their spiritual beliefs at all. Others find they are angry and blame God because there is no one else to blame. Some turn away from religion altogether.

When one baby was diagnosed with renal failure, the mother could not help but ask, “What did my innocent little baby do to deserve this?” She and her family regularly prayed for a miracle—that the baby’s kidneys would work again and he would be well. Her prayers went unanswered and she became down-hearted, disgusted, and angry. She stopped going to church for a while, not only because she had a baby who was ill, but because the preacher’s sermons made her mad. Did she lose her faith? “My religion was definitely tested,” she says. “But, I look at things differently now. I pray for strength and courage and guidance—not miracles.”

Some dialysis patients and their families were never religious, and kidney failure and dialysis did not change their beliefs. They adjust to kidney failure by finding the strength they need within themselves, and from their friends and families.
At just 16 months old, Alex became ill, was hospitalized, and needed a feeding tube and peritoneal dialysis. His parents, Debbie and Sam, took turns staying with him while the other stayed home with their 6-year-old son, John. Alex was on CCPD at home for eight months until he grew large enough to receive a living-related kidney from his mother. When the transplant failed after a year, he returned to CCPD. After some problems with CCPD, Alex began hemodialysis and, in 1990, at age four, he became the youngest home hemodialysis patient in the U.S.

Alex and his family have been no strangers to illness, hospitals, and the many treatments for kidney disease. Of course, each surgery and each new treatment meant changes for the entire family—changes Debbie believes made her family even closer. “We were a close family before all this,” says Debbie. “But, what it has done is made us appreciate the smaller things in life. After spending so much time in hospitals, I really appreciate just being home now,” Debbie says. “I appreciate coming home and having nice, soft carpeting instead of the noisy linoleum at the hospital. I know that sounds crazy, but I think some people take for granted what we now appreciate.”

Though she spends a lot of time at home setting up the kidney machine and monitoring Alex during his treatments, Debbie uses the first hour of dialysis to do aerobics while Alex does his homework. Then, while Alex reads, watches TV, or plays video games, Debbie may check on supper for the family or just enjoy some quiet time. “It’s a settle-down time,” says Debbie of dialysis. “It’s not a siesta time—I still have to check on Alex at least every 30 minutes—but it is a rest time when I just enjoy being at home.”
Debbie is busy outside the home, working in the two drug stores her pharmacist husband owns, and attending activities through church, clubs, and her sons’ school and athletic programs. She doesn’t consider her life chaotic, but she does appreciate time at home with her family. “I’m one of those people who believes in the whole family sitting down to dinner together,” she says. She also notes that, at times, her whole family will gather to talk and joke in the room where Alex is doing dialysis.

While Debbie enjoys being at home, she admits she is sometimes envious when friends and neighbors talk about their summer vacation plans. Though the family has traveled to Disney World, Boston, and Washington, D.C., Debbie finds traveling can be difficult because so much planning is needed, and because some dialysis centers are not set up for children. The boys both love swimming, so to get around the hassles of far-away vacations, the family takes regular day trips to the beach.

“I don’t feel like I’m being stuck with all this,” says Debbie of her home life. “I’m happy. This is heaven compared to what we’ve been through.” Recalling the hospital’s intensive care unit where she met families of children with serious injuries, cancer, or other illness from which they never recovered, Debbie is reminded of how truly lucky she is today.

If you are looking for spiritual guidance, make an appointment with a clergy person who may be able to help you sort out your feelings. If you do not belong to a church, synagogue, or mosque and you would like to, your social worker may be able to refer you to a hospital chaplain or other resource.

**Remembering You**

In your efforts to meet the patient’s needs, you may sometimes forget about you. Even though you have been through a lot of changes, you are still the same person and you need to feel good about yourself.

Situations differ, depending on each patient’s physical condition, treatment choice, personality, feelings, and other factors. If you are a home hemodialysis partner or the patient is very ill, you may find yourself spending more time at home. If you are the retired spouse of a patient who goes to the dialysis center for several hours a day, three or more times per week, you may have extra time on your hands.

Keep doing as many of your favorite activities as you possibly can. You will probably find taking some time for yourself will make you both more compatible and happier. In fact, the more the patient does for him or herself, the quicker and easier rehabilitation will be, because a new sense of independence can be exciting and encouraging.
**Considering Employment**

Employment helps people feel useful and fulfilled, and brings in income and benefits, such as health insurance. The emotional support of co-workers is also an advantage. But work can also be stressful and tiring, even without the extra stresses of a family member with a chronic illness. If you are working and thinking of quitting your job to help your loved one at home, carefully think about both your needs first. You may need more income if your spouse on dialysis is not working. If your loved one is not working and your job has health insurance coverage for both of you, you may not be able to find other health insurance to cover dialysis. If you were not working before, you may even want to find a job for extra income and health insurance coverage in case the patient loses coverage. Keeping or finding a job or volunteer work can help you remain independent and productive and may help the patient stay independent.

Think about ways you can be available if the patient needs you, without giving up too much of your own freedom and limiting activities you enjoy. Getting a pager could help you keep in touch. The dialysis social worker can help you find options to keep you from the resentment that is common when life becomes focused on your being a nurse or caregiver instead of a spouse or friend. *Remember, you can help the patient’s emotional and physical needs more when you tend to your own needs.*

**Thinking About Volunteer Work**

Volunteer work can also offer personal satisfaction. Many family members of kidney patients join organizations that promote kidney disease awareness, education, and research. Some speak out for organ donation or other issues. Through these activities, you can meet people with common interests and gain a feeling that you are not alone and you are not letting kidney disease get the best of you—you are making a commitment to try to make it better for everyone. Churches, schools, hospitals, clubs, non-profit organizations, and professional societies are always looking for members and volunteers. Through these activities, you can learn, meet new people, and share your unique talents with others. Sometimes through volunteering, employment opportunities may develop.

