

AAKP PATIENT PLAN

Phase 1 *Diagnosis to Treatment Choice*

The Independent Voice of Kidney Patients Since 1969™



American Association
of Kidney Patients
aakp.org

Please note, the material in the AAKP Patient Plan® series is intended for educational purposes only. Individuals are encouraged to consult their physician and health care team for medical information specific to their care.

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AAKP PATIENT PLAN[©]

Phase 1: Diagnosis to Treatment Choice

Since you first heard the words “end-stage renal disease” (ESRD) and “kidney failure,” and reacting with fear and anger, you have probably been wondering what happens now... this is a normal reaction. Everyone facing kidney disease has concerns and questions about the future. The future may seem un-clear and dreams and plans change, but there is good reason to have hope as treatment options for kidney failure are always getting better.

The American Association of Kidney Patients (AAKP) is here to help you deal with kidney disease. The AAKP is the **oldest** and **largest** fully **independent kidney patient organization** in the U.S. Founded in 1969 by six dialysis patients, with doctor encouragement, our Founders helped create the End Stage Renal Disease (ESRD) Program, saving more than one million lives since 1973.

Dedicated to improving the quality of life and long-term outcomes for kidney patients through **education, advocacy, patient engagement** and the fostering of **patient communities** – AAKP fights for early detection; increased kidney transplantation and pre-emptive transplantation; full patient choice either at-home or in-center dialysis; protection of the patient/physician relationship; promotion of innovation; and the elimination of barriers for patient access to available treatment options. We want to help you achieve the best possible quality of health and quality of life.

As patients, we have already taken the journey you are about to take. We believe the knowledge and experience we have gained along the way can be of great value to you and your family in dealing with the choices and concerns you will face. This is why we created the AAKP Patient Plan[©].

The AAKP Patient Plan[©] can be thought of as a road map or travel guide. We hope the book will serve as both an informational resource letting you know what to expect, identifying what your needs will be, who will help you, and what you need to know to live your best life.

The AAKP Patient Plan[©] is designed to address questions and concerns at each step of your kidney 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: Getting Help and Starting Dialysis

Phase 3: Understanding Your Treatment

Phase 4: Ongoing Treatment

During each of these phases you can keep control of your life by staying active, asking questions and learning as much as you can about your specific disease and treatment options. 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.

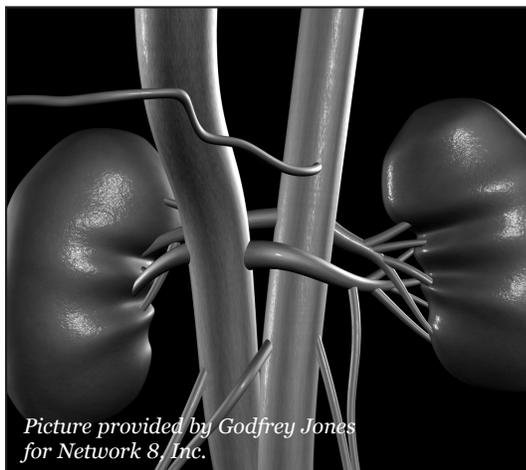
A Friendly Note: Throughout this book, you'll see my comments. I'm here to remind you that you're not alone in this journey. You have a support team of health care professionals, family and friends – consider AAKP one of your friends. Also, speaking from experience, it helps to know you're not the first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

Change can sometimes be too much. As you learn about your condition and take an active part in your health care, you'll begin to feel that you are once again gaining control of your life. 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 at the end of the book.

Doctors, health care professionals, and even some patients can sometimes make understanding hard by using words you may not understand. If you do not understand a word or instructions, stop and have it explained to you. You have a right to have everything explained to you until you understand how it will affect your body. During this process, you will also learn how to talk with the many medical people who will now be part of your life, and learn how kidney disease will fit into your life. 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 health care. Watch for the "Friendly Note" key that gives you helpful hints. Remember, you're not on this journey 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.

