AAKP PATIENT PLAN©

AAKP PATIENT PLAN

Providing Today's Patients With Answers For Tomorrow

DIAGNOSIS TO TREATMENT CHOICE

1 *Phase One*

The American Association of Kidney Patients wishes to thank all the patients, family members, professionals and companies who gave generously of their time and resources in order to provide all patients with the AAKP Patient Plan©.

The AAKP Patient Plan© Team spent countless hours developing this program and making it a reality. Their devotion to the program ensured its success. The Team members included: Brenda Dyson (patient), Frank Soldovere (professional), Judy Weintraub, MS (patient), Bonny Wilburn (patient), Manuel Zapata (patient) and Rosa Rivera-Mizzoni, MSW, LCSW – Team Leader.

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To our sponsors, Amgen, Inc., Baxter Healthcare, Fresenius Medical Care, Kidney Care Foundation, Shire and Sigma Tau Pharmaceuticals, thank you for the generous sponsorships that provided patients with this very important resource.

Last, but certainly not least, thank you to our fellow patients, who told AAKP exactly what you needed and wanted to help you and your family as you experienced the journey with kidney disease.

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AAKP RESOURCES

aakpRENALIFE
This patient magazine is produced six times a year. It contains information for those who are experiencing kidney failure. Topics featured include dialysis, transplantation, medical questions and dietary concerns.

Kidney Beginnings: The Magazine
AAKP's magazine for those with chronic kidney disease (CKD). It features information on the kidneys, answers to common questions about CKD and stories from patients who have adjusted to living with kidney disease. It is published four times a year and subscriptions are free.

AAKP Renal Flash
The second Wednesday of each month, AAKP transmits this newsletter via the Internet. It provides valuable information to patients, family members and professionals about living with kidney disease, legislative information and AAKP activities.

Kidney Transplant Today
Transmitted the first Tuesday of each month, this electronic newsletter is devoted to those interested in learning about kidney transplantation or have already received a transplant. It features news on transplants, advances in medications, research, programs about transplants and much more.

Kidney Beginnings: The Electronic Newsletter
The first Thursday of the month, AAKP electronically tr ansmits this newsletter for those with CKD or approaching kidney failure. It features news on kidney disease, treatments, research, programs and much more.

www.aakp.org
AAKP's Web site, located at www.aakp.org, displays many of AAKP's materials and brochures. The site is also linked to more than 400 sites, allowing for easy access to topics of interest for renal patients.

Chapters
AAKP has chapters throughout the country to provide a local resource for kidney patients. These chapters function as support groups to serve patients in their communities.

AAKP Hemodialysis Advisory
This brochure discusses the importance of enough dialysis, how to calculate URR and Kt/V, the importance of proper nutrition, how blood should be drawn and questions patients should ask their doctor about dialysis.

AAKP Peritoneal Dialysis Advisory
This brochure discusses the importance of enough dialysis, the significance of proper nutrition, how often residual function and peritoneal membrane functions should be measured, benefits of a well-functioning catheter and questions patients should ask their doctor about dialysis.

Understanding Your Hemodialysis Access Options
This 16-page brochure outlines various access devices available for patients on hemodialysis. It offers a brief description of arteriovenous fistulas, grafts, catheters and subcutaneous access devices, as well as benefits and drawbacks of each. In addition, it includes a brief section on how to properly care for each access device.

Understanding Your Hemodialysis Options
This 16-page brochure provides a description of hemodialysis treatments, including conventional, short daily and nocturnal. This brochure offers a detailed explanation of physical, emotional and social aspects associated with each treatment and includes the benefits and drawbacks for various treatment options.

Understanding Your Peritoneal Dialysis Options
This brochure describes methods of peritoneal dialysis and the benefits and drawbacks of each type of treatment. It also includes a 10-question self-assessment quiz for patients to take to their physician to help assess whether they may or may not be good candidates for peritoneal dialysis.

AAKP Nutrition Counter: A Reference For The Kidney Patient
Included in this 24-page, pocket-sized brochure are nutritional values for more than 300 commonly used foods, as well as menu items from 11 fast food restaurants. Nutritional values include protein, calorie, sodium, potassium and phosphorus levels.

AAKP has numerous articles from past magazines available, which address such topics as diet, transplantation, social issues, family matters and much more. Please contact the National Office at (800) 749-2257 or info@aakp.org to request a complimentary copy of any of our brochures and articles or to inquire about a specific topic of interest. AAKP's Web site also displays useful information for the renal patient.

AAKP PATIENT PLAN©

PHASE 1: DIAGNOSIS TO TREATMENT CHOICE

Since you first heard the words "end-stage renal disease" (ESRD) and "kidney failure," you have probably been wondering what happens now… this is a typical reaction. Everyone facing kidney disease has concerns and questions about the future. The future may seem uncertain and dreams and plans changed. But there is help available.

The American Association of Kidney Patients (AAKP) is here to be your guide. As the only national organization directed by kidney patients for kidney patients, we are in a unique position to understand the needs and concerns of kidney patients. It is our mission to help fellow kidney patients and their families deal with the physical, emotional and social impacts of kidney disease. We want to help you achieve the best possible quality of health and quality of life.

As ESRD patients, we have already taken the journey you are about to take. We think the knowledge and experience we have gained along the way can be of great value to you and your family. This is why we developed the AAKP Patient Plan©.

The AAKP Patient Plan© can be thought of as a road map or travel guide. But it is also much more. The series of books will tell you what to expect, what your needs will be, who will help you, what you need to know and how to make your journey a success.

The AAKP Patient Plan© is designed to address questions and concerns at the various phases of the disease process. We have divided the plan into phases to guide you through the treatment process. The phases include:

Phase 1: Diagnosis to Treatment Choice
Phase 2: Access and Initiation
Phase 3: Stabilization
Phase 4: Ongoing Treatment

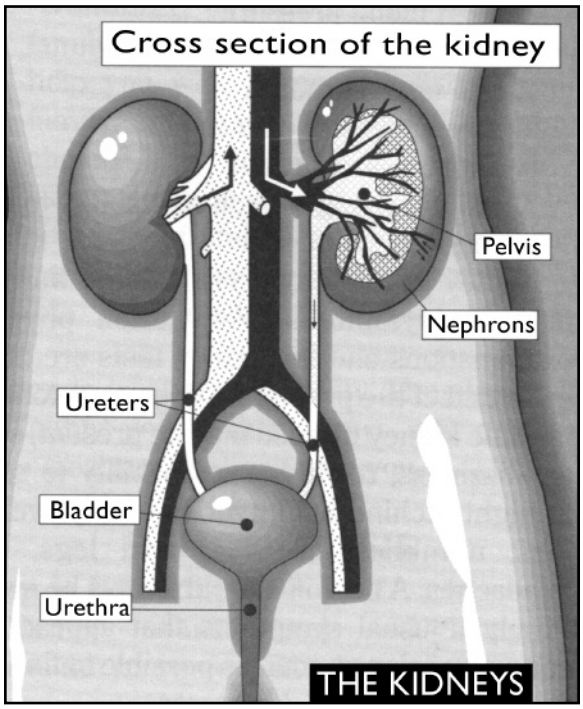
During each of these phases you can keep control of your life by staying active and learning as much as you can about the disease and treatment. Being told you have a chronic illness changes your life. As fellow patients, we know that learning what to expect and what your options are will help you to be less afraid and more hopeful. The more you know, the better able you are to make choices that are best for you and your family.

A Friendly Note: Throughout this book, you'll see my comments. I'm here to remind you that you're not alone in this journey. You have a support team of healthcare professionals, family and friends – consider AAKP one of your friends. Also, speaking from experience, it helps to know you're not the first person to go through this.

Change can sometimes be overwhelming. As you learn about your condition and take an active part in your healthcare, you'll begin to feel in control. In this phase, you'll learn the basics of kidney disease, your treatment choices and medications. Definitions to underlined words can be found in the glossary. You'll also learn how to talk with the many medical people who will now be part of your life, and how kidney disease will fit into your life. There's a lot to learn in a short time! Each of the pieces of this adjustment will be broken into parts so you can read it at your own speed and choose the information that's most important to you now. There's also plenty of room to write your comments, notes and questions in the margins. We encourage you to use this as your own tool for your healthcare. Watch for the "Friendly Note" key that gives you helpful hints. One patient described this phase as similar to when you're on a road trip and your car is getting close to empty. You start to look at the road map and street signs to find a gas station when you need it. The AAKP Patient Plan© can be your road map as you start your journey with end-stage renal disease. Remember, you're not on this trip alone; there are many people who will help you along the way.

– KIDNEY FUNCTION AND FAILURE –

What Are The Kidneys And What Do They Do?



Picture provided by Godfrey Jones for Network 8, Inc.

Kidneys are like a 24-hour cleaning machine for your blood. Kidneys are twin organs shaped like kidney beans. They're located below the rib cage in the middle of your back. In adults, each kidney is about the size of a closed fist. The kidneys are attached to your bladder by tubes called ureters. These tubes carry urine from the kidney to the bladder. The kidneys filter your blood and form urine. The bladder holds the urine until your body gets rid of it when you urinate. Each day, the kidneys pump about 200 quarts of blood through 140 miles of tubes and millions of filters. Though most people are born with two kidneys, some are born with one kidney and lead normal lives. People can live a normal life with as little as 20 percent of their total kidney function.

Most people don't know all of the things kidneys do to keep them alive and healthy until something goes wrong. The kidneys:

- **Remove waste products from the blood.** As your body works, it builds up waste products that need to be removed. The kidneys are the "garbage collectors" that remove the waste from your body in the form of urine.
- **Remove extra fluid.** Kidneys get rid of the extra water in your body.
- **Adjust levels of minerals and other chemicals.** Kidneys balance important minerals and chemicals in your body like sodium, potassium, calcium and phosphorus.
- **Produce hormones.** Kidneys make hormones that help control your blood pressure. They also help to make red blood cells that carry oxygen to your whole body.

Why Did My Kidneys Fail?

When the kidneys stop working they can no longer keep the body healthy. This means they can't remove the wastes or extra fluid from your body. Because the wastes and extra fluid have nowhere to go, they build up and can cause you to feel sick. When the kidneys stop working, this is called kidney failure. There are two kinds of kidney failure:

- **Acute Renal Failure** usually happens quickly and can be temporary. The kidneys can stop working due to such things as the loss of blood, a severe burn, infections, medications or certain types of poisoning. Dialysis may be needed for a short time while the kidneys heal. With acute renal failure, normal kidney function can return after the kidneys heal from the injury.