**Making Time for You**

Continue to enjoy hobbies, exercise, time with friends, and other activities. Take some time away from home to shop, go to church, visit friends, or go out to lunch. Make new friends. Renew old friendships. Whatever makes you feel like a whole person—a well person—you should find time to do. Even though you have to adjust to your loved one’s kidney disease and dialysis, you are not the one who is sick.
**Traveling Together or Alone**

If you love to travel, you do not have to let dialysis keep you home. With advance planning, and depending on insurance coverage, dialysis patients are usually able to travel with you. Flexible hemodialysis schedules may allow for day trips or long weekends away without the need for dialysis during the trip. Ask the doctor about such trips or even about your dream vacation—it may very well be possible. By arranging for hemodialysis in your vacation city or by having peritoneal dialysis supplies shipped to your destination, you can enjoy relaxing trips or exciting adventures with your family. Travel can even include cruises where hemodialysis is performed on board the ship. Traveling dialysis arrangements need to be made at least four to eight weeks in advance—more if you are going to a vacation hot spot. Payment arrangements vary, so be sure to ask. Talk with the renal social worker about who assists patients in making their traveling dialysis plans. And talk to the renal dietitian about making good food choices away from home.

If the patient cannot or will not go along on your dream vacation, consider ways that you could still make the trip. Vicki and Bruce did just that. She had always dreamed of going to Australia, but her husband did not want to dialyze outside the U.S. They compromised by taking a two-week vacation—the first week was spent together in Hawaii. From there, Vicki went on to Australia while Bruce stayed in Hawaii and enjoyed the islands with his daughter.
In 1978, Eddie Taylor was an All-State high school football player looking for college scholarships and dreaming of playing with the pros. During a routine athletics physical, however, he was diagnosed with high blood pressure and wasn’t allowed to continue playing football.

Eddie still went to college and continued to stay active, playing basketball and softball, and running. He took his blood pressure medication for a while, but felt fine without it and eventually stopped taking it.

At 21, Eddie got married.

At 22, his kidneys failed.

“If I’d known I had kidney problems, I wouldn’t have gotten married,” says Eddie, who thought it was unfair to his wife, Brenda, to deal with being married to someone on dialysis after only a year of marriage. He explained this to Brenda and gave her the option of getting out of the marriage.

“I married him, not his kidneys,” says Brenda. “I never thought about leaving. I felt like if it was me who got sick, he’d have stuck with me.”

Shortly after Eddie’s kidneys failed, his doctors told the Taylors that if they wanted to have children, they should begin trying soon, since dialysis treatments can cause sterility. A year later, they had a daughter, Quinetta.

Brenda admits the first year after Eddie started dialysis was hard, especially with the added emotional stress of pregnancy.

“I was in shock for the first year or so,” says Brenda. “I was young, and I didn’t know much about dialysis or what to expect.”

Eddie tried to find out more about dialysis by reading books and materials from the dialysis center. The first book he read—written back in 1955—said dialysis patients did not live long.

Fearing he didn’t have long to live, Eddie went through some emotional times and longed to reach milestones in his family life.

“He’d say things like, ‘I sure hope I’m around to see the baby born,’ or ‘I hope I make it to see her first birthday.’ I tried to be optimistic, but everything felt so unstable,” says Brenda.

Every time Eddie left home for the dialysis center, Brenda would sit at home waiting by the phone. She was waiting for a call from the center saying something had happened and he had passed away.
After reading more and talking with the dialysis social worker and nephrologist, the Taylors learned that a lot had changed since 1955. “Kidney failure is not a death sentence,” says Eddie. “At first, I didn’t make any plans because I didn’t know if I was going to be around. Then, one day, I realized I was going to live.”

As Eddie learned to adapt to life on dialysis, Brenda also had to learn to adapt to changes that come with living with someone on dialysis... the special diet, her husband’s mood swings, her own feelings of uncertainty, to name a few.

“One night at 1 a.m. Eddie left home and took the train downtown and I was wondering what was going on,” says Brenda. “Later he said he just had too much coming at him at one time. I just had to be patient and let him get a grip on what was happening.”

At first, Brenda didn’t feel she had anyone to talk to about what was going on in her life. Though she came from a close family of 12 brothers and sisters, she didn’t feel they would understand her feelings.

“My resources for coping had to come from inside,” says Brenda. “I prayed a lot, and I believed whatever happened was meant to happen.”

She also tried to keep a positive attitude while Eddie adjusted to his treatments. “After I accepted dialysis was going to be part of our life, I tried to incorporate it into our life rather than having it take over our life,” says Brenda.

Because Eddie had always been extremely independent, Brenda had to walk the thin line between being helpful and being overprotective. “I never babied him or made him feel like he had a handicap,” Brenda says of her husband. “Dialysis to me was like his work. I go to work, he goes to the clinic; it’s just something we do.”

Brenda, today an administrative assistant at a large academic medical center, continued to work. “Work gave me balance and helped keep things in perspective. It was an entirely different environment for me than being home,” she says.

Eddie took advantage of a vocational rehabilitation program that allowed him to earn his real estate license and work in a job with flexible hours. Like Brenda, he says work takes his mind off other things, such as feeling sick.

While it took some time for Eddie and Brenda to adjust, daughter Quinetta grew up thinking all daddies went to a dialysis center three times a week. When she was about 7 years old, Eddie and Brenda educated her more about dialysis.

Brenda’s advice for other family members new to life with a loved one on dialysis is to be patient. “It does get better, and it does get easier,” she says. “It can be rough in the beginning while you work out a schedule and diet and treatments, but you’ll get the feel of things. Now, I just don’t know anything different.”

In 1997, Eddie Taylor was named Patient of the Year by the Illinois Chapter of the National Kidney Foundation. In his acceptance speech, Eddie credited his success to the help and encouragement of his wife of sixteen years—Brenda.
Health care professionals are often a great resource for you as well as the patient. They can answer your questions, calm your fears, and provide educational resources. They can also encourage you, tell you about the “normal” course of events, and get you in touch with other families in similar situations.

In addition to the patient and family, the team includes several professionals. In fact, under Medicare regulations, each dialysis facility must provide a nephrologist, registered nurse, registered dietitian, and social worker to meet the needs of dialysis patients. Other professionals may be called to help as needed.

**Nephrologist**

A nephrologist is a doctor with special training in the diagnosis and treatment of kidney disease. The nephrologist works with the dialysis team, including the patient, to develop a treatment plan to meet the patient’s needs. The nephrologist sees the patient regularly at the dialysis center or at an office, to check on the patient’s health. Most nephrologists also meet with family members who have questions or want to learn more about the patient’s condition.