Nearly all of us are born with two kidneys. Kidneys are “vital organs” meaning you need them in order to live. The kidneys are 24-hour cleaning machines for your blood. Kidneys are twin organs shaped like kidney beans. They’re located below the rib cage in the middle of your back. Each kidney has about one million blood cleansing parts called nephrons. In adults, each kidney is about the size of a closed fist. Each kidney is separately attached to your bladder by tubes called ureters. Both ureters carry urine from the kidney to the bladder. The kidneys clean 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. A healthy adult passes a minimum of a pint (2 cups) of urine a day in order to remove wastes from your body in the form of urine. A small amount of daily urine output is a major signal of kidney failure that may either be acute (short term) and reversible or chronic - termed end-stage renal disease (ESRD). Acute kidney injury (AKI) is a sudden episode of kidney failure or kidney damage that happens within a few hours or a few days. The trauma that occurs could lead to end-stage renal disease. However, end-stage renal disease is usually caused by chronic kidney disease (CKD) and happens over a long period of time.
- **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 which are chemicals carried within the bloodstream to action sites throughout the body allowing many aspects of good health including controlling blood pressure. A hormone called EPO (erythropoietin) stimulates the bone marrow to make hemoglobin, the substance that allows red blood cells to carry oxygen throughout the body. A major reason that kidney failure causes weakness and tiredness is that failing kidneys do not make enough EPO, which causes too few red blood cells and anemia.

Stages of Chronic Kidney Disease

Kidney disease is common, affecting 14% of the population (NIDDK.nih.gov), roughly one in seven persons in the United States. Perhaps you found out about it through a screening program or a visit to your doctor. Most people who develop kidney disease have no symptoms, but many do have risk factors such as a history of diabetes or hypertension (high blood pressure). Many people have a family history or there can be a genetic condition that causes kidney disease, such as Polystic Kidney Disease, Fabry Disease, FSGS, etc. Kidney disease is more common in certain ethnicities, such as African Americans and Hispanics.

Detection of CKD

Chronic kidney disease (CKD) can be diagnosed by measuring the serum creatinine level and combining it with your age, race and gender. When considering kidney disease evaluation, the serum creatinine alone is not a reliable indicator, because it varies greatly according to one's muscle build. Several groups have studied the GFR measurements and developed a formula by comparing the demographic factors of age, race, gender and the serum creatinine level with a very accurate determination of the GFR made using radioisotopes. This mathematical formula can be easily accessed on the Internet (<http://mdrd.com>), and is known as the estimated glomerular filtration rate (eGFR). This computerized version gives a fairly easy to use and accurate picture of what the level of kidney function is.

Factors such as dehydration, fasting, working out, or an acute urinary tract or viral infection can interfere with the serum creatinine result, causing it to be falsely elevated. For this reason, a kidney disease diagnosis is determined based upon at least two abnormal GFR values three months apart. In the absence of an abnormal eGFR, the presence of markers such as an increased amount of protein in the urine or an abnormal ultrasound can indicate kidney disease.

When considering the stage of kidney disease one must also consider the urine albumin. Albumin is a type of protein found in the blood, and its presence in the urine indicates damage to the delicate filter referred to as the glomerulus. Perfectly normal kidneys do not allow albumin to pass into the urine. Previously a 24 hour urine collection was needed to determine how much protein is in the urine. A simple and accurate alternative is to measure a spot urine albumin ratio first thing in the morning and compare it with urine creatinine measured from the same sample. The ratio equates to the 24 hour specimen very well and is much more convenient than a patient collecting their urine in a container for a total of 24 hours and delivering it to a lab.

The urine albumin can be classified to be either less than 30 mg albumin to gram of creatinine (<30 mg/gm), This is called A1 in the new nomenclature. It is considered normal. The next classification is between 30 and 299 mg albumin and gram creatinine (30-299 mg/gm). This is referred to as A2, and has a worse prognosis. The final classification is equal to or greater than 300 mg/gm. This associates with a worse prognosis.