- **Chronic Kidney Disease (CKD)** can happen slowly and is usually caused by damage to your kidneys in the form of a disease. **End-Stage Renal Disease (ESRD)** occurs when the kidneys no longer work. In ESRD, normal kidney function doesn't return. Therefore, you will need dialysis or a kidney transplant in order to stay alive.

There are many reasons why kidneys fail. Different diseases can cause ESRD. Some kidney diseases are inherited, while others are caused by pre-existing health conditions. Some causes of kidney disease include:

- **Diabetes** is a disease of high blood glucose (sugar) levels. It can cause changes in the structure and function of blood vessels and abnormal metabolism of carbohydrates, fat and protein. Over time, the small vessels of the kidney are affected, causing destruction of the nephrons (the filters of the kidneys).

- **Hypertension** or **High Blood Pressure** damages the blood vessels in the kidneys and reduces the blood supply to the kidneys. If you control it, you may be able to slow down the kidney damage.

- **Glomerulonephritis** is a swelling of the filters of both kidneys. This is sometimes due to infection. It involves slow, progressive damage. Early diagnosis is difficult because there are no symptoms in the early stages of this disease.

- **Nephrotic Syndrome** is a non-inflammatory disease. It causes amounts of protein to pass from the blood into the urine. As a result of the loss of protein, large amounts of water stay in your body. This results in overall swelling in your body, called edema.

- **Polycystic Kidney Disease** is an inherited disease. With this disease, abnormal sacs, called cysts, develop in the kidneys. These cysts may contain fluid, gas or tissue. As these cysts grow, they block normal kidney function. Cysts may be painful because of the blockages. If you have polycystic kidney disease you still urinate in normal amounts, but the harmful waste products aren't removed from the body.

- **Systemic Lupus Erythematosus** causes swelling in all organs in the body, including the kidneys.

- **Chronic Pyleonephritis** or **Kidney Infection** is an inflammation of the tissues of the kidneys, surrounding the filters. Infection and other forms of inflammation can cause kidney failure, if left untreated.

- **Kidney Stones** can form anywhere in the urinary tract. The stones may cause painful or pain-free blockages in the drainage system of the kidney. When this happens, the kidneys can be damaged due to the pressure of urine backup or infections.

What Is The Difference Between Pre-ESRD And ESRD?

Pre-ESRD, or chronic kidney disease (CKD), is the time between the diagnosis of a kidney disease until the time you begin treatment with either dialysis or a transplant. It may be a brief period lasting only a few weeks, or it may be months or even years. During this stage you might visit a kidney doctor (nephrologist). Your nephrologist will monitor your condition. His goal is to treat you in order to help your kidneys work as long as possible. Your nephrologist can give you the best information on how long it may be before you need dialysis or a transplant. Once you begin dialysis, you should see your nephrologist on a monthly basis.

Your doctor may prescribe certain things to help your body adjust to the slowing down of your kidney function.

A Friendly Note: Remember, the pre-ESRD phase is when your kidneys are beginning to shut down. This means certain waste products and fluids may build up in your body. I got high blood pressure when my kidneys started to fail. This may also happen to you. Don't worry; your doctor will prescribe medicines, dietary changes and certain blood and urine tests to check your kidneys.

ESRD is permanent kidney failure. Once you reach this point, you will need to begin treatment with dialysis or receive a transplant in order to live.

What Are The Symptoms And Signs Of Chronic Kidney Disease?

Here are some symptoms you may experience when your kidneys don't work properly:

- A change in how often you urinate
- Edema – swelling of the face, feet, belly and other areas
- High blood pressure
- Loss of appetite or nausea
- Bad taste in your mouth, often described as ammonia smelling
- Feeling tired or weak
- Mental changes such as an inability to concentrate, confusion
- Headaches

Keep in mind that you might not have any of these symptoms and still have kidney failure. Once you start dialysis, many of these symptoms will stop. You'll begin to feel better and more like yourself after several treatments.

How Do I Deal With All These Emotions?

A Friendly Note: I'm not telling you this to scare you, only to help you understand what is happening to you. Your kidney failure is going to cause a few changes in your life. Everyone reacts a little differently in how they respond to kidney failure. You may find these changes challenging or you may adjust easily. It's important to remember that the lifestyle changes you make affect not only you, but also your family, friends and co-workers. These changes may include diet restrictions, new medications and treatment schedules. You'll learn to deal with anxieties, fears and physical changes. Although these changes may seem hard, with time and support, you can make the transition. For me, it was very helpful to talk to those around me about my feelings and concerns. I also learned that it's important to listen to their feelings too. They're adapting to things as well. It also helped to talk to others with ESRD who were further into the process. I found that others had similar concerns and struggles. With patience, understanding and flexibility, you can learn to cope with the physical and emotional changes taking place – I did.

Your healthcare team (nurses, social workers, doctors, dietitians and others) is available to answer questions. They'll also listen and respond to your feelings. Talking about your feelings or concerns is often the first step toward helping you and/or your family better understand what you're experiencing. Don't be afraid to ask questions of your healthcare team. There are no dumb questions! If you don't understand an answer, ask again and again until you do. It's difficult to adapt to your newly diagnosed condition when feelings of sadness, anger, frustration or fear are held inside of you. Talking about these feelings with healthcare professionals, family and/or friends is one of the most helpful things you can do.

Depression and anxiety are two common feelings you may experience. These feelings are normal when a person suffers a loss or illness like kidney failure. Sadness, anger, loss of appetite, trouble sleeping, lack of interest in sex or daily living can be signs that you're feeling depressed. Anxiety can cause feelings of uneasiness or fear. It may also cause physical signs like a fast pulse rate, tiredness, irritability, excessive sweating and nervousness.
Your feelings may change. Just because you feel one way today, doesn't mean you'll feel the same way tomorrow. There are several phases you may go through in adapting to renal disease, including: sadness and grief, anger, despair and isolation. Your family and friends may also have similar feelings.

A Friendly Note: While you may not feel all of the emotions listed in this section, it's still important to know about them. It helped me to understand that what I was feeling was normal.

- **Sadness** and **grief** are normal reactions when you learn you're losing kidney function. Grief is a common way people respond to loss.

- **Anger** is a normal response to losing your health. You may feel angry with your doctors because they can't cure the problem. You may be mad at your family for not understanding your feelings. The anger should be worked through to avoid turning into a physical problem such as asthma, ulcers or other health conditions.

- **Fear** of the unknown is a common response. This is a time when there are a lot of unknowns about what the future holds. There's also a fear about learning how to treat ESRD. However, through education, you can overcome your fears.

- **Despair** may occur if you're overwhelmed. You may feel hopeless. You could have a lowered self-esteem, pride or sense of usefulness. Concerns about your ability to do things you enjoy can leave you in despair. This is a very normal emotion when you have major changes in your life.

- **Isolation** is when you pull back from the people you usually depend on. You may distance yourself from family and friends who want to help you. You may not want to depend on other people. You may feel people don't want to hear about your disease. Remember, your family and friends want to help you.

By talking with your family, friends, other people with kidney disease and/or medical professionals, you can begin solving problems and making adjustments that are right for you.

A Friendly Note: You're now going through a time when you realize life has changed and your activities may need to change too. You may need to scale down your activities, such as changing from long distance running to jogging through the park. It's not as bad as it may sound right now. Yes, you'll experience changes, but with education, support and your healthcare team, you can do this!

Once you have information and some time to let things sink in, you'll be able to make ESRD a part of your life. You will realize your life is different and will accept the differences. The mental and physical changes that occur during the onset of ESRD are at times overwhelming. As your treatment becomes a part of your daily life, however, you'll resume many of your normal activities. The emotional phases which people experience are normal. Treating kidney disease doesn't mean that everything goes back to how it

was before, but with the right support, treatment and determination, you can create a new balance to your life. Your dreams and goals can still be realized.

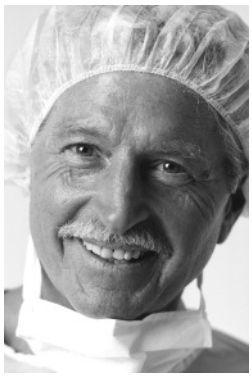
How Do I Tell My Family And Friends?

Deciding who to talk to and who to tell that you have kidney disease is an individual decision. Some people choose to tell everyone they meet. Others choose to talk with only a few select friends and family members. The first few people you tell will probably be the hardest as you struggle with the words. Most people say that it gets easier each time. If you think about what went well with the first discussions and how you would like to change part of your explanation, it will become easier.

People often ask how to tell family and friends. There are no "cookie cutter" phrases that work for everyone. Sharing the news in an honest, open and direct way is the best approach. This can be challenging. We want to protect those we love and care about. Unfortunately, when family members or friends don't know something or feel something is hidden, their imaginations often take over and they may begin to think the worst. For this reason, it's just as important to be open when explaining your ESRD with young and old alike. It's amazing what information children can understand when you take the time to explain things and answer their questions. Remember, your family and friends may experience many of the feelings you did when you found out. It's O.K. for them to feel sadness, fear, despair and isolation.

A Friendly Note: I learned early on, the more people I told about my kidney disease, the more people I'd have available to lean on for support. Whatever choice you make, it will be right for you.

– YOUR HEALTHCARE TEAM –



Many people are involved in caring for someone with ESRD. This team approach is helpful to make sure all of your needs are met. Although helpful, it can be confusing to sort out who is who and who does what. The people you'll meet are: the nephrologist, nurses, technicians, dietitian/nutritionist and the social worker. Each of these people is responsible for certain areas of your care. You, however, are the expert on you and your family. You need to be part of the team to help everyone understand what you need. You need to let the team know how ESRD affects you and your family. Working together as a team will help you to receive the treatment and care that will work best for everyone.

- **Nephrologist** - The nephrologist is a doctor who has had special training on how to treat kidney disease. Your nephrologist will work with you and the rest of the healthcare team. A plan to treat your disease and manage your health will be developed. You'll see your nephrologist on a regular basis, either at his office or at the dialysis center. Your nephrologist will monitor your health. He will make changes as needed to help you stay healthy. The nephrologist is there to answer questions you and your family may have. Take a written list of questions with you when visiting your doctor to help you remember your questions.

- **Nurses** - The experienced registered nurse (RN) is an excellent person to answer questions about your treatment choices and daily care. In addition to the registered nurse, there are many other nurses who care for you, from licensed practical nurses (LPN) to nursing aids or nursing assistants (NA). Nurses may serve as educators for predialysis or new dialysis patients. They're often the people who perform dialysis treatments or supervise technicians performing dialysis. They may also train you and your family for home dialysis. Most nurses realize that answering your questions now will make you healthier in the future. Medicare regulations require that a licensed health professional, such as a registered nurse or licensed practical nurse, be at the facility and on duty at all times when a person is on hemodialysis.