**Nurse**

Medicare regulations require that a licensed health professional (doctor, registered nurse, or licensed practical nurse) must be on duty at all times while patients are on hemodialysis. Depending on the dialysis center, a nurse may do the hemodialysis treatment or supervise technicians who do the treatment. A nurse may serve as a dialysis educator who explains different methods of dialysis to predialysis or new dialysis patients. Or, the nurse may train patients and family members for home dialysis. An experienced registered nurse in the dialysis center is an excellent resource for answering questions.

Family members need to understand why a change was made, or why it is important to follow what was prescribed. If you have any doubts about a treatment, ask the nurse or doctor. While nurses are often busy, most understand that informed patients usually do better and knowledgeable family members are important allies. They also realize that time spent answering questions now may prevent problems later.
**Technician**
Most dialysis centers use patient care technicians to help patients during in-center hemodialysis. Technicians may help put the patient on and take the patient off the dialysis machine and monitor vital signs during the treatment. They can also help the patient feel more comfortable during hemodialysis and answer basic questions about the process. However, nurses and social workers are often better prepared to fully answer your questions because of their education and experience.

Sometimes, a dialysis unit will also have equipment or reuse technicians who maintain the dialysis machines, order supplies, and disinfect the dialyzers after use.

**Dietitian**
You should talk to the renal dietitian to understand good food choices and blood chemistries. When you find out how certain foods and fluids affect your loved one, you will be less likely to offer food that should be avoided. Controlling food and fluid may be the most difficult adjustment patients and family members make. You may find that you feel guilty eating a banana or other favorite food the patient should avoid. When you cook for your family, you may need to be flexible to ensure meeting everyone’s nutritional needs.

A dietitian can recommend cookbooks written for the dialysis patient and offer tips on how to make healthy and delicious meals everyone in your home can enjoy. The dietitian can give you information about foods you may have questions about. The wife of one patient, determined to build a collection of interesting and appetizing recipes for her family, talked with her husband’s dietitian, learned how to find the nutritional breakdown of certain foods, and then bought the same textbook the dietitian used.

The dietitian may also give you helpful hints for being a good example for the patient, rather than a boss or controller. The dietitian may also be able to give tips for dining out and special occasions. Dietitians are usually happy to answer your questions over the phone as well as in person.

**Social Worker**
The social worker in a dialysis center, or renal social worker, can provide you with a wealth of information. You and your loved one can expect to talk with the social worker within days or, at most, two weeks after starting dialysis. In fact, if possible, patients should see a renal social worker for counseling and education before they begin dialysis.
The social worker will ask the patient questions about lifestyle, goals, medication, insurance, transportation issues, family support, and other topics. The social worker will then work with the patient to overcome many problems. Renal social workers are often good at explaining complex issues in easy-to-understand words. If the social worker cannot help you, he or she will help you find resources in the hospital, or community.

According to federal guidelines, renal social workers are required to have master’s degrees and training in counseling. They can be excellent resources. Most social workers prefer that family members come to appointments with patients to learn and ask questions. Another “set of ears” during talks about complicated paperwork issues is often helpful when the patient is trying to learn so much new information. The social worker can also meet with you or offer counseling to discuss how dialysis is affecting your life as a family member of a patient. The social worker’s services are included in the charges for dialysis treatment, so be sure to take advantage of this valuable resource.

Other Professionals
Your loved one may also see a surgeon to create a dialysis access, a transplant surgeon and transplant team to discuss transplantation, a vocational rehabilitation counselor to help the patient keep working or begin working, a physical therapist to help improve stamina and physical fitness, and an occupational therapist to help with hand strength or daily activities. Billing or government representatives may help explain benefits and forms. Finally, the pharmacist is an important ally who can help answer medication questions.

Getting the Most Out of the Dialysis Team
Professionals agree: patients benefit from being responsible for communicating their needs to the health care team. Your role is to encourage your loved one to take the initiative. You should assist when needed, but resist being the one who asks questions first.

When you and the patient take active roles in learning about treatment, you will both be more comfortable and able to let the health care team know what you want. Remember, however, it is ultimately up to the patient how involved he or she wants you to be. Let your loved one know you care and are willing to assist in medical matters, but encourage him or her to take responsibility first.
Here are a few tips for patients, family members, and friends when communicating with medical personnel:

1. **Write down questions as the two of you think of them.** For concerns that need immediate attention during work hours, call the doctor or the dialysis center. When the dialysis center is closed, call the on-call nurse or the doctor’s after-hours number. You may feel like you are being a pest, but your health care team should appreciate your concern. They know that helping you understand something now is likely to prevent problems later.

2. **Do not use the dialysis center as an emergency room.** If a patient is in distress, call an ambulance or go to a hospital emergency room (ER). If neither of you is sure it is an emergency, call the dialysis nursing staff or doctor and tell them the symptoms first. They may ask you to come to the center or direct you to the hospital ER. Bringing a very sick person to the dialysis center instead of the ER can waste valuable time in an emergency.

3. **Ask to be included in the patient care conference.** The government requires the dialysis team to meet about each patient’s short-term care at least every six months. Long-term care is also discussed once per year. These conferences give an update on the patient’s progress.

4. **Be informed.** Ask questions of the dialysis team and other informed patients or family members. If you do not think the answers are satisfactory, look elsewhere. Get a second opinion from another nephrologist, or contact the American Association of Kidney Patients, National Kidney Foundation, National Kidney and Urologic Disease Information Clearinghouse, or the patient services coordinator of your ESRD Network (see Resources section). Your librarian may also help you find information.

5. **Know the grievance procedure.** If you and the patient have a problem with the dialysis care, find out about the center’s grievance procedure. Complaining to the wrong person may not help. Every dialysis center is part of an ESRD Network which has a grievance policy. Most centers have an internal policy, too. If you are not satisfied after the grievance process, find out what other options for dialysis are available in your area. You can also contact the American Association of Kidney Patients if you have not been able to solve the problem.

6. **Understand the dialysis center’s schedules.** Sometimes a patient may have a problem that delays the start time on hemodialysis. The longer a patient dialyzes, the better he or she will feel, so it is important for each patient to dialyze for the prescribed time. Unfortunately, patients scheduled for hemodialysis after another patient has a problem may have to wait a little while. If you plan to drive your loved one home after hemodialysis, you may want to call ahead to be sure he or she is running on time.
Knowing Patient’s Rights and Responsibilities

All new patients should receive a copy of Patient Rights and Responsibilities from the dialysis center. Read this. It contains information to help you know what to expect from the health care team, what they expect from you and the patient, and how to file a grievance.