The KDIGO classification system is simple to understand and useful for diagnosing purposes. Stages 1 through 5 are referred to as G (for GFR) G1 through G5 and are combined with albumin (A1,A2,A3). A heat map chart published by KDIGO gives a color-coded indicator of what the expectations or prognosis indicators are for a patient. (<https://goo.gl/images/WxpE52>). It has been estimated that very few patients will actually develop kidney failure - around 1.3% (Levy, Coresh. Lancet 2012;379(9811):165-80). Based on the National Institute of Health Statistics, there are 468,000 patients undergoing dialysis and 193,000 patients who live with a successful kidney transplant. There are around 113,000 patients starting dialysis each year.

www.mdrd.com
www.kidney.org
www.nkdep.nih.gov

Classification

CKD Stage 1 and CKD Stage 2 - Stage 1 is characterized by a GFR of greater than 90 mL/min/1.73m². Although kidney function is normal, there may be evidence detected by performing a urinalysis evaluation or a renal ultrasound of some kidney damage. Stage 2 is similar to stage 1; the change in GFR here is between 60 and 89 mL/min/1.73m².

In Stages 1 and Stage 2 patients are advised to develop an action plan with their physician to treat the underlying cause of their early kidney disease, especially diabetes and hypertension. They are also advised to alter their lifestyle regarding dietary habits and activity. Diet control can make a major difference in how the patient progresses once diagnosed with kidney disease. Additionally, patients with these two stages should be aware of medications that can harm the kidneys, and either reduce their dosages or avoid them altogether. A physician and pharmacist can provide valuable information on what medications should be prescribed and what over-the-counter medications should be avoided. Finally, patients with seemingly minor changes in kidney function may have a poorer outcome in surgery, and before undergoing anesthesia or an operation, the physician and anesthesiologist should be extra cautious to avoid changes in blood pressure or prolonged procedures.

Many patients who are elderly have reduced kidney function as a nature progression of aging. It is not necessary to be alarmed at a lower GFR number as for many, it will not affect prognosis unless there are other problems such as taking medications that are known to harm the kidney or having a surgical procedure where the blood pressure cannot be controlled.

CKD Stage 3 kidney disease is now divided into two additional sections, stage 3a (GFR 45-59 ml/min/1.73 m²) and stage 3b (GFR 30-44 ml/min/1.73m²). This was changed because the risk of progressive kidney disease is worse for the stage 3b patients than 3a.

Here, the action plan focuses on the same principles as stages 1 and 2. In addition, early signs of kidney disease may become apparent. These include metabolic acidosis, anemia and an elevation in the parathyroid hormone levels. (This hormone comes from glands in the neck and affects bone metabolism.) Patients with CKD have a higher rate of heart disease. These factors will be evaluated and addressed during the visit to your doctor.

CKD Stage 4 kidney disease patients have a GFR between 15 and 29 cc/min/1.73m². In stage 4 the disease is more progressive, and there is a likelihood the patient will progress to Stage 5 and require renal replacement therapy. Here, the action plan is to try to protect the kidneys by remaining on the proper diet, continuing medications, especially for underlying causes such as diabetes and hypertension, avoiding medications that are dangerous to the kidney and adjusting ones lifestyle. Imaging and surgical procedures must be done with careful planning and caution.

In stage 4, you should receive education, guidance and support through classes and seminars that are conducted by members of your healthcare team. You should learn ways to protect your kidneys and delay disease progression through these classes, and the more you learn, the more prepared you will become should you end up needing renal replacement therapy such as dialysis or a kidney transplant.

Some patients who reach stage 4 also have many other disease conditions that may interfere with how fast or slow they progress, and whether they are too ill to benefit from renal replacement therapy. For others, the possibility of a kidney transplant will be discussed. Some patients undergo kidney transplantation without ever reaching the point where dialysis is started - this is called a pre-emptive transplant. The two major types of dialysis therapy are peritoneal dialysis and hemodialysis. Both can be performed at home. Home hemodialysis allows the patient to remain independent, continue working or being active, and maintain control of their healthcare. For patients who cannot perform home hemodialysis or peritoneal dialysis, staff assisted hemodialysis is available in a dialysis center. For more information on hemodialysis, home hemodialysis, peritoneal dialysis and kidney transplantation, visit www.aakp.org to download or order a copy of AAKP's Understanding series brochures.