- **Technician** - Most dialysis centers have technicians who help begin and end your dialysis treatment. They monitor your vital signs during treatment. They may also maintain the machine, order the supplies and clean the dialyzer after each use. Reuse occurs in some centers. The dialyzer is cleaned after your treatment and reused for your next treatment. Although

technicians may be able to answer basic questions about the day-to-day process of dialysis, they may not be able to answer healthcare questions.

- **Dietitian** - The renal dietitian will help you make good food choices and understand your blood chemistry results. Watching what you eat and drink may be one of the hardest changes you make. A dietitian can help you make meal choices that will help keep you healthy. The dietitian can also help you make diet choices for special occasions or when you're dining out. Dietitians aren't there to police you, but to work with you to make the best choices possible.

- **Social Worker** - The social worker can provide you with a great deal of information, from financial resources to coping and support systems. There are federal regulations that require renal social workers to have a master's degree. The social worker may not always have the answer, but can link you with the right person in the clinic, hospital or community. The social worker can explain hard-to-understand information in easy-to-understand words. A social worker will often ask you questions about your lifestyle, goals, medication, insurance, transportation, family members and how they are affected by your ESRD. Social workers can help you solve problems and knock down the stumbling blocks that may keep you from making treatment a part of your life.

A Friendly Note: You're not alone. There are people who can answer your questions. Even if you're on home dialysis or peritoneal dialysis, you and your family have many people available to help guide you through this adjustment phase. Use their skills to your benefit; after all, it's your health.

How Do I Talk To My Healthcare Team?

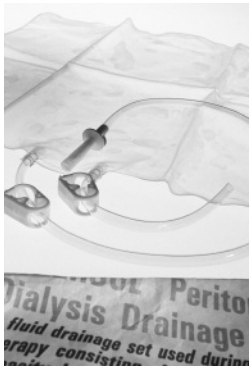
Many people find it helpful to have a notebook for writing down questions for the healthcare team. If you're like most people, you have questions that you think of at home, and then when you see the team, it's hard to remember the questions you had. A notebook can be a good way to make sure your questions are answered. If you ask someone a question and aren't satisfied with the answer, you should ask someone else. Get a second opinion. There are many organizations that can be helpful to you, which include the American Association of Kidney Patients, the National Kidney Foundation, your ESRD Network, etc. (See the appendix on page 41 for a list of helpful organizations)

Another way to receive information is to ask to be included in any meetings about your treatment. At least twice a year, your healthcare team meets to talk about your care and plan for your future care. You have the right to participate

in the planning of your medical treatment. The more information you have about your healthcare, the more power and control you have over your disease and treatment.

A Friendly Note: You have the right to get information in a way that's easy to understand. There should be a shared respect between you and the rest of your healthcare team. It's like the old saying: "treat others as you would like to be treated."

– TREATMENT OPTIONS –



In this section, we will discuss the various treatment options and what each option means for you. Before you make a decision about what type of treatment you want, discuss the options with your nephrologist. Not every treatment will work for every person. There are many factors that determine which treatment option is best for you. You and your nephrologist will need to look at your type of kidney disease, how far you live from a dialysis center, your physical abilities and your support system, along with your lifestyle and emotional state. If you choose one type of treatment now, it doesn't mean that you can't move to another type in the future. In fact, there may be times when you have to change treatment types for medical reasons. In any event, it's helpful to discuss the pros and cons of each treatment choice.

A Friendly Note: I've always been the type of person who asks a lot of questions when making decisions. Now, I was deciding what type of treatment I wanted. I had hundreds of questions rolling around in my mind. I asked every one of my questions. We don't always hear information the first time. So, don't worry if you need to ask for information to be repeated. This is your health and your decision; do what's best for you.

What Are The Available Treatment Options?

There are three types of treatment for kidney failure. The options are: hemodialysis, peritoneal dialysis and transplantation. Dialysis is a medical word that means cleaning the blood by artificial means. During dialysis, wastes and extra fluid that build up with kidney failure are removed from the blood.

A person can receive a kidney transplant from another person (a donor) through surgery. The kidney is placed in your abdomen. The transplanted kidney will do the work your old kidneys did.

A Friendly Note: Many people think a transplant is a cure. This is not true. Transplantation is not a cure; it's a treatment option. It's important to realize your body can reject the kidney soon after the transplant, or even weeks, months or years later.

What Happens If I Don't Choose Treatment?

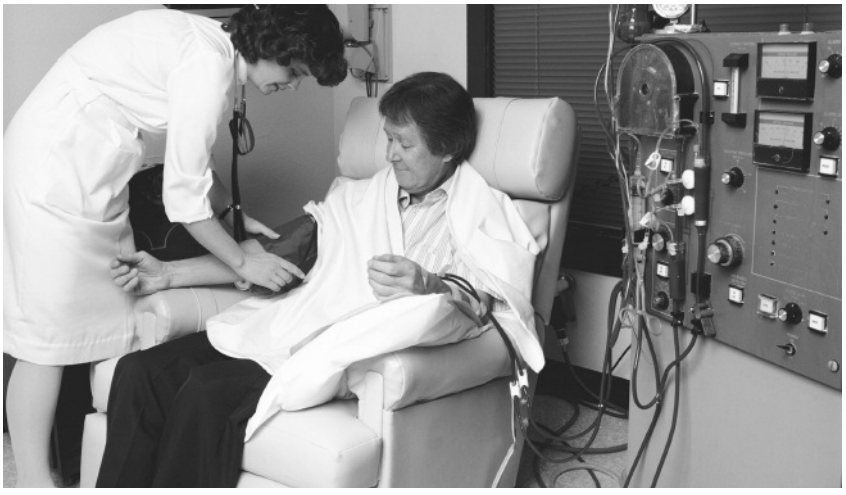
There are some people who choose either no treatment or decide to stop treatment. You must understand that if you don't choose a treatment option, you'll die. As your kidneys have been failing, there have been toxins building up in your body that have left you feeling ill. Most doctors will encourage you to

begin treatment for a few months in order to see if you feel better with treatment. You and your healthcare team can talk about your wishes if you choose to stop treatment at any time. They will help you understand what it means and what to expect once treatment is stopped.

What Is Hemodialysis?

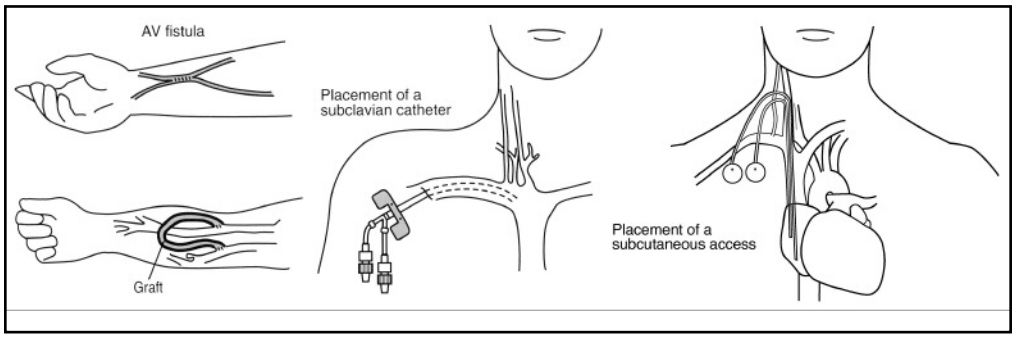
Hemodialysis is the most commonly used method for treating ESRD. Hemodialysis is a way to clean your blood using a dialysis machine. This machine has a special filter called a dialyzer. The dialyzer works as an artificial kidney. It strains the toxins and removes extra fluid that builds up when your kidneys aren't working. The artificial kidney doesn't completely replace your original kidneys' function. Remember, your kidneys worked 24 hours a day, seven days a week. Hemodialysis takes a few hours a day, a few days a week. During a dialysis treatment, your blood is carried through plastic tubes to the dialyzer to be cleaned. Once your blood is cleaned, it's returned from the dialyzer to your body through another plastic tube. It might look like there's a lot of blood outside of your body. Actually, there's only about one cup of blood in the tubing and dialyzer at any time during a treatment. Hemodialysis is usually done three times per week. Each treatment is usually four hours in length. However, as you learn later on, there are different ways to do hemodialysis. Your nephrologist prescribes the length of your treatment. The time depends on your body size, laboratory results and medical condition.

Most people do best and stay healthy when they follow the renal diet, take prescribed medications and spend the prescribed time on dialysis. There are certain guidelines and standards you can learn about. These help you to know you're receiving optimal dialysis. Phase 3 of the AAKP Patient Plan© explains these guidelines further. You should expect and demand that guidelines be met. It's to your benefit for long-term good health.



What Is A Hemodialysis Access And How Does It Work?

Before hemodialysis can begin, you need to have a way to safely remove and return the blood to your body. Your veins aren't strong enough or big enough to run your blood through the dialyzer. To prepare for dialysis, you will need surgery to create an access.



There are four types of accesses: a fistula, graft, catheter or subcuteneous device.

A fistula, or arteriovenous fistula, is created by directly connecting an artery and a vein. Studies show that a fistula produces the best results for dialysis.

A graft, or arteriovenous graft, is created by connecting an artery and vein with an artificial tube.

A catheter is inserted into a vein in the neck or chest to allow temporary hemodialysis until the fistula is healed and ready for use. Subcutaneous (under the skin) devices are made of small metallic devices, which are usually implanted in the upper chest area. These devices are connected to two hollow, flexible catheters that are connected to large veins in the central nervous system. Guidelines recommend that the catheters and subcutaneous devices only be used on a temporary basis.