Patient’s rights in this document include confidentiality and rights to information. If you feel the patient’s rights have been violated, you both can and should seek to fix the situation.

The Patient Rights and Responsibilities list gives responsibilities for the patient. Too often, patients consider themselves helpless victims and look to their health care providers as all-knowing. But, as the patient responsibilities section points out, patients play a large and important role in their own care.

For example, patients must tell the truth, follow the treatment plan, and speak up when they have pain or feel sick. Medicine is not an exact science—the health care team can only help the patient when they completely understand the symptoms and situation.

Because family members and friends play such an important role in supporting the patient, you must take some responsibility for the patient’s health as well. Do not rely on the “experts” to know everything or to fix problems that happen when the patient does not follow recommendations. Play an active role in helping the patient follow the treatment plan and watch for symptoms and questions that need to be discussed with the dialysis team.

Learning About Advance Directives

Advance directives outline the patient’s wishes for medical care in case he or she is unable to express them due to a medical crisis. All dialysis patients are wise to have documents filled out, signed, and kept in a safe place. A living will is one form of an advance directive. The living will allows a person to state what medical procedures he or she does or does not want performed. Another type of advance directive, a durable power of attorney for health care decisions, names the person who would make health care decisions if the patient cannot.

One social worker brings up the subject of advance directives by asking, “If you were in an emergency and could not speak for yourself, would you want your family to speak for you, a stranger, or a court of law?” Of course, most patients answer this question with “family.” If a patient cannot speak or make these decisions, a hospital may refuse to allow you or other family members to decide,
unless your loved one has an advance directive. As a family member, you may or may not be involved in the patient’s decisions, but you should be aware of them and know where the completed advance directive documents are, in case they are needed.

Many people avoid talking about advance directives because they do not want to think about something bad happening. One social worker recommends thinking about it like car insurance: buying car insurance will not cause you to have an accident. Signing advance directives will not cause you to get sick. Both are just safety nets to protect you and your family if the unexpected does happen.

Laws about advance directives vary from state to state. Your social worker should know the best methods to ensure the patient’s wishes are followed. He or she can also help you and the patient through the process.

**Conclusion**

Patients need to be in charge of their own care. The more independent they are, the better they do physically and emotionally. Family members and friends play a key role by giving support and encouragement. You can help the patient by learning about kidney failure and its treatments and supporting the patient’s treatment choices, exercise routine, diet, work, and other activities.

Your relationship with the patient can be made stronger by both of you talking openly about each others’ feelings, fears, and concerns. You can also work well with the dialysis team by learning about dialysis, asking questions, and using the knowledge of the health care team when you have concerns.
As you talk to the patient and dialysis professionals, you will learn more about dialysis. You may be surprised how quickly you pick up new words and abbreviations for kidney disease and its treatments. To help you get a head start, the following list of common terms may be useful. Keep in mind, though, this is just a sample of terms—if you do not understand a certain word or procedure, be sure to ask a health care professional.

**Acute renal failure**
Kidney failure that happens quickly—within days or a week. It is often caused by injury or drug interactions. Acute renal failure can usually be reversed.

**Adequacy**
Enough dialysis to avoid symptoms of uremia. See Kt/V and URR.

**Anemia**
A shortage of red blood cells to carry oxygen to the body’s tissues. Symptoms include paleness, shortness of breath, weakness, irregular heartbeat, fuzzy thinking, fatigue, and sexual problems.

**Arterial line**
Tubing connected to a needle inserted into the hemodialysis patient’s vascular access. During dialysis, the arterial line carries blood away from the body and into the dialyzer (artificial kidney) on the dialysis machine.

**Arteriovenous (AV) fistula**
A blood vessel that is made by surgically sewing together an artery and a vein (often in the forearm) to create the rapid blood flow from the heart needed for efficient hemodialysis. It is also commonly called a native fistula or fistula.

**Arteriovenous (AV) graft**
An access that is made by connecting one end of a piece of artificial vein to the patient’s vein and the other end to the patient’s artery. The graft is a larger vessel with the rapid blood flow needed for efficient hemodialysis. It is commonly called a graft.

**Bilateral nephrectomy**
Removal of both kidneys.
**BUN**

Blood Urea Nitrogen. A waste product, or toxin, that appears in the blood as protein from food is digested. BUN levels are a measure of how well dialysis is removing wastes from the blood. Normal ranges of BUN in healthy people are 5-18 mg/dL in children, 7-18 mg/dL in adults, and 8-20 mg/dL in adults over 60 years old. Higher levels are present in patients with kidney failure.

**CAPD**

Continuous Ambulatory Peritoneal Dialysis. Patients using this form of dialysis put dialysate fluid into the abdomen through a surgically placed catheter, or tube. This fluid comes in contact with the peritoneal membrane, a thin layer of tissue around the abdominal organs. Some of the toxins in the blood pass from blood vessels in the wall of the peritoneal membrane into the dialysate. The fluid, which may change from clear to slightly yellow, is then drained out of the body through the catheter. The process is usually repeated four or five times per day.

**Catheter**

A tube. In peritoneal dialysis, a small catheter is permanently inserted into the abdomen to allow dialysate fluid to enter and exit. Sometimes a central venous catheter is inserted into the subclavian or internal jugular vein just below the collar bone or in the neck or groin to allow temporary blood access for hemodialysis.

**CCPD**

Continuous Cycling Peritoneal Dialysis. Like CAPD, dialysate fluid is drained into the abdomen through a catheter. Instead of changing the fluid several times each day as in CAPD, a machine changes the fluid several times each night while the patient sleeps.

**Chronic renal failure**

Kidney failure that takes place over a long period of time. Chronic renal failure is usually not reversible.

**Creatinine**

Creatinine is produced normally by muscles and is used to measure kidney function. It is always higher than normal in dialysis patients. Normal ranges of creatinine are 0.3-0.7 mg/dL in children birth to three, 0.5-1.0 mg/dL in children 3-18 years old, and 0.6-1.3 mg/dL in adults.

**Dialysate fluid**

A fluid used for dialysis that consists of a mixture of water, glucose, and certain elements (electrolytes) the body needs. Dialysate usually contains sodium,
magnesium, chloride, potassium, and calcium. During dialysis, waste products in the blood pass through a porous (filtering) membrane or dialyzer into the dialysate fluid.