Each modality of care requires preparation. Prospective kidney transplant recipients undergo a thorough evaluation. If they have a suitable living donor, it must be determined whether or not they match directly with the recipient, or can participate in an extended donor program. Some patients may not have a living donor and are placed on the deceased donor list. Peritoneal dialysis patients must have a plastic catheter placed into their abdomens around 2 to 3 weeks prior to beginning therapy. Those who initiate hemodialysis should have an arteriovenous fistula or graft placed in their arms several weeks prior to starting hemodialysis. These are surgical procedures. Unfortunately, many patients do not have either a fistula, graft or peritoneal dialysis catheter placed, and must undergo hemodialysis through a central venous catheter until a fistula or graft can be placed. It is the goal to have the PD catheter, fistula or graft placed well before dialysis is started, so that the transition to renal replacement therapy during the fifth stage of kidney disease can be smoother.

CKD Stage 5 kidney disease patients have a GFR less than 15 ml/min/1.73m². During this stage the patient will undergo renal replacement therapy, either a kidney transplant, starting a home

therapy such as peritoneal dialysis or home hemodialysis, or begin dialysis in the dialysis center. Some patients are very sick and debilitated and may wish to avoid renal replacement therapy, altogether, and undergo palliative care.

Stages of Chronic Kidney Disease (CKD)	GFR*	% Kidney Function
CKD Stage 1: Normal kidney function	90 or higher	90 – 100%
CKD Stage 2: Mild loss of kidney function	89 – 60	89 – 60%
CKD Stage 3a: Mild to moderate loss of kidney function	59 – 45	59 – 45%
CKD Stage 3b: Moderate to severe loss of kidney function	44 – 30	44 – 30%
CKD Stage 4: Severe loss of kidney function	29 – 15	29 – 15%
CKD Stage 5: Kidney failure	Less than 15	Less than 15%

*The GFR number indicates how much kidney function is remaining. As kidney disease worsens, the GFR number (and percentage of kidney function) goes down. **Your GFR will tell you an approximate percentage of kidney function, but your doctor will need to check the amount of albumin (protein) in your urine as well.

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 or uremia (greek for urine in the blood). There are two kinds of kidney failure:

- **Acute Renal Failure** also called tubular necrosis usually happens quickly and can be short termed. 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. In some causes of acute kidney injury, such as a bad reaction to a medicine for a headache or a contrast agent given during an X-ray examination, it is usual for normal kidney function to return within days, once the kidneys heal from the injury. Other times, kidney function may not return after an acute kidney injury and the kidneys are permanently damaged caused kidney failure and the need for a renal replacement therapy such as dialysis or a kidney transplant.
- **Chronic Kidney Disease (CKD)** can happen slowly, over time, 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 a form of renal replacement therapy, such as 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 health conditions that the patient already has. Some causes of kidney disease include:

- **Diabetes** is a disease of high blood glucose (sugar) levels. High glucose level is a sign that the body can no longer make or use the hormone insulin which allows glucose to be an energy fuel. When the glucose level is high for a long period of time, 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 break-down 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 protein to pass from the blood into the urine. As a result of the protein loss (mainly albumin), large amounts of water stay in your body. This results in overall swelling in your body, called edema.
- **Polycystic Kidney Disease (PKD)** 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 PKD you still urinate in normal amounts, but the harmful waste products aren't removed from the body. PKD is the fourth most common cause of ESRD in the United States.
- **Systemic Lupus Erythematosus** is an immune disorder. It causes swelling in all organs in the body, including the kidneys.
- **Chronic Pyleonephritis** or **Urinary Tract Infection** is an inflammation of the tissues of the kidneys, surrounding the filters. It is more common in women than men. Infection and other forms of inflammation can cause kidney failure, if left untreated. Chronic pyleonephritis can cause pain when urinating, frequent urination and sometimes pain in the sides or over the kidneys.
- **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. Common causes of kidney stones include gout and unusual activity of the parathyroid glands in the neck.