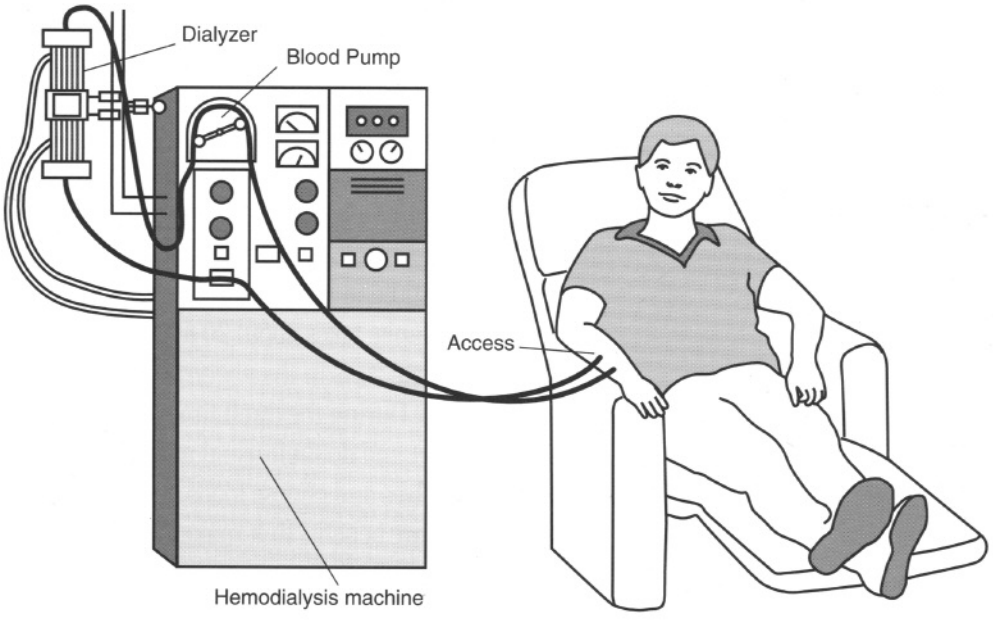
Your access site is often referred to as your "lifeline." Though most often found in the arm, your access can also be placed in your leg. It's important to care for it properly. This ensures that your dialysis treatments can go on as scheduled. Each time you have a treatment, your access should be checked for blood flow problems and early signs of infection. Signs of adequate blood flow are when there's a buzzing or rushing feeling and a pulse can be felt in your access. If these signs aren't in place, call your nephrologist and dialysis unit immediately. Clotting and infection are easier to treat when they're found early. Early signs of infection include redness, swelling or warmth to the touch. Keep your access clean and dry between treatments.

Before needles are placed in your access site, wash your access. Anyone placing the needles into your access should wash their hands and put on gloves. To keep your access working properly, avoid wearing tight clothes or jewelry on your access and avoid sleeping on that arm or leg. Be careful not to bump or cut your access. Do not let anyone take your blood pressure, draw blood or put an IV into the arm or leg that has your access site. Catching access problems early can make them much easier to treat. If you're unsure about the condition of your access, call your nephrologist or dialysis center.

For further information about hemodialysis access, call AAKP and request "Understanding Your Hemodialysis Access Options."

How Does Hemodialysis Work?

During each dialysis treatment, two needles are put into your fistula or graft. Each needle is connected to a hollow plastic tube. One line takes the dirty blood out of your body. Once your blood is clean, the other tube carries the clean blood back to your body. Each dialysis machine has many gauges and alarms. You may find this overwhelming at first. The machine makes sure that your treatment is safe by monitoring your blood pressure, how quickly your blood moves through the tubing and how much water is removed. You may find comfort in touring a dialysis center before your first treatment. Call the facility to make an appointment in which you can meet staff and possibly patients. Feel free to bring along family or friends to ask questions and become comfortable with the dialysis machine and treatment. Remember, you can never ask too many questions. If you're armed with information,



you'll feel more comfortable and in control.
Hemodialysis can be done at an outpatient dialysis clinic or in your home. Hemodialysis is normally done three days a week for four to four and a half hours. In an outpatient dialysis center, nurses and technicians who have special training place the needles and tubing and monitor the machines. Home dialysis requires you and a partner to complete a training course. The training will prepare you both to understand the dialysis machine. You'll learn how to safely perform each step of a dialysis treatment at home. Types of home hemodialysis include short daily (typically for a few hours each day), nocturnal (typically for several hours while you sleep) and conventional (typically three times a week for about four hours each time). For information on types of home hemodialysis, call AAKP at (800) 749-2257 and request "Understanding Your Hemodialysis Options." Not all facilities offer home hemodialysis as an option. When choosing a nephrologist, you should ask if this is a choice. When dialysis is done at home, your equipment and supplies are delivered to you. Many people expect a mail package delivery of supplies and are surprised to find a semi-truck pull up in front of their home to deliver the needed equipment and supplies.

In order to make a decision about the best treatment for you, it's important to know both the "good" things (the pros) and "not so good" things (the cons) about hemodialysis treatments in your home and in an out-patient center.

IN-CENTER HEMODIALYSIS	
PROS	CONS
• You have trained professionals with you at all times. • Medical help is available quickly if there's an emergency. • You can interact with other people who are on dialysis. • You don't have to care for and store a machine. • Your treatments are usually three times per week.	• Staff who aren't familiar with you may be working with you. • You must follow the rules of the dialysis center. For example: number of visitors or eating restrictions during treatment. • Your treatments are scheduled by the dialysis center. • You're required to travel to and from the dialysis center three times per week.

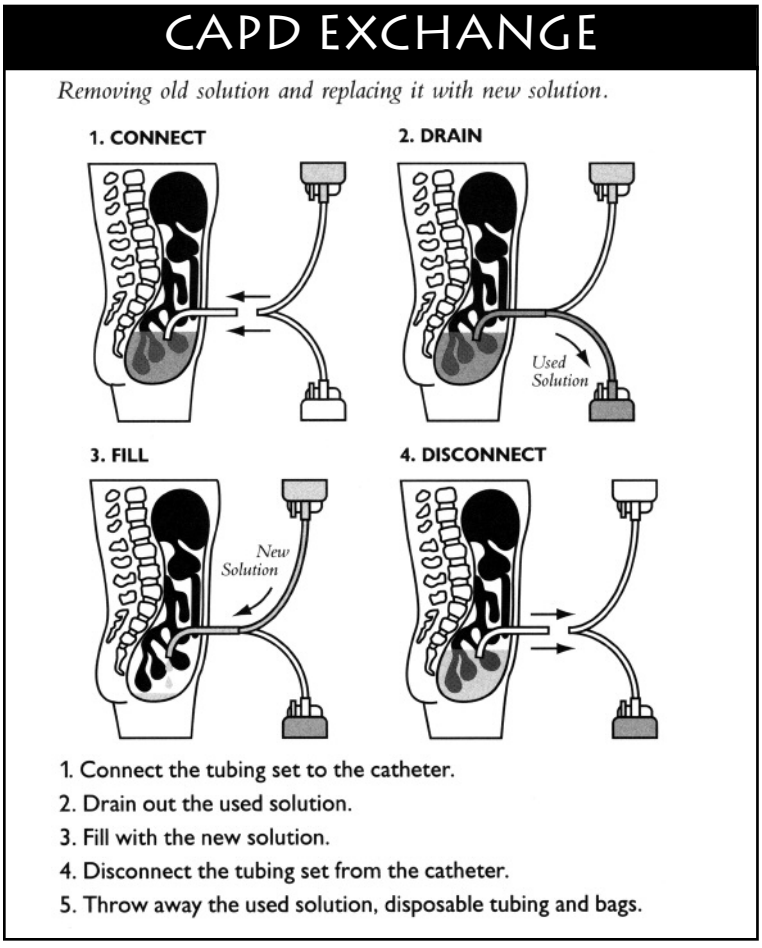
HOME HEMODIALYSIS	
PROS	CONS
• The same person helps you with your treatment each time. • You decide if you want to have visitors or if you want to eat. • You decide when you want to dialyze, within the number of hours and days ordered by your doctor. • You don't have to travel to and from a dialysis center. • You have more control over your treatment and life, which allows you more independence. • You have access via the phone (or a clinic appointment) to a nurse, dietitian and social worker to answer questions or to solve problems you may have with the dialysis treatment.	• You and your partner will need to be trained for several weeks for home hemodialysis. • You'll need to have room to store the machine and supplies. • You and your treatment partner will learn to "troubleshoot" emergencies, but you'll need to call paramedics for medical help if you have an emergency. • You'll have less chance of meeting and talking with other people on dialysis. For many people, it's helpful to talk with other people in the same situation. • May cause stress for your family.

A Friendly Note: As with any decision you make in life, you need to weigh the pros and cons. This will help you make a decision that's best for you and your family. Don't be overwhelmed by this chart or the other charts listed later. The more information you gather, the easier your decision will be to choose what's best for you. To learn more about additional forms of hemodialysis, request AAKP's brochure "Understanding Your Hemodialysis Options."

What Is Peritoneal Dialysis?

Peritoneal dialysis also cleans the blood like hemodialysis but in a different way. It doesn't use an artificial kidney or dialyzer. Peritoneal dialysis (or PD) uses a space in your belly called the peritoneal cavity. Your abdominal cavity (belly) is lined with a membrane called the peritoneum. This membrane surrounds your intestines, bowel and other organs. Although this lining is there to help protect your organs, it has many little holes that can be used to strain waste products and other chemicals from your blood. Just like the dialyzer in hemodialysis, PD keeps the good things, like your blood cells and proteins, and gets rid of the bad things called toxins.

The way peritoneal dialysis works is that your peritoneal cavity is filled with a germ free liquid called dialysate. This liquid sits in your peritoneal cavity while waste products and fluids move from your blood through the peritoneal membrane. Remember, this membrane acts like a strainer. It keeps the good things in your body and only lets the toxins and extra fluid go through. The dialysate, along with the toxins and extra fluid, are then drained out of your body. The peritoneal cavity is then refilled with the clean dialysate and the process begins again. Each time the dialysate is drained and refilled, it's called an exchange. The number of times you exchange fluid depends on which type of peritoneal dialysis you choose and on your prescription.



What Is A Peritoneal Access And How Does It Work?

Before you can begin peritoneal dialysis, you need to have a way to safely put clean dialysis fluid into the peritoneal cavity and remove the dirty fluid. In order to make this happen, a soft, flexible tube, called a catheter, is surgically placed into your abdomen. The bottom part of the catheter is put into the peritoneal cavity. The middle part of the tube runs under the skin of your

abdomen. The top part (which is about 3-4 inches long) stays outside of your abdomen. The part that stays outside of your body can be taped flat against your skin. It takes anywhere from two to four weeks for your surgery to heal. During this time, you must keep the catheter clean and dry. Once your site is healed, showers are better to take than baths. If you take a bath, you're exposing your catheter to germs that have washed off your body. For similar reasons, you should not swim in lakes, rivers, ponds, pools or spas. Your nephrologist, however, may tell you ways in which you may swim in the ocean or clean, private, chlorinated swimming pools. Daily catheter care includes keeping your exit site clean and dry and securing the catheter to your abdomen.

Preventing infection is especially important. When germs get into your peritoneal cavity, they can cause an infection. This infection is called peritonitis. Peritonitis will make you feel sick with stomach pain and a fever. Most germs and infections can be treated with antibiotics, but there are some that are very hard to treat. Each time you have peritonitis, it can scar your peritoneal membrane. The more scarring you have, the more difficult it is for your peritoneal membrane to strain waste products and water. If the peritoneal membrane becomes too scarred, you may have to change to hemodialysis in order to get adequate dialysis.