**Dialysis**
The movement of very small, microscopic particles (toxins) from one side of a porous (filtering) membrane to another. Waste products and excess chemicals (electrolytes) in the blood pass through the membrane into a solution that does not contain those toxins. Both peritoneal dialysis and hemodialysis pass blood through a membrane to filter out waste products and fluid into dialysate.

**Dialyzer**
A plastic artificial kidney that contains thousands of very thin, hollow, tube-like membrane fibers. Blood flows through the inside of the hollow membranes. The fibers are surrounded by dialysate. Toxins from the blood move through the membranes and into the dialysate. The blood remains inside the hollow tubes and is returned to the body, once cleaned.

**Disequilibrium**
Headaches and dizziness during dialysis. Disequilibrium can occur if dialysis removes a lot of fluid very quickly, or if blood pressure drops.

**Dry weight**
A patient’s weight without excess fluid. A patient can lose several pounds of fluid weight during a dialysis session. The actual amount depends upon the amount of fluid consumed between dialysis treatments.

**Dwell time**
The length of time peritoneal dialysis patients keep fresh dialysate in the abdomen. After the dwell time is over, used dialysate is replaced with fresh dialysate either by the patient (using CAPD) or by a cycler machine (CCPD).

**Edema**
Swelling in soft tissues, especially in face, hands, feet, and ankles. May be caused by drinking too much liquid between dialysis treatments or inadequate dialysis.

**EPOGEN® (EPO)**
(Epoetin alpha) A DNA-engineered form of the human hormone erythropoietin used to treat anemia. EPO sends a message to the bone marrow to make more red blood cells, so patients have more energy and endurance.

**Erythropoietin**
A hormone produced by healthy kidneys that signals the bone marrow to make red blood cells.
**ESRD**
End-stage renal disease, or permanent kidney failure. ESRD occurs when kidney function is approximately 10% to 15% of normal or less, and the patient needs dialysis or a kidney transplant to live.

**Exchange**
The process of draining used peritoneal dialysate from the abdomen and putting in fresh dialysate. An exchange may be done by the patient or by a cycling machine.

**Fistula**
See Arteriovenous (AV) fistula.

**5 E’s**
The core principles of successful rehabilitation: Encouragement, Education, Exercise, Employment, and Evaluation.

**Graft**
See Arteriovenous (AV) graft.

**Hematocrit**
(Hct) The percentage of red blood cells in whole blood. Normal hematocrit is from 37% to 47% for women and from 42% to 52% for men. The NKF-DOQI recommended target hematocrit range for dialysis patients is 33% to 36% and most patients need regular doses of EPO and iron to stay at this level. Without enough red blood cells to carry oxygen to the tissues, patients feel tired and listless.

**Hemodialysis**
A type of dialysis in which the patient’s blood is removed from the body and cleansed by a dialyzer, i.e., an artificial kidney. The patient’s blood travels through needles placed into a specially created blood vessel. Blood is passed through the dialyzer, cleansed, and then returned to the body.

**Hypertension**
High blood pressure. This can be caused by too much salt intake, fluid build-up, or too much of the hormone renin, produced by the kidneys. Hypertension can cause headache, blurred vision, blindness, heart damage, and stroke.

**Hypotension**
Low blood pressure. This can occur if large amounts of fluid are removed from the blood vessels too quickly during dialysis. Hypotension can cause a fast pulse, dizziness, and sometimes nausea, vomiting, or fainting.
**Kidney failure**

Loss of the ability of the kidneys to remove fluid and toxins from the body. The two most common causes of kidney failure are diabetes and high blood pressure. It may also be caused by other viral or hereditary disorders. Kidney failure is less often caused by damage related to medications, or by other conditions such as kidney stones or injuries.

**Kt/V**

This is a formula for prescribing adequate dialysis and checking to see if the patient is receiving enough dialysis. Kt/V is calculated by multiplying toxins removed, called clearance (K), by the amount of time (t) of the dialysis treatment, and dividing by the volume (V) of water in the body. The doctor uses blood tests to learn if the patient is getting enough dialysis. The recommended prescribed Kt/V for hemodialysis is 1.3, with a minimum actual Kt/V of 1.2. The recommended prescribed Kt/V for peritoneal dialysis is a minimum weekly Kt/V of 2.0. These figures are the floor, or minimum, only. A formula for calculating Kt/V for hemodialysis can be found in the AARP Advisory: Inadequate Hemodialysis Increases the Risk of Premature Death, listed in the Resources section at the back of this booklet.

**LORAC**

The Life Options Rehabilitation Advisory Council. This group is made up of health care professionals, patients, business leaders, and researchers dedicated to helping dialysis patients realize their fullest potential.

**Modality**

A type or mode of treatment. In ESRD, the modalities of treatment include hemodialysis, peritoneal dialysis, and transplant.

**Nephrology, nephrologist**

The study of the kidneys. It is the medical specialty that deals with the diagnosis and treatment of kidney disease. A nephrologist is a physician who specializes in studying the kidneys and helping patients with kidney problems.

**Neuropathy**

Nerve damage. It can be caused by diabetes. It can also be caused by uremia, or a build-up of toxins in the body. Too little dialysis over time can lead to nerve damage. Neuropathy can cause weakness, burning, tingling, and numbness, especially in the feet and lower legs, but also in the hands.

**Peritoneal dialysis**

A form of dialysis that uses the body’s own peritoneal cavity to hold dialysate fluid. The peritoneal membrane acts like a filter to allow toxins, excess chemicals,
and fluid to move into dialysate. Peritoneal dialysis “exchanges” fresh dialysate for used dialysate, often several times a day. Exchanges can be done by the patient (see CAPD) or by a machine (see CCPD), or in some cases both types of exchanges are combined to help the patient get enough dialysis. Combination therapy may be called “PD Plus.”

**Peritoneal membrane**
The porous, double-layered, sac-like lining that surrounds the abdominal organs in the body's peritoneal cavity.

**Peritoneum**
The area surrounded by the peritoneal membrane, which includes the abdominal organs.

**Rehabilitation**
A return to stable health, a positive outlook, and enjoyable activities that make people feel better physically and mentally. A successful rehabilitation program uses medical treatment, counseling, education, diet, and exercise, with help from the “5 E’s”: Encouragement, Education, Exercise, Employment, and Evaluation.