What Is The Difference Between CKD And ESRD?

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 should 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 will work with you to try and delay or slow the progression of kidney disease. Some things your nephrologist may prescribe include, but are limited to are: medications to manage conditions causing kidney disease (such as diabetes and hypertension), modifying your diet, exercise, weight loss if needed, and to stop smoking if you are a smoker.

Your nephrologist can give you the best information on how long it may be before you need dialysis or a kidney transplant, however it's important to know that not everyone will progress to end stage renal disease.

A Friendly Note: Remember, the CKD 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, diet changes and certain blood and urine tests to check your kidneys.

What Are The Symptoms And Signs Of Chronic Kidney Disease?

Kidney disease is commonly referred to as a “silent illness” since many people don't experience signs or symptoms until they are close to kidney failure. This is why it's very important to manage potential risk factors for kidney disease such as diabetes and hypertension, understand your lab numbers to know what your estimated GFR number is and to know if you have a family history of kidney disease. Below 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
- See “foam” in your urine
- Have frequent muscle cramps, especially in your legs
- Have very dry, itchy skin

Keep in mind that you may have one, more or none of these symptoms and still have kidney failure.

– YOUR ROLE IN PRE-ESRD –

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 getting use to new things as well. It also helped to talk to others with kidney disease 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 health care 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 health care team. There are no dumb questions! If you don't understand an answer, ask again and again until you do. It's difficult to change to your newly diagnosed condition when feelings of sadness, anger, frustration or fear are held inside of you. Talking about these feelings with health care 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 getting use 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 kidney disease. 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 health care team, you can do this!

Once you have information and some time to let things sink in, you'll be able to make handle anything obstacle kidney disease throws at you. You will realize your life is different and will accept the differences. The mental and physical changes that occur during the on-set of kidney disease are at times too much to handle. 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 discussion 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 kidney disease 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 okay for them to feel sadness, fear, despair and isolation. It’s also very helpful to talk with others who have kidney disease and have experience with different treatment options such as different types of dialysis or a kidney transplant. These fellow patients likely have gone through very similar experiences as you and can share their stories, along with their ups and downs. Finding a local support group or joining a patient organization such as the American Association of Kidney Patients can help provide you with the education, resources, support and information needed to understand your condition, manage your care, make informed decisions about your treatment options, and give you the strength to continue to achieve your aspirations!

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 HEALTH CARE TEAM –



Many people are involved in caring for someone with kidney disease. 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 are 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 kidney disease affects you and your family. Working together as a team will help you to receive the treatment and care that will work best for you.

- **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 health care 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 health care 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.

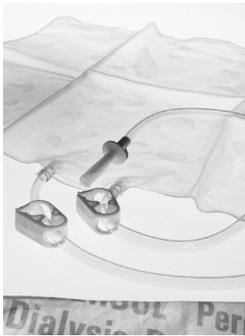
How Do I Talk To My Health Care Team?

Many people find it helpful to have a notebook for writing down questions for the health care 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 48 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 health care 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 health care, 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 health care 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 many treatment options and what each option means for you. Before you make a decision about what type of treatment you want, talk about the options with your nephrologist. Not every treatment will work for every person. There are many things that determine which treatment option is best for you. You and your nephrologist will need to look at your type of kidney disease, other chronic illnesses you have, your goals and preferences, 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 every treatment choice. You can organize your questions for the discussion of the advantages and challenges into three categories (benefits, risks, and burdens):

- **Advantage** - the benefits of the treatment compared to other treatment options (e.g., will I live longer; will I feel better with this treatment compared to another treatment);
- **Challenge** - the risks of the treatment compared to other treatment options (e.g., what are the complications I might suffer; what are my risks for being admitted to the hospital each year on treatment; what are the side effects; what are the chances I will die with this treatment); and
- **Challenge** - the difficulties of the treatment compared to other treatment options (e.g., How much time is required for the treatment; how much time does it take to recover from the treatment; how will I feel between treatments; how will I feel after treatment; how difficult is the diet required for this treatment; how many medicines must I take, what are the possible stresses on my family).