How Does Peritoneal Dialysis Work?

There are two types of peritoneal dialysis. One is Continuous Ambulatory Peritoneal Dialysis (CAPD) and the other is Continuous Cycling Peritoneal Dialysis (CCPD). Your doctor will look at your body size, lifestyle, lab tests and your ability to do the dialysis steps. She will talk with you about which kind of peritoneal dialysis may work best for you. Both types of peritoneal dialysis are continuous. They give you around the clock treatment, which is how healthy kidneys work. This means your diet may be less restricted.

Continuous Ambulatory Peritoneal Dialysis (CAPD) is the most common type of peritoneal dialysis. It can be done in any place that's clean and well lit. Exchanges are usually done every four to six hours during the day. The only equipment you need is a bag full of dialysate fluid and the plastic tubing that comes attached to the bag. CAPD uses gravity to drain and fill the abdomen with dialysate. You connect the dialysate bag and tubing to your catheter. The dialysate bag is hung above your head on a hook or pole. This bag remains clamped until later. The solution that has been sitting (dwelling) in your peritoneal cavity is drained out through tubing connected to an empty bag on the floor. That bag fills with your body's toxins and fluid collected in the dialysate solution. When you finish draining, the bottom tubing is clamped and you open the clamp on the tubing attached to the clean dialysate

CONTINUOUS AMBULATORY PERITONEAL DIALYSIS (CAPD)

PROS	CONS
•Can be done in many locations, which makes it easier to travel. •No needles. •The schedule can be more flexible. •You may have fewer fluid and diet restrictions than on hemodialysis. •No machine is needed. •Training is easier than home hemodialysis. •Increased independence.	•Treatments are every 4-6 hours every day. •Not all facilities offer CAPD. •Your abdomen is always full of fluid, which may increase the size of your belly. •You have a catheter in your abdomen. •Everything must be very clean during the exchanges. •Increased risk of infection either in the peritoneal cavity or at the site of your catheter. •Storage of supplies.

CONTINUOUS CYCLING PERITONEAL DIALYSIS (CCPD)

PROS	CONS
• You can go about your daily routine. • You don't need a partner like home hemodialysis. • Training is easier than home hemodialysis. • Dialysis is usually done while you sleep. • You may have fewer fluid and diet restrictions than on hemodialysis. • No needles are needed. • You can easily switch to CAPD when you're traveling.	• A machine is needed. • You may have to do an exchange during the day. • You may be awakened during the night by the machine's noises. • You have a catheter in your abdomen. • Everything must be very clean during the exchanges. • Increased risk of infection either in the peritoneal cavity or at the site of your catheter. • Storage of supplies.

bag. The dialysate flows into the peritoneal cavity by elevating the bag above your head and letting the fluid drain in by gravity. Once you have filled your peritoneal cavity with clean dialysate, you can detach the tubing, and empty the used dialysate into the toilet. The clean fluid sits in the peritoneal cavity for about four to six hours. During this time you're free to go about your regular activities. Each exchange takes about 30 minutes to complete. Most people begin their exchanges in the morning and then end their day with one just before bedtime.

Continuous Cycling Peritoneal Dialysis (CCPD), sometimes called Automated Peritoneal Dialysis (APD), is done at home with a machine called a cycler. This is done at night while you sleep. The catheter is connected to the cycler machine. For eight to ten hours each night the machine fills and drains the dialysate from the peritoneal cavity. The machine keeps repeating this process throughout the night. In the morning, clean dialysate is left in the peritoneal cavity after you disconnect from the machine. One or two manual exchanges may be prescribed during the day.

A Friendly Note: Just like hemodialysis, peritoneal dialysis has both pros and cons. You'll need to look at both to see if peritoneal dialysis suits your lifestyle best (on previous page). This information is given to you so you and your family can make a decision that's best for your overall health and well-being.

What Is Transplantation?

Many people view a kidney transplant as a cure, but it's simply another treatment option. When a kidney from another person is put into someone whose kidneys are no longer working, it's called a kidney transplant. Usually one kidney is put in during a transplant. One healthy transplanted kidney can do the work of two. The transplant involves an operation, which usually takes about three hours. Once you have the transplant operation, you'll take medications as long as you have a working transplant. These medicines help your body accept the kidney and are called anti-rejection medicines.

A Friendly Note: Anti-rejection medicines have some side effects, but they're usually manageable. Some of the most common side effects are high blood pressure, a decrease in your body's immune system, weight gain, raised cholesterol, ulcers, facial hair, stretch marks, fullness in your face and changes in skin tone and color. However, just because these are common side effects, it doesn't mean you'll have all or any of them.

Before you can have a transplant, you must be evaluated by a transplant center. Though you must be diagnosed with ESRD, it is not necessary to be on

dialysis to be eligible for a transplant. Doctors, nurses and social workers will talk with you and give you medical examinations to help decide if a transplant will work for you. They will also look at how well you currently follow your dialysis and/or medication schedule. In addition, they will link you to financial programs that may help you pay for the anti-rejection medications. They also look at your blood type and tissue make-up. The closer they match the new kidney in blood type and tissue to yours, the better the chance the new kidney will be accepted into your body and begin working.

A Friendly Note: Transplantation also has both pros and cons. Read this list carefully to see if this is the best choice for you. However, not everyone can have a transplant. You may have medical conditions or health problems that prevent you from choosing a transplant. Remember, you can always talk to your healthcare team. They can tell you why a transplant may or may not be best for you.

TRANSPLANT	
PROS	CONS
• You may feel healthier and have more energy than on dialysis. • Frees you from dialysis. • Fewer fluid and diet restrictions than on dialysis. • Improved feeling of well being and feeling "normal." • You're able to work full time without having to worry about your dialysis schedule.	• Transplant requires major surgery. • You may have to wait for a kidney. • Side effects from medications. • Risk of infections. • Changes in how you look. • Cost of the medicines. • You have to take daily medications to avoid rejection. • Your transplant may not last a lifetime.

What Are The Different Types Of Transplants?

There are three kinds of kidney transplants. They are living-related, living non-related and cadaver. Each of these types of transplants has the chance to work as long as the blood and tissue type match.

- A living related donor is a blood relative who agrees to give you one of his or her kidneys. It's important to remember just because you're related doesn't mean you will be a match. Blood and tissue type are tested to determine if the kidney is a good match for you.

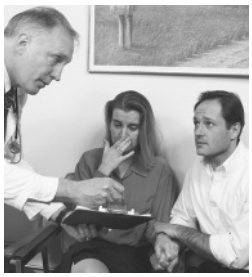
- A living non-related donor is a person who isn't related to you. The person is tested for blood and tissue type. If the person is a match, he may donate a kidney to you. The donor can be a friend, spouse or co-worker who agrees to this donation. During the last several years, this has become a more common type of transplant.

- Cadaver (non-living) donors are those people who have recently died. The individual or their family has made the decision to donate their organs (such as lungs, heart, liver and kidneys) for others to use. This is the most common type of transplant today. With a cadaveric transplant, your name is put on a national list. When a kidney becomes available, your blood and tissue type are compared to the cadaver kidney. Finding just the right kidney may take a short time or several years.

With each of the three types of kidney transplants, there will probably be an option that's best for you. You can talk to your nephrologist and the transplant center team. They can help you determine what options are available to you. As most people choose the cadaver donor transplant, there's a long list of people who are waiting for kidneys. The wait for each person is different depending on the blood and tissue type of both you and the donor.

During the transplant operation, the new kidney is usually put into the front of your body near your hip. Unless your old kidneys are causing you high blood pressure or are infected, they're not removed. Once the operation is done, your new kidney may not begin working for a few days or a few weeks. You may need to have dialysis until your new kidney starts working. Once it works, you'll no longer need dialysis. If the kidney doesn't work, you'll need to return to or remain on dialysis.

- YOUR RIGHTS AND RESPONSIBILITIES -



There are some basic rights and responsibilities you have as a person with ESRD. You should receive a copy of your rights and responsibilities when you enter a dialysis unit. If you do not receive one, ask for it. This will tell you what to expect from your healthcare team and what they expect from you. There are some rights that are common among all units.

What Rights Do I Have?

You have the right to be told about:

- Your rights and responsibilities.
- Your medical condition in a way that's easy for you to understand.
- The treatment options available to you.
- The rules of the medical facility, such as visitors, eating etc.
- The services available at the facility.
- The process of dialysis including dialyzer reuse.
- What expenses will be billed to you if they're not covered by insurance or Medicare.

You also have the right to:

- Be seen by the entire healthcare team to plan your treatment.
- Based upon availability, receive treatment at the facility of your choice, providing they have space and you meet the medical, legal and insurance requirements of that facility.
- Decide if you want to be part of any research studies.
- Receive dialysis at a time that allows you to work at your job or attend school, if possible.
- Decide to accept or refuse any treatment or medicine that has been prescribed for you.
- Be told about advance directives.

Above all, you have the right to be treated with respect. You are an individual. This means that you have unique needs. Your treatment will affect you and your family in a unique way. You also have the right to privacy. Your medical condition and treatment must be kept confidential, unless you say differently. Your medical records can't be shared with anyone without your knowledge and permission.

What Responsibilities Do I Have?

Along with your rights, there are certain responsibilities you have as a patient. You have the right to refuse medical treatments or medicines that have been prescribed. However, you then have the responsibility to tell your healthcare team if you choose to decline treatment or medications. They may

be able to work with you to come up with a plan you can follow. You have the responsibility to let people know if you don't understand your medical condition or treatment plan.

In addition, you have the responsibility to:

- Arrive on time for your treatments or clinic visits.
- Let people know if you're going to be late or miss a treatment or appointment.
- Treat patients and staff as you would like to be treated with respect and consideration.
- Inform staff if you have medical problems.
- Follow the rules of the unit.
- Arrange transportation to and from treatment. There are people in your treatment facility who can help you with this.

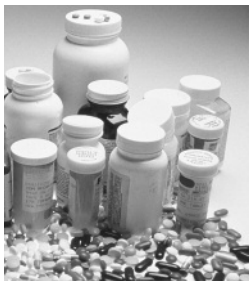
How Can I Keep Track Of My Progress?

To keep yourself as healthy as you can be, it's important to understand your treatments, their effect and how that affects your health. As we suggested earlier, many people find it helpful to keep a notebook with them to write down questions they have. Sometimes when there's so much to learn, it's hard to know what questions to ask. Remember when you were in school and you had to keep notes on all the information you learned? Having kidney disease is a learning process too. (See page 47 for a list of questions that many people have. You can use this list to check off the questions you would like to have answered.)