**Renal**
Related to the kidneys.

**Toxins**
Chemical waste products produced by the metabolic processes of the body, such as digesting food, breathing, and mental and physical activity.

**Uremia**
A condition of excess toxins or impurities in the blood. Symptoms include weakness, lack of energy, poor appetite, weight loss, metallic or ammonia taste in the mouth, skin color changes, and worsening memory.

**URR**
Urea Reduction Ratio. Like Kt/V, URR is a way to measure dialysis adequacy. It is based on a ratio of the predialysis BUN level to the postdialysis BUN level. (See BUN). Patients can calculate their URR themselves using a formula contained in the **AAKP Advisory: Inadequate Hemodialysis Increases the Risk of Premature Death**, listed in the Resources section at the back of this booklet. The URR value should be 65% or higher.

**Venous line**
In hemodialysis, the tubing that returns the clean blood from the dialyzer back to the patient through the access.
Your social worker can tell you about facility resources and local organizations that can help you with specific issues. In addition, the following list of educational resources may be especially helpful to you. Many of these resources are available free of charge, but be sure to ask.

**Sources of Information**

**American Association of Kidney Patients (AAKP)**

*The Voice of All Kidney Patients*

100 South Ashley Drive, Suite 280
Tampa, Florida 33602
(800)749-2257
e-mail: aakpnat@aol.com
Web Site: [http://www.aakp.org](http://www.aakp.org)

For information on membership or the local chapter nearest you, please call (800)749-2257. Call or write the American Association of Kidney Patients to obtain a number of helpful publications for patients and families, including:

**AAKP Advisory: Inadequate Hemodialysis Increases the Risk of Premature Death.** Addresses issues of nutrition, hemodialysis adequacy, and the correct way to draw blood to measure hemodialysis adequacy. Formulas for figuring Kt/V and URR are included.

**AAKP Advisory: Inadequate Peritoneal Dialysis Increases the Risk of Malnutrition, Hospitalization, and Premature Death.** Addresses issues of nutrition, peritoneal dialysis adequacy, and the correct way to measure peritoneal dialysis adequacy.

**aakp RENALIFE.** A quarterly magazine for kidney patients and their families.

**Americans with Disabilities Act of 1990: Your Rights in the Workplace.** Answers common questions about how the Americans with Disabilities Act is likely to affect working patients.

**Blood Chemistry Values.** Lists blood chemistry values for dialysis patients and describes signs and symptoms which may occur when levels are not normal.

**The Importance of Having Enough Iron.** Addresses patient concerns about hematocrits and effective use of iron supplements. Also available in Spanish.

**Na-K-Phos Counter: A Reference for the Dialysis Patient.** Pocket-sized English/Spanish brochure providing sodium, potassium, and phosphorus counts for various foods and national chain restaurants.

**When Kidneys Fail: Straight Talk About Your Options.** Brochure discusses the pros and cons of various treatment options. Also available in Spanish.
American Kidney Fund (AKF)

_We Carry the Torch for Kidney Patients_

6110 Executive Boulevard, Suite 1010
Rockville, Maryland 20852
AKF HELPLINE: (800) 638-8299
e-mail HELPLINE: helpline@akfinc.org
Web Site: http://www.arbon.com/kidney

The American Kidney Fund is a national voluntary health organization dedicated to improving the daily lives of people with chronic kidney disease. The AKF’s primary goal is to relieve the financial burden of chronic kidney failure through Patient Aid programs. The AKF HELPLINE responds to questions from kidney patients, their families, and the general public. The AKF has a number of publications, some available in Spanish or large-print versions. A partial list is included below:

_The American Kidney Fund Helps When Nobody Else Will_. Brochure describes the purpose of the AKF.

_Diabetes and the Kidneys_. Booklet describes the challenges of having both diabetes and kidney failure.

_Diet Guide for the CAPD Patient_. Brochure explains the role of calories, sodium, potassium, phosphorus, fluids, vitamins and minerals, and fiber in the CAPD diet.

_Diet Guide for the Hemodialysis Patient_. Provides information about calories, sodium, potassium, phosphorus, fluids, vitamins and minerals, fiber, and the diabetic diet for ESRD patients.

_Give a Kidney: You Can Give Someone a Second Chance_. Brochure answers some of the common questions about organ donation.

_Facts About Kidney Diseases and Their Treatment_. Brochure describes kidneys, normal functioning, several common kidney diseases, and treatments for kidney failure.

_Kidney Disease: A Guide for Patients and Their Families_. Includes basic information about how kidneys work and treatments available when they fail.

_Kidney Disease Strikes African Americans_. Brochure explains why African Americans have a higher risk of kidney failure, and how they can help prevent kidney disease and stay healthy.

_Kidneys for Kids_. Brochure explains kidney transplantation, blood and tissue typing, hospital stays, and medications, in language children can understand.
ESRD Networks

The 18 regional ESRD Networks work with dialysis providers and transplant centers to assure that patients receive quality care and that Medicare dollars are used effectively. The Networks collect data, work toward quality improvement, promote patient satisfaction, and maintain clearinghouses of ESRD information.

Forum of ESRD Networks. 1527 Huguenot Road, Midlothian, VA 23113. Phone: (804) 794-2586, Fax: (804) 378-7351, e-mail: forum@richmond.infi.net

This home page links to all Network home pages.