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. If there doesn't seem to be enough time to get your questions asked and answered, ask for another appointment just to discuss your questions (often called a "family conference"). Take a friend or family member with you when you ask your questions. Two heads are better than one. Two mouths are better than one. And four ears are better than two. This is your health and your decision; do what's best for you using the best information available.

What Are The Available Treatment Options?

Treatment can be divided into:

- Active Medical Management
- Kidney Transplant
- Peritoneal Dialysis
- Home Hemodialysis
- Staff assisted in-center hemodialysis

Each will be discussed in detail below.

What Is Active Medical Management?

For many people kidney disease progresses due to complications from diseases such as hypertension and diabetes. Sometimes, the kidney patient has dementia, severe peripheral vascular disease, a history of strokes, heart attacks or heart failure. Sometimes severe lung disease, malnutrition or cancer accompany kidney disease. In some situations, patients are very elderly and debilitated. In all of these circumstances, the patient, their family and their doctors must weigh the benefits and burdens of treatment, such as a transplant or form of dialysis. The risks of repeated hospitalizations, and the mere prolongation of life without quality make it less worthwhile to begin dialysis therapy, , undergoing surgery or frequency of dialysis therapy may be too much for a patient who is already very ill and has additional complications. The patient and their family may choose a more conservative care, referred to as active medical management.

Active medical management means intensive efforts to keep people functioning and comfortable without dialysis or ungoing kidney transplant surgery by preventing or treating the symptoms of body changes associated with severe, advanced kidney failure. Active medical management means treating symptoms that may occur such as itching, shortness of breath, weakness, swelling, loss of appetite, nausea, vomiting and pain well enough to maintain comfort and the best quality of life possible under the circumstances. Active medical management consists of medications, diet change and the creation of a comfortable environment. Hospice care is an example of active medical management.

You always have the moral, ethical and legal right to never start dialysis, or to stop dialysis at any time and begin active medical management. Regardless of whether or not one starts dialysis, in the very final stages of disease, the kidneys progressively deteriorate and eventually shut down completely. At this point a natural death will occur in 8 to 15 days. Although, none of us like to think about death, it is an absolute certainty for us all. For patients who die from kidney disease, particularly at home with hospice support or in a hospice facility, death is almost always gentle, peaceful and without discomfort.

What Is A Kidney Transplant?

In the ideal circumstance, a kidney transplant should be placed before the patient ever reaches the point of needing dialysis, which is called a pre-emptive transplant. ideal treatment option - allowing patients to return a more life normal with more normal kidney function. 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, you do not need to be on dialysis to be given a chance to receive 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 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 the list on the next page 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 health care team. They can tell you why a transplant may or may not be best for you.

TRANSPLANT	
Advantages	Challenges
<ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> Transplant requires major surgery. You may have to wait for a kidney. Side effects from medications. Cost of the medicines. You have to take daily medications to avoid rejection for the life of the transplanted kidney. 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 it 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.

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- 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 or she may donate a kidney to you. The donor can be a friend, spouse or co-worker who agrees to this donation. Or it may be from a person you do not know - such as someone who heard your story and wants to donate a kidney or someone who is a donor in a paired-exchange program.
 - 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 receive a 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.

To learn more information on kidney transplantation, please review AAKP's Understanding Kidney Transplantation brochure.

What Is Peritoneal Dialysis

Peritoneal dialysis (PD) cleans the blood using a space in the belly called the peritoneal cavity. This cavity is lined with a membrane called the peritoneum, which also covers the organs and intestines and protects them. It keeps the good things like proteins and red blood cells inside your body, but acts as a filter to allow the straining of waste products, potassium, urea and bad things called toxins to cross from the blood vessels to the cavity.