Many people find it helpful to have a list of phone numbers and medications posted by the phone and on the inside of their notebook. (See page 48 and 49 for charts you can use.) In addition, the notebook is a good place to keep track of medical records. This notebook is also a great place to keep track of how you're feeling and what you're experiencing.

A Friendly Note: After I'd been on hemodialysis for a while, I was amazed when I looked back and saw how far I'd come. I was so proud of my ability to cope and how much I'd regained control of my health. By keeping track of this kind of information, I had made a map of where I'd been. I also used my notebook as an inspiration to look toward my future.

- MEDICATIONS -



What About Medicine?

Kidney disease can affect your whole body and how you feel. To help you feel better and help your body become strong again, it's important to receive optimal dialysis, take your medicines, watch your diet and get regular exercise. When you combine all of these things together, you'll be able to feel your best.

It's your right and responsibility to understand what medicines you're taking, why you're taking them and how to take them. For example, some medicines should be taken with meals and other medicines should be taken on an empty stomach. It's important to tell your medical team if you have stopped or changed your medicines. Stopping or changing medicines may affect other areas of your treatment. When you have kidney failure, medications may be prescribed to: help your body make red blood cells, control blood pressure, help replace vitamins and minerals, keep your bones strong, get rid of phosphorus that builds up when your kidneys aren't working, and treat infection or other illnesses you may have.

There are some common medications you may be prescribed:

- **Iron** is used to make hemoglobin in red blood cells. Hemoglobin carries oxygen from your lungs to the rest of your body.
- **Blood pressure medicine** is used to keep your blood pressure under control. If it's not controlled, you could have a heart attack or a stroke.
- **Vitamins** are used to help replace the vitamins lost during dialysis. You may also need vitamins because of your diet restrictions.
- **Calcium** helps keep your bones strong and keeps your heart muscles healthy.
- **Phosphorus binders** help your body "tie up" the phosphorus that can build up in your body. Not taking your binders can lead to long-term bone disease.
- **Antibiotics** help your body fight infections. When your kidneys aren't working, antibiotics can build up in your body. Thus, if another doctor gives you an antibiotic, be sure to ask your nephrologist if the dose is O.K.

What Medicines Should I Avoid?

A Friendly Note: Non-prescription drugs are something you want to watch out for. Many people take over the counter medicines or have home remedies, which they take to help them feel better. When you have kidney failure, some of these medicines or remedies may make you sick or could even be life threatening. Make sure you tell your medical team about all medicines and remedies you're taking.

There are some common medicines to avoid:

- **Alka Seltzer,** baking soda or other bubbling remedies. These are high in sodium!
- **Milk of Magnesia** or antacids containing magnesium. Magnesium can build up and cause neurological problems.
- **Aspirin,** unless ordered by the doctor. Aspirin can affect the clotting abilities of the blood and may cause bleeding.
- **Enemas and laxatives** should be avoided as they cause you to become dehydrated or to lose needed minerals.
- **Vitamins or food supplements** may have potassium and magnesium.
- **Any "cure all" remedies, herbs and over the counter medicines** that have not first been discussed with your nephrologist.

What Is Alternative Or Complimentary Medicine?

In recent years, there has been a growing trend to explore and use alternative medicine or complementary medicine. These are treatments that are used in addition to traditional western medicine. Common kinds of these treatments include acupuncture, herbal remedies, chiropractic therapies, over-the-counter medicines, mind-body techniques and others. Some mind and body techniques, such as breathing exercises and visualization, are safe and effective to help manage stress. Although some people find benefit in these types of treatments and medicines, there may be harmful side effects. Tell your doctor about all the medical treatments you're using. Before trying any complementary therapies or medicines, please check with your nephrologist.

A Friendly Note: On page 48 and 49 are handy medication sheets.Use them to keep track of your medicines and how to take them.

- PAYING FOR TREATMENT -

You may be worrying about how to pay for treatments and medicines. There are many options to help pay for your dialysis treatments that include Medicare, private insurance, medical assistance, Social Security and in some states, renal programs. Your social worker can help you review the options available to you.

What Does Medicare Cover?

The federal government, through the Medicare ESRD Program, pays much of the cost for ESRD treatment, even if you're under the age of 65. If you have an employer group health plan or policy, most expenses will be covered.

There are three ways to qualify for Medicare coverage if your kidneys no longer work and you need regular dialysis or have had a kidney transplant, and:

- You are more than 65 or have a disability and you were already receiving Medicare benefits before your kidneys failed.

Or

- You have worked long enough to be insured under Social Security, the Railroad Retirement Board, or as a government employee.

Or

- You are the husband, wife or child (under 18 years old) of someone who has worked long enough to qualify.

If you have ESRD and qualify for Medicare coverage, it doesn't matter how old you are. You can receive Medicare coverage no matter what your age. In most dialysis centers and clinics there's someone who will help you apply for Medicare. Usually that person is the social worker or someone who works in the financial office. The other way to apply is to call the Social Security office in your area.

Medicare has two parts: Part A that pays for inpatient hospital expenses and Part B that pays for outpatient medical expenses. You must have Part A in order to receive Part B. Medicare Part B pays for most of the dialysis or transplant costs. You'll have to make a payment (called a premium) for Part B coverage. In order for you to keep your coverage, you have to pay your Part B premium on time. If you're not able to pay your premium, talk to your social worker.

Medicare will pay for 80 percent of what they define as a reasonable cost for treatment, unless you have private insurance. Although Medicare pays for

much of the treatment cost related to dialysis and transplantation, there are some things not paid for by Medicare. If you have a kidney transplant, Medicare will pay for the anti-rejection medicines and other medical costs for three years. Medicare may pay for some medicines used for home dialysis.

Learning all of the ins and outs of Medicare can be pretty confusing. Talk to your social worker for help understanding what is and isn't covered by Medicare. If you still have questions, you can call the **Medicare Patient Hotline** at **800-633-4227** or visit the Medicare web site at **www.medicare.gov.** You should also read, "Medicare Coverage of Kidney Dialysis & Kidney Transplant Services," the Medicare handbook that explains the entire program.

What Does My Group Health Insurance Cover?

You may have employer group health insurance through your employer or your spouse's employer. Employer group health insurance often pays for the entire cost of treatment. If your employer group health insurance pays for 80 percent for the first 30 months of dialysis, Medicare pays for the remaining 20 percent. After 30 months, Medicare will become the primary payor at 80 percent and your employer-based insurance will pay the 20 percent. Employer group health insurance may also help pay for your prescription medications. There are many types of private insurance including group policies, managed care groups and health maintenance organizations (HMOs). If you already have begun dialysis, current law does not permit you to enroll in Medicare HMOs. If you're choosing an insurance plan, make sure you know what is covered by each of your choices so you can pick the plan that's best for you. Legally, you're protected from being denied insurance due to a "pre-existing medical condition." This law doesn't allow employers and group insurance plans to deny you coverage just because you have ESRD. As long as you have insurance through a group policy or plan and want to change insurance to another group policy or plan, you can't be denied coverage. If you need help, talk to your social worker. He can help you understand the coverage and guide you with your decisions.

A Friendly Note: I didn't like dealing with insurance issues and I'm sure you're no different. Luckily, you can get expert advice from those who can help. This includes contacting your social worker, your state insurance commissioner, your insurance company, or even the American Association of Kidney Patients. Don't be afraid to ask.

What Is Medical Assistance?

Medical assistance is an individual state program that may help pay for treatment expenses that are not covered by Medicare. They may also help pay for your treatment if you do not qualify for Medicare. Medical assistance is called different things in different states. It's sometimes called Medicaid, Public Aid or Public Assistance. To qualify for this, your income level must not be above a certain dollar amount. To apply for medical assistance or a state kidney program, you can talk to your social worker or contact your county social services department.

What About Social Security Benefits?

Social Security benefits may be another way to receive some financial support. Benefits may be available through Supplemental Security Income (SSI) or Social Security Disability Income (SSDI). These aren't funds to pay for treatment, but they can help you pay for the day-to-day costs of living if you qualify. Again, if you have questions about whether you qualify, talk to your social worker or call the **Social Security Administration** at **800-772-1213.**

- THE GOVERNMENT'S ROLE IN HEALTHCARE -

The Medicare ESRD Program is the only federal program that pays for disease-specific services for Americans. The program covers people who have ESRD if they're insured under Social Security or are spouses or dependent children of a person who qualifies. This allows almost every United States citizen or legal resident with ESRD to receive either dialysis treatments or a transplant.

Before 1972, when the United States government created the Medicare ESRD Program, dialysis treatment was very expensive and only available to people who could pay for it. To fix this problem, healthcare professionals and patients worked together to convince Congress that Medicare should pay for ESRD treatments. They argued that if someone was on dialysis they could lead a normal life, but without treatment, they would die. They also argued that if people had financial coverage they could go back to work and once again be active members of their families and communities.

What Are The ESRD Networks?

After Congress amended the Social Security Act in 1972 to provide Medicare to people with ESRD, they created groups of representatives from the kidney community to make sure people were receiving quality care. They divided up the country into sections called Networks. These Networks, referred to as ESRD Networks, are contracted through the Centers for Medicare & Medicaid Services (CMS). Each Network has several employees in it including a director, a nurse, a social worker, and most important, people with ESRD. Each Network also has several volunteer committees including: a medical review board, a grievance committee and a patient advisory committee. Because Medicare is a federal program, the Networks work with, and for, CMS. CMS works with the ESRD Network Organizations to ensure that people who are receiving Medicare due to ESRD get quality care. They also make sure that if you're having problems with your care, such problems are quickly resolved. If you have questions or problems with the care you're receiving, you can call your Network for assistance. We have included a list of the Networks (pgs. 43-45) and their contact information in an appendix at the back of the book.

- CONCLUSION -

In conclusion, there's a lot to learn and many questions to be answered. Keep asking questions until you have answers that you understand. You have both the right and the responsibility to understand ESRD and the treatment options available to you. As confusing as this may be to sort out, the bottom line is many people on many levels are working to make sure you receive the care you need and that you can afford the needed treatments. You can receive help and guidance from people at your clinic or dialysis unit. You can receive help from people within your community. Your ESRD Network is there to help you. Your family and friends care about you. Remember, you aren't alone! There are people along the way who will work with you to create a safe and caring environment, a place where your questions can be answered, your anxieties lessened and your concerns put to rest, as you begin your journey with end-stage renal disease.