Network 1. Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont. ESRD Network of New England, Inc., PO Box 9484, New Haven, CT 06534. Phone: (203) 387-9332, Fax: (203) 389-9902, e-mail: network1@connix.com

Network 2. New York. ESRD Network of New York, Inc., 1249 Fifth Avenue, A-419, New York, NY 10029. Phone: (212) 289-4524, Fax: (212) 289-4732, e-mail: nyersd@aol.com

Network 3. New Jersey, Puerto Rico, Virgin Islands. TransAtlantic Renal Council, Cranbury Plaza, 2525 Route 130—Building C, Cranbury, NJ 08512. Phone: (609) 395-5544, Fax: (609) 655-3432, e-mail: tarcnet3@worldnet.att.net

Network 4. Delaware, Pennsylvania. ESRD Network Organization #4, University of Pittsburgh Medical Center, 200 Lothrop Street, Pittsburgh, PA 15213. Phone: (412) 647-3428, Fax: (412) 683-6814, e-mail: network4@al.isd.upmc.edu

Network 5. Maryland, Virginia, Washington, DC, West Virginia. Mid-Atlantic Renal Coalition, 1527 Huguenot Road, Midlothian, VA 23113. Phone: (804) 794-3757, Fax: (804) 794-3793, e-mail: net5@richmond.infi.net

Network 6. Georgia, North Carolina, South Carolina. Southeastern Kidney Council, Inc., Lake Plaza East, 900 Ridgefield Drive, Suite 150, Raleigh, NC 27609. Phone: (919) 876-7545, Fax: (919) 876-9433, e-mail: net6@interpath.com

Network 7. Florida. ESRD Network of Florida, Inc., One Davis Boulevard, Suite 304, Tampa, FL 33606. Phone: (813) 251-8686, Fax: (813) 251-3744, e-mail: esrdnw7@ibm.net

Network 8. Alabama, Mississippi, Tennessee. Network 8, Inc., PO Box 55868, Jackson, MS 39296. Phone: (601) 936-9260, Fax: (601) 932-4446 e-mail: network8@misnet.com

Network 9. Indiana, Kentucky, Ohio. Tri-State Renal Network, Inc., 911 East 86th Street, Suite 202, Indianapolis, IN 46240. Phone: (317) 257-8265, Fax: (317) 257-8291, e-mail: tsrn@quest.net
Network 10. Illinois. Tri-State Renal Network, Inc., 911 East 86th Street, Suite 202, Indianapolis, IN 46240. Phone: (317) 257-8265, Fax: (317) 257-8291, e-mail: tsrn@iquest.net

Network 11. Michigan, Minnesota, North Dakota, South Dakota, Wisconsin. Renal Network of the Upper Midwest, Inc., 1360 Energy Park Drive, Suite 200, St. Paul, MN 55108. Phone: (612) 644-9877, Fax: (612) 644-9853, e-mail: esrd11@tccn.com

Network 12. Iowa, Kansas, Missouri, Nebraska. ESRD Network, Northpointe Circle II, Suite 105, 7509 NW Tiffany Springs Parkway, Kansas City, MO 64153. Phone: (816) 880-9990, Fax: (816) 880-9088

Network 13. Arkansas, Louisiana, Oklahoma. ESRD Network Organization #13, 6600 N. Meridian Avenue, Suite 155, Oklahoma City, OK 73116. Phone: (405) 843-8688, Fax: (405) 842-4097, e-mail: pphilliber@esrdnetwork13.com

Network 14. Texas. ESRD Network of Texas, Inc., 14114 Dallas Parkway, Suite 660, Dallas, TX 75240. Phone: (972) 503-3215, Fax: (972) 503-3219


Network 18. Southern California. Southern California Renal Disease Council Inc., 6255 Sunset Boulevard, Suite 2211, Los Angeles, CA 90028. Phone: (213) 962-2020, Fax: (213) 962-2891, e-mail: Network18@aol.com

Government Resources


End-Stage Renal Disease: Choosing a Treatment That's Right for You. This and a variety of other materials are available from the National Kidney and Urologic Diseases Information Clearinghouse. Write to: Box NKUDIC, 3 Information Way, Bethesda, MD 20892, or call (301) 654-4415.

National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC). Has many resources for dialysis patients and professionals. Write to: Box NKUDIC, 3 Information Way, Bethesda, MD 20892, or call (301)654-4415.


National Kidney Foundation (NKF)

Dedicated to Taking Kidney and Urinary Tract Diseases from Treatment to Cure

30 East 33rd Street
New York, New York 10157
(800)622-9010
Web Site: http://www.kidney.org

For information about membership or the local NKF chapter nearest you, please call (800)622-9010. All of the National Kidney Foundation's many publications (some available in Spanish) are listed in their Educational Resource Directory. A few sample publications are mentioned below:


Dining Out with Confidence. Brochure offers practical tips for making good food choices at a variety of types of restaurants.

Emergency Meal Planning. Brochure helps families plan food supplies to keep on hand for emergencies, such as power outages or natural disasters.
EPO: Treating Anemia in Chronic Renal Failure. Discusses what EPO is and how it works to treat anemia.

Family Focus. A quarterly publication for kidney patients and their families.

Fitness After Kidney Failure: Building Strength Through Exercise. Offers practical tips for types of exercises to try, when to start, and when to stop.


Nutrition and Changing Kidney Function. Brochure provides information about how nutritional needs change as kidney function declines.

Parent Connection. Quarterly publication for parents, grandparents, and other caregivers of children with kidney disease.

Sexuality and Chronic Kidney Failure. Booklet answers common questions that ESRD patients and families may have about ESRD and sexuality.

Southwest Cookbook for People on Dialysis. (English/Spanish) El Paso Chapter Council on Renal Nutrition and the National Kidney Foundation of Texas, Inc. Available to dialysis facilities through Amgen Professional Sales Representatives (800) 282-6436.

Transplant Chronicle. A publication for organ recipients and their families.

**Rehabilitation Resource Center**

*Dedicated to Helping Dialysis Patients Realize Their Fullest Potential*

Life Options Rehabilitation Program
414 D’Onofrio Drive
Madison, WI 53719
(800) 468-7777
E-mail: web@lifeoptions.org
Web Site: http://www.lifeoptions.org

The Rehabilitation Resource Center, supported by Amgen Inc., has information about rehabilitation for kidney patients and their loved ones. Call (800)/468-7777 to receive the publications below:

Bridging the Barriers: For Patients and Their Families. Booklet discusses the “5 E’s” of renal rehabilitation: Encouragement, Education, Exercise, Employment, and Evaluation.
Employment: A Guide to Work, Insurance, and Finance for People on Dialysis. Booklet provides information about how kidney failure is paid for, including the Medicare ESRD program and private health insurance. Also covers employment and disability issues for patients who are working or would like to work.

Renal Rehabilitation Report. A free bi-monthly newsletter for patients and ESRD professionals.

United Network for Organ Sharing (UNOS)
1100 Boulders Parkway, Suite 500
PO Box 13770
Richmond, Virginia 23225
(804) 350-8541
Web Site: http://www.unos.org

Financing Transplantation: What Every Patient Needs to Know. Answers common financial questions patients ask before considering a transplant.