The sterile fluid that is drained in is called the dialysate, and it is drained out of the abdominal cavity carrying the removed toxicins from your blood that your damaged kidneys can no longer remove. Each time fluid is removed and replaced, it is called an exchange. Prior to starting PD, a soft, flexible catheter is surgically placed into the cavity. It takes two to four weeks to completely heal. The catheter has three sections, the bottom part goes into the abdominal cavity, and the middle part is tunneled under the skin. The top part comes out through an opening called the exit site and stays outside the body where it is taped flat against the skin.

Your training team will emphasize measures you should take to keep the tube clean and free from infection. These include tips on where to swim and how to bathe, and what to do if you think you

are developing an infection. Preventing infections is critical to prevent bacterial contamination of the abdominal cavity, a serious condition known as acute peritonitis. Although this is a very serious condition, it is now relatively rare because of the strong emphasis placed on training. An infection is usually treatable with antibiotics, but does result in scarring of the peritoneum and after a while makes the continuation of PD more challenging.

With regard to peritoneal dialysis, with the exception of active ulcerative colitis or Crohn's Disease, there are few contraindications, assuming the patient has a suitable home environment. Obesity is not a contraindication to PD. Peritoneal dialysis has an advantage over in-center hemodialysis as it allows for more frequent treatments, mimicking more closely the function of a normal working kidney. Patients do not need a family member or care partner to do PD treatments and treatments can be done at home or during travel - as long as the environment is clean and sterile to reduce the risk of infection. PD allows for a more normal lifestyle and is ideal for patients who are employed. A key factor to success of the peritoneal dialysis experience is the training program. Patients who are well trained to provide careful meticulous self care have a low incidence of catheter failure. In this population, the incidence of a peritoneal infection - peritonitis, is also very low.

Continuous ambulatory peritoneal dialysis - CAPD - This can be done anywhere and does not require special equipment. The exchanges can be done over four to six hours around the clock, and take around 30 minutes to complete. The PD dialysate bag is hung onto a pole and a tube connected to your PD catheter. Fluid is allowed to fill your abdomen and the catheter is clamped. You are free to continue your daily activities until around 4 to 6 hours later where the bag is placed on the floor. Fluid containing toxins drains by gravity into the bag. The bag and tubing are detached, and the bag emptied into the toilet. You then repeat the cycle.

Continuous cycling peritoneal dialysis - CCPD - This is much more convenient. Here a larger bag is hooked through a machine that automatically cycles the fluid in and out of your abdominal cavity while you sleep. You connect and disconnect the bag much the same as with CAPD, and you leave some of the fluid in your abdomen to remove even more wastes. You may do up to two exchanges during the day. Thus, you have the majority of the day completely free to enjoy daily activities. This is ideal for patients who must continue working as it does not interfere with their work schedule.

Current data suggests that only 6.9% of ESRD patients are being treated with peritoneal dialysis. In recent years, advances in technique have resulted in a greater survival and a higher quality of life with less complications. The biggest hindrance to the patient ever receiving peritoneal dialysis is a lack of education or opportunity.

You, as a patient, should begin education about the different modalities available to you long before you ever need them (CKD Stage 3b and 4), and be able to acquire the confidence to make a choice based upon your personal needs and desires, as well as those of your family.

Regardless of the modality you initially select, you must maintain your health and understand that you do have the right to switch to another treatment option should your circumstances or preferences change.

Patients who chose home peritoneal must be very motivated, and will have to work very hard to assure success. The gratification of having a flexibility lifestyle and more independence makes it worthwhile for many patients.

To learn more information on peritoneal dialysis, please review AAKP's Understanding Your Peritoneal Dialysis Options brochure.