A Friendly Note: Congratulations, you have completed the first phase in your journey with kidney disease. Did you write down all your questions so you can share them with a member of your healthcare team? Remember, it's to your benefit to ask questions, work with your healthcare team and take an active role in your health. When you're ready to receive ***Phase 2, Access to Initiation****, return the postage-paid card inside this book to AAKP. But take your time and make sure you understand what is going on with your health. You will know when you are ready to move to the next phase. The control to decide when you're ready to receive more information is left in your hands. Good luck and I'll meet you again in the next phase.*

AAKP EXISTS

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

MEMBERSHIP

Membership Application

☐ I am not interested in membership at this time; however, I would like to receive a complimentary package of information.

To join AAKP, complete this form and send it with your payment to:
AMERICAN ASSOCIATION OF KIDNEY PATIENTS
3505 E. FRONTAGE RD., SUITE 315
TAMPA, FLORIDA 33607-1796

Membership Information:

Name: _____

Street Address: _____

_____

City: _____ State: _____

Zip: _____

☐ Transplant ☐ Hemodialysis ☐ CAPD
☐ CCPD ☐ Family Member ☐ Pre-ESRD
☐ Other _____

I am already a member of AAKP, but I would like to make a donation of $ _____

Indicate your AAKP membership category below:

☐ Patient/Family Member ($25)
☐ Professional Member ($35)
☐ Sustaining ($100)
☐ Institutional Member ($150)
☐ Life Member ($1,000)

☐ Check Enclosed (payable to AAKP)
☐ Please charge my credit card:
☐ Visa ☐ MasterCard ☐ AmEx ☐ Discover

Account Number _____

Expiration Date _____

Signature _____

✂ Please cut along dotted line.

Founded in 1969, AAKP continues to be the only organization directed by kidney patients, for kidney patients. AAKP is devoted to the interests and concerns of people with 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.

HOW YOU CAN JOIN AAKP

Patient/family membership in AAKP is $25 annually. Professional membership is also available for $35 per year. Please contact AAKP at (813) 636-8100 for international rates. To join, just fill out the membership application form and send it with your payment to AAKP. For immediate membership, call AAKP at (800) 749-AAKP. Please have your credit card information ready.

HOW AAKP HELPS YOU

AAKP offers you the following benefits:

- Subscription to AAKP's magazines, aakpRENALIFE & Kidney Beginnings: The Magazine.
- An opportunity to subscribe to AAKP Renal Flash, Kidney Beginnings: The Electronic Newsletter, Kidney Transplant Today & AAKP Public Policy Briefing, Internet newsletters transmitted monthly.
- A Web site (www.aakp.org) displaying useful healthcare information and providing links to other renal-related sites.
- A membership packet filled with a wide range of informational brochures on issues affecting the care and treatment of kidney patients.
- An opportunity to attend our Annual Convention, a three-day event featuring seminars addressing treatment options, rehabilitation, and psychological and social concerns of renal disease patients.
- Local AAKP Chapters (where available) that provide social and educational support to you and your family with meetings, newsletters and group activities.
- Special interest brochures that address current medical issues.
- Assurance that AAKP is representing your interests by defending the Medicare ESRD Program.

GLOSSARY

GLOSSARY

Access: General term used to describe the site where the needles for the hemodialysis process are connected to your body. See also Fistula and Graft.

Acute Renal Failure: A condition in which the kidneys suddenly stop working. In most cases, the kidneys can recover from almost complete loss of function.

Ambulatory Peritoneal Dialysis (APD): See Continuous Cycling Peritoneal Dialysis.

Anemia: The condition of having too few red blood cells. If the blood is low on red blood cells, the body does not get enough oxygen.

Arteriovenous Fistula: See Fistula.

Arteriovenous Graft: See Graft.

Bladder: The balloon-shaped organ inside the pelvis that holds urine.

Cadaver: An individual who has recently died and his or her organs are given for transplantation. See also Transplantation.

Catheter: (1) Sterile tubing that is inserted into a vein in the neck or chest to allow for temporary hemodialysis. (2) Sterile tubing that is surgically placed in the abdomen which allows for the exchanges in peritoneal dialysis.

Chronic Renal Failure: Slow and progressive loss of kidney function over several years, often resulting in end-stage renal disease (ESRD). People with ESRD need dialysis or transplantation to replace the work of the kidneys. Also reffered to as Chronic Kidney Disease or CKD.

Continuous Ambulatory Peritoneal Dialysis (CAPD): The most common type of peritoneal dialysis. With CAPD, the blood is always being cleaned. The procedure uses a system of bags and tubing. No machine is required.

Continuous Cycling Peritoneal Dialysis (CCPD): A form of peritoneal dialysis that uses a machine. The machine automatically performs the exchanges while the person sleeps and typically involves three to five exchanges. This is also sometimes called Ambulatory Peritoneal Dialysis (APD).

Cycler: Term used to describe the machine that is used to perform continuous cycling peritoneal dialysis (CCPD).

Diabetes (diabetes mellitus): A condition characterized by high blood sugar resulting from the body's inability to use sugar (glucose) efficiently. In type 1 diabetes, the pancreas is not able to make enough insulin; in type 2 diabetes, the body is resistant to the effects of available insulin.

GLOSSARY

Dialysis: The process of cleaning wastes from the blood artificially. See also Hemodialysis and Peritoneal Dialysis.

Dialyzer: A part of the hemodialysis machine that removes wastes and extra fluid from the blood.

Edema: Swelling caused by too much fluid in the body.

End-Stage Renal Disease (ESRD): Total chronic kidney failure. When the kidneys fail, the body retains fluid and harmful wastes build up. A person with ESRD needs treatment to replace the work of the failed kidneys.

Erythropoeitin: A hormone made by the kidneys to help form red blood cells. Lack of this hormone may lead to anemia.

Exchange: Term used to describe each time the dialysate used in peritoneal dialysis is drained and refilled.

Fistula (arteriovenous fistula): Surgical connection of an artery directly to a vein, usually in the forearm, created in patients who will need hemodialysis.

Graft (arteriovenous graft): Surgical connection of an artery and a vein with an artificial tube.

Glomerulonephritis: Inflammation of the glomeruli. Most often, it is caused by an auto-immune disease, but it can also result from infection.

Glomeruli: Plural of glomerulus.

Glomerulus: A tiny set of looping blood vessels in the nephron where blood is filtered in the kidney.

Hemodialysis: The use of a machine to clean wastes from the blood after the kidneys have failed. The blood travels through tubes to a dialyzer, which removes wastes and extra fluid. The cleaned blood then flows through another set of tubes back into the body.

High Blood Pressure: See Hypertension.

Hypertension: High blood pressure, which can be caused either by too much fluid in the blood vessels or by narrowing of the blood vessels.

Iron: A nutrient required by your body's cells. Normally, it is supplied by the types of food eaten. Individuals experiencing kidney failure may not absorb enough iron in their diet. This leads to anemia.

GLOSSARY

Kidneys: The two bean-shaped organs that filter waste from the blood. The kidneys are located near the middle of the back.

Living Non-Related Donor: An individual who is willing to donate a kidney, but not related by blood to the person needing it. See also Transplantation.

Living Related Donor: An individual who is willing to donate a kidney and is related to the person needing it. See also Transplantation.

Nephrologist: A doctor who treats patients with kidney problems and related hypertension.

Nephron: A tiny part of the kidneys. Each kidney is made up of about one million nephrons, which are the working units of the kidneys, removing wastes and extra fluids from the blood.

Nephrotic Syndrome: A collection of symptoms that suggest kidney damage. Symptoms include high levels of protein in the urine, lack of protein in the blood and high blood cholesterol.

Peritoneal Cavity: The space in the abdomen that holds the major organs. The inside of this space is lined with the peritoneum.

Peritoneal Dialysis (PD): Cleaning the blood by using the lining of the belly (abdomen) as a filter. A cleansing solution, called dialysate, is drained from a bag into the belly. Fluids and wastes flow through the lining of the belly and remain "trapped" in the dialysate. The dialysate is then drained from the belly, removing the extra fluids and wastes from the body. See also Continuous Ambulatory Peritoneal Dialysis and Continuous Cycling Peritoneal Dialysis.

Peritoneal Membrane: A sac, resembling cellophane with tiny holes, that serves as a lining of the abdominal cavity and holds organs in place within the peritoneal cavity.

Peritoneum: The lining of the peritoneal cavity.

Peritonitis: An inflammation of the peritoneal membrane. This inflammation causes an infection in the peritoneal membrane. Peritonitis is treated with antibiotics that are included in a special type of peritoneal dialysate.

Phosphorus Binders: Medications or substances that prevent the phosphorous in your body from removing too much calcium in your body. Calcium makes your bones and teeth strong.

GLOSSARY

Polycystic Kidney Disease: An inherited disorder characterized by many grape-like clusters of fluid-filled cysts that make both kidneys larger over time. These cysts take over and destroy working kidney tissue. PKD may cause chronic renal failure and end-stage renal disease.

Reuse: A procedure in hemodialysis where the dialyzer is cleaned and tested after each dialysis session and before being reused during the next treatment. Dialyzers are not reused on different people. The cleaned dialyzer is reused on the same person only.

Subcutaneous Device: Subcutaneous (under the skin) devices are made of small metallic devices, which are usually implanted in the upper chest area. These devices are connected to two hollow, flexible catheters that are connected to large veins in the central nervous system.

Transplantation: The surgical procedure of placing a kidney from a donor to the recipient. There are three types of donations: cadaver, living-related and living non-related.

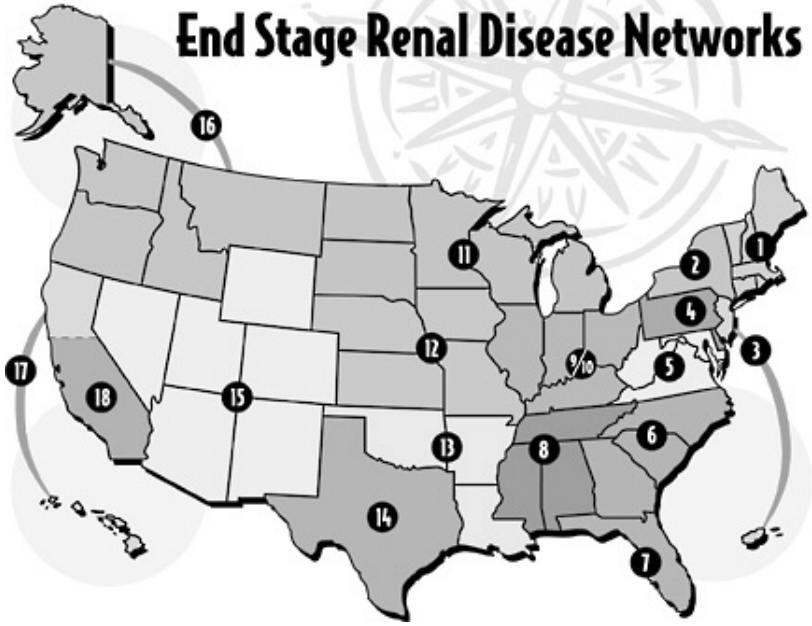
Ureters: Tubes that carry urine from the kidneys to the bladder.