Questions Every Patient Should Ask. Provides a list of questions patients might ask when visiting a transplant center.

What Every Patient Needs to Know. Provides information on the national organ procurement and transplantation network, explains how the transplant waiting list works and how organs travel to the people who receive them.

Other Selected Resources
About Kidney Dialysis and Transplants. Available from Channing Bete, 200 State Road, South Deerfield, MA 01373. (413) 665-7611.

Choices. Available from Baxter Healthcare Corporation—Dialysis Division, 1425 Cook Road, Deerfield, IL 60015.

Cooking the Renal Way. Revised 1993. Includes nutrient analysis and has sections on seasonings, diabetic desserts, and holiday menus. Available for $10.00 from the Oregon Council on Renal Nutrition, PO Box 29133, Portland, OR 97270.

Creative Cooking for Renal Diabetic Diets. Contains exchange guidelines, serving/portion guide, fluid calculations, and nutrient values for each recipe. Available for $16.45 including shipping, from Senay Publishing, PO Box 397, Chesterland, OH 44026, or call (800) 850-6987.

Directory of Prescription Drug Patient Assistance Programs. Provides information to help patients who have difficulty paying for medications. Available from Pharmaceutical Manufacturers Association, 1100 Fifteenth Street NW, Washington, DC 20005. (800) 762-4636 or (202) 835-3460.


For Patients Only. Bi-monthly publication for patients with ESRD and their families. Available from Contemporary Dialysis & Nephrology. For subscription information, please call (818)704-5555.


Help for Children from Infancy to Adulthood. A directory of national organizations, hotlines, and other resources. Available from Rocky River Publishers, PO Box 1679, Sheperdstown, WV 25443. (304)876-2711.

Jodi Stolove’s Chair Dancing. One of three videos of fun exercises to be done while seated. Available from Chair Dancing International Inc., 2640 Del Mar Heights Road, Suite 183, Del Mar, CA 92014. (800)551-4FUN (800-551-4386).

Menu Magic. More than 100 recipes and three weeks of menu ideas with nutrient analysis by recipe and by menu. Available for $15.00, including shipping, from the Council on Renal Nutrition of Dallas/Ft. Worth, NKF Texas, 13500 Midway Road, Suite 101, Dallas, TX 75244.


The Renal Family Cookbook. Contains nutrient analysis and index. Available for $5.95 from Multimed Publications, 3995 Bathurst Street, #301, Downsview, Ontario, Canada M3H 5V3.

The Renal Gourmet. Cookbook by renal patient includes use of herbs, spices, flavored vinegars, wines, and fruit for no-salt recipes with nutrient analysis. Available for $21.00, including shipping, from Emenar Inc., 320 Charmille Lane, Woodale, IL 60191, or call (800)445-5653.

Southwest Cookbook for People on Dialysis. English/Spanish cookbook of TexMex recipes. Available free from renal dietitians or Amgen Professional Sales Representatives.


What Can I Eat? A Nutritional Guide for Persons with Kidney Disease. English/Spanish renal diet guide with information on convenience foods, reading food labels, dining out, and which foods to avoid, limit, and enjoy. Available for $9.65, including shipping, from the California Dietetic Association, Los Angeles District, PO Box 3506, Santa Monica, CA 90408, or call (310) 454-4916.

Your Kidneys, Your Bones, and You. (English/Spanish) Abbott Laboratories. Available from Abbott Renal Care, Department R10, Building AP34, 200 Abbott Park Road, Abbott Park, IL 60064. (800) 457-9472.
REFERENCES


The AAKP exists to serve the needs and interests of kidney patients and their families.

AAKP was founded in 1969 by kidney patients for kidney patients. Our purpose is to help fellow patients and their families cope with the emotional, physical, and social impact of kidney disease.

As a member, you will meet people with similar experiences. You will learn about kidney disease, how to control it, and who to turn to for help. In other words, we are here to help you with the answers and guidance you need to live a full and productive life.

AAKP offers you the following benefits:

- Subscription to AAKP’s quarterly magazine RENALIFE
- A membership packet filled with a wide range of pamphlets and brochures on issues affecting the care and treatment of kidney patients
- An opportunity to attend our annual convention, filled with seminars that deal with the treatment, rehabilitation, and psychological and social concerns of renal disease patients
- Local chapters in your community that provide social and educational support to you and your family with meetings, newsletters, and group activities
- Special interest brochures that address changing medical technology
- Assurance that AAKP is representing your interests by defending the ESRD Medicare program

Patient/Family membership in AAKP is $25 annually.

To join us, just fill out the membership application form below, and send it in with your check or VISA®/Master Card® information to:

American Association of Kidney Patients
100 S. Ashley Drive, Ste. 280
Tampa, FL 33602

For immediate membership, call AAKP directly at:

(800) 749-AAKP

Please have your VISA®/Master Card® ready.

Name: ________________________________  ________________________________
Street Address: ________________________________  ________________________________
City: _______ State: _______ Zip: _______  Telephone (include area code): ________________________________

☐ Transplant  ☐ Hemodialysis  ☐ CAPD  ☐ CCPD  ☐ Family Member

Indicate which AAKP membership category below:

☐ Patient/ Family ($25)  ☐ Professional ($35)  ☐ Life ($1,000)
☐ I’m already a member of AAKP, but I’d like to make a donation of $ _______  ☐ Check enclosed (payable to AAKP)
☐ Please charge my credit card: ☐ Visa®  ☐ Master Card®

Account Number: ________________________________  Exp. Date: _______
Signature: ________________________________
New Life, New Hope was written for patients, their families, and their friends to help them learn about dialysis and how it will affect their lives. This booklet is not intended as a substitute for medical counseling or legal or other professional advice, and should not be considered as such.

Readers must recognize that some suggested activities, exercise in particular, involve certain risks, including the risk of severe injury, disability, or death. These risks cannot be completely eliminated even when done under expert supervision. Use of these materials indicates acknowledgment that the American Association of Kidney Patients (AAKP), Amgen Inc., Medical Media Associates, Inc., and the Life Options Rehabilitation Advisory Council will not be responsible for any loss or injury sustained in connection with, or as a result of, the use of this booklet.

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If medical, legal or other professional advice is required, please seek the personalized service of a competent professional.