ADVANTAGES	CHALLENGES
<ul style="list-style-type: none"> • Flexible schedule and increase independence • Unlike home hemodialysis, you don't need a partner and training is easy • Usually done while you sleep, freeing up daytime requirements • Fewer fluid and diet restrictions than thrice weekly hemodialysis • No needles • You can easily travel with your cycler and have supplies shipped to your destination, or you can switch to CAPD when you're traveling • Ongoing (continuous) dialysis simulates normal kidney function • Often provides better blood pressure control • Prolongs remaining kidney function. 	<ul style="list-style-type: none"> • A machine is needed • You may have to do an extra exchange during the day • You may be awakened during the night by the cycler machine's noises • Requires the insertion of a permanent catheter • Not all dialysis facilities offer CCPD (You have the right to request a transfer to a doctor/facility that prescribes CCPD). • The dialysate is glucose based and insulin requirements will change in diabetics and some patients gain weight • Procedures must be closely followed to reduce the risk of infection in the peritoneal cavity or at the exit site • Storage space is needed in your home for supplies.

What Is Home Hemodialysis?

Hemodialysis is the most commonly used method of cleaning the blood in patients with kidney disease. It uses a machine that has a filter referred to as the dialyzer. The filter has a membrane that is made of a thin, plastic tube that is porous. Toxins from the blood are filtered through the dialyzer membrane along with extra water. The fluid that also flows through the dialyzer, but on the opposite side of the membrane is "balanced" so that at the end of treatment the serum electrolytes and other mineral minerals are normal.

Most patients undergo hemodialysis through an arteriovenous access that has been surgically placed under the skin. Needles are places into the fistula or graft access on the arterial and venous sides, and a blood pump pushes blood through plastic tubing to the dialyzer and back again. Several gauges and monitors monitor the treatment.

For every drop of blood that leaves the body through the tubing, a drop returns. At any one time there is about one cup of fluid in the dialyzer system. Home hemodialysis can be done every day for just two hours while in center hemodialysis is generally done three (or four) days a week.

The machines used in the dialysis centers are generally larger, while the ones designed for home are smaller and more compact. They use cartridges that make the set up and take down of the dialysis equipment easy.

Currently, 1.55% of the population of dialysis patients are on home hemodialysis, but the concept of home hemodialysis is not new. In fact, it was originally the main option available for patients prior to the passage of laws that allowed for federal funding for dialysis care. Limitations to home hemodialysis include the requirement that the patient have a suitable partner willing to learn and help with therapy, a high level of motivation and willingness to learn and follow all the dialysis procedures, the ability to either self cannulate the access or have ones partner perform the procedure. Drop out from the home program is common because of patient and partner burnout, access site infection, and the patient moving from dialysis to a kidney transplant.

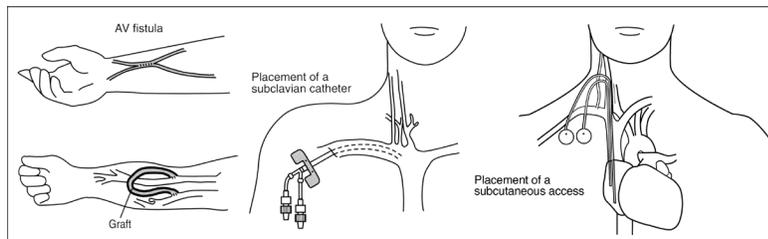
While the steep learning curve and the demands on the patient and family are very high, they also have the benefits of allowing the patient and family flexibility in terms of time management and independence. Patients can choose the time they desire to perform their treatments, do not have to travel back and forth to a dialysis center, and thus can continue to work and remain gainfully employed. Many patients are never offered the opportunity to learn hemodialysis because they initiate therapy directly from a hospital. However, patients who are dialyzing in the center always have the opportunity to change to an alternate modality, and many physicians regularly discuss these alternate options during routine dialysis rounds.

Dialysis always has two components, removing extra fluid you gained between treatments, and filtering the blood. You will learn to control the fluid gains between treatment by watching your dietary sodium intake, and to minimize the excess intake of fluid, potassium and phosphorus.

ADVANTAGES	CHALLENGES
<ul style