Urethra: The tube that carries urine from the bladder to the outside of the body.

Urine: Liquid waste product filtered from the blood by the kidneys.

APPENDIX

ESRD NETWORKS



ESRD Network of New England
(Connecticut, Maine, Massachusetts,
New Hampshire, Rhode Island, Vermont)
30 Hazel Terrace
Woodbridge, CT 06525
Phone: (203) 387-9332
Fax: (203) 389-9902
www.networkofnewengland.org

ESRD Network of New York, Inc.
1249 Fifth Avenue, A-419
New York, NY 10029
NY State Toll Free:
(800) 238-3773
Phone: (212) 289-4524
Fax: (212) 289-4732
www.esrdnetworks.org/networks/net2/net2.htm

Trans-Atlantic Renal Council
(New Jersey, Puerto Rico, Virgin Islands)
Cranbury Gates Office Park
109 S. Main St., Suite 21
Cranbury, NJ 08512-9595
Phone: (609) 490-0310
Fax: (609) 490-0835
www.tarcweb.org

ESRD Network, Inc.
(Delaware, Pennsylvania)
40 24th Street, Suite 412
Pittsburgh, PA 15222
Patient Only Toll Free:
(800) 548-9205
Phone: (412) 325-2250
Fax: (412) 325-1811
www.esrdnetworks.org/networks/net4/net4.htm

Mid-Atlantic Renal Coalition
(Maryland, Virginia, Washington, DC, West Virginia)
1527 Huguenot Road
Midlothian, VA 23113
Toll Free: (866) 651-6272
Phone: (804) 794-3757
Fax: (804) 794-3793
www.esrdnet5.org

Southeastern Kidney Council
(Georgia, North Carolina, South Carolina)
1000 St. Albans Drive, Suite 270
Raleigh, NC 27609

ESRD NETWORKS

Toll Free: (800) 524-7139
Phone: (919) 885-0882
Fax: (919) 855-0753
www.esrdnetwork6.org

FMQAI: The Florida ESRD Network
4350 W Cypress Street, Suite 900
Tampa, FL 33607
Toll Free: (800) 826-3773
Phone: (813) 383-1530
Fax: (813) 354-1514
www.fmqai.com/ESRD/esrd.htm

Network 8, Inc.
(Alabama, Mississippi, Tennessee)
P.O. Box 55868
Jackson, MS 39296-5868
Toll Free: (877) 936-9260
Phone: (601) 936-9260
Fax: (601) 932-4446
www.esrdnetworks.org/networks/net8/net8.htm

The Renal Network
(Indiana, Kentucky, Ohio, Illinois)
911 East 86th Street, Suite 202
Indianapolis, IN 46240
Phone: (317) 257-8265
Fax: (317) 257-8291
www.therenalnetwork.org

Renal Network of the
Upper Midwest, Inc.
(Michigan, Minnesota, North Dakota,
South Dakota, Wisconsin)
1360 Energy Park Drive, Suite 200
St. Paul, MN 55108
Toll Free: (800) 973-3773
Phone: (651) 644-9877
Fax: (651) 644-9853
www.esrdnet11.org

ESRD Network 12
(Iowa, Kansas, Missouri, Nebraska)
7505 NW Tiffany Springs Pkwy, Suite 230
Kansas City, MO 64153
Phone: (816) 880-9990
Fax: (816) 880-9088
www.network12.org

ESRD NETWORKS

ESRD Network 13
(Arkansas, Louisiana, Oklahoma)
4200 Perimeter Center Dr., Suite 102
Oklahoma City, OK 73112-2314
Toll Free: (800) 472-8664
Phone: (405) 942-6000
Fax: (405) 942-6884
www.network13.org

ESRD Network of Texas, Inc.
14114 Dallas Pkwy, Suite 660
Dallas, TX 75254
Phone: (972) 503-3215
Fax: (972) 503-3219
www.esrdnetwork.org

Intermountain ESRD Network
(Arizona, Colorado, Nevada,
New Mexico, Utah, Wyoming)
1301 Pennsylvania Ave, Suite 750
Denver, CO 80203-5012
Toll Free: (800) 783-8818
Phone: (303) 831-8818
Fax: (303) 860-8392
www.esrdnet15.org

Northwest Renal Network
(Alaska, Idaho, Montana,
Oregon, Washington)
4702 42nd Avenue, SW
Seattle, WA 98116
Phone: (206) 923-0714
Fax: (206) 923-0716
www.nwrenalnetwork.org

TransPacific Renal Network
(Northern California, Hawaii, American Samao, Guam, Saipan)
4470 Redwood Hwy, Suite 102
San Rafael, CA 94903
Toll Free: (800) 232-3773
Phone: (415) 472-8590
Fax: (415) 472-8594
www.network17.org

Southern California Renal Disease Council, Inc.
6255 Sunset Boulevard, Suite 2211
Los Angeles, CA 90028
Toll Free: (800) 367-4767
Phone: (323) 962-2020
Fax: (323) 962-2891
www.esrdnetwork18.org

ADDITIONAL RESOURCES

American Association of
Kidney Patients (AAKP)
(800) 749-AAKP
www.aakp.org

American Kidney Fund
(800) 638-8299
www.akfinc.org

Children's Organ Transplant
Association (COTA)
(800) 366-2682
www.cota.org

National Kidney Foundation
(800) 622-9010
www.kidney.org

National Transplant
Assistance Fund
(800) 642-8399
www.transplantfund.org

Nephron Information Center
www.nephron.com

Transplant Recipients
International Organization
(800) 874-6386
www.trioweb.org

United Network for Organ Sharing
(UNOS)
(888) 894-6361
www.unos.org

Free Medications or Medication Grants

Glaxo-Wellcome (Imuran)
(800) 722-9294

Novartis Patient Assistance
Program (Cyclosporine)
(800) 257-3273

Prescription Drug Patients
Assistance
(800) 762-4636

PROGRAF/Fujisawa Patients
Assistance Program
(800) 477-6472

The Transplant Foundation
(804) 285-5115

Diseases

American Diabetes Association
(800) 342-2383
www.diabetes.org

Kidney Cancer Association
(800) 850-9132
www.nkca.org

National Kidney and Urologic
Disease Information
Clearinghouse
kidney.niddk.nih.gov

National Organization for Rare
Disorders (NORD)
(800) 999-6673
www.rarediseases.org

Polycystic Kidney Disease (PKD)
Foundation
(800) 753-2873
www.pkdcure.org

QUESTIONS TO ASK YOUR HEALTHCARE TEAM

- √ What has caused my kidneys to fail?
- √ Can you explain the various treatment choices?
- √ How will each treatment impact my special needs?
- √ What medical tests have I had done?
- √ What medical tests can I expect to have done in the next three months?
- √ What medicines have I been prescribed?
- √ What does each medicine do?
- √ What medicines should I avoid?
- √ Should I be following a special diet?
- √ Should I be exercising? What types of exercises can I do?
- √ How often should I see my nephrologist?
- √ Who do I contact in an emergency?
- √ How will kidney failure affect intimacy?
- √ Who can I talk to about the emotions I am having?

MY IMPORTANT MEDICAL INFORMATION

IMPORTANT MEDICAL INFORMATION	
Primary Doctor Name: _____ Phone number: _____	**Dialysis Center** Name: _____ Phone Number: _____
Nephrologist (Kidney Doctor) Name: _____ Phone Number: _____	**Emergency Contact** Name: _____ Phone Number: _____
Nurse Name: _____ Phone Number: _____	**Insurance Plan #1** Name: _____ Phone Number: _____ Policy Number: _____
Dietitian Name: _____ Phone Number: _____	**Insurance Plan #2** Name: _____ Phone Number: _____ Policy Number: _____
Social Worker Name: _____ Phone Number: _____	**Other** Name: _____ Phone Number: _____
Pharmacy Name: _____ Phone Number: _____	**Other** Name: _____ Phone Number: _____

MY IMPORTANT MEDICAL INFORMATION

MEDICATIONS			
MEDICINE	DOSE	WHEN	SPECIAL INSTRUCTIONS

NOTES

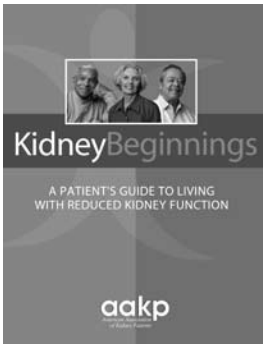
aakp

Resources

aakpRENALIFE - This patient magazine is produced six times a year. It contains information for those who are experiencing kidney failure. Topics featured include dialysis, transplantation, medical questions and dietary concerns.

www.aakp.org - This is the official Web site of the American Association of Kidney Patients. It features numerous educational materials from AAKP, a list of our programs, the latest AAKP news and links to several other educational Web sites.

Kidney Beginnings: A Patient's Guide To Living With Reduced Kidney Function - Created by AAKP, this educational piece addresses the concerns of those at risk for kidney disease and their family members. The book features information on the kidneys and how they work, diabetes, hypertension, various medical tests, emotional issues, common medications and much more.



Various Educational Brochures - AAKP also produces specialized packets for those at various stages of kidney disease, from those who have recently been diagnosed to the long-term patient. These free educational packets provide specific information to help patients and their families deal with the physical, emotional and social impact of kidney disease.

AAKP Nutrition Counter: A Reference For The Kidney Patient - Included in the pocket-sized brochure are nutritional values for standard portions of more than 300 commonly used foods, as well as menu items from 11 fast food restaurants. The nutritional values include protein, calorie, sodium, potassium and phosphorus levels – dietary values that must be closely monitored in kidney patients. Available in English & Spanisg, this 24-page brochure is an excellent guide for kidney patients who wish to develop a proper meal plan.

Kidney Beginnings: The Magazine - AAKP's magazine for those with chronic kidney disease and their families. The magazine features information on the kidneys, answers to common questions about chronic kidney disease and stories from patients who have adjusted to living with kidney disease. It is published four times a year and subscriptions are complimentary.

For more information or to request copies of any of the above materials, call the AAKP National Office at (800) 749-2257.

aakp
American Association of Kidney Patients

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Toll Free: (800) 749-2257 • Phone: (813) 636-8100 • Fax: (813) 636-8122
info@aakp.org • www.aakp.org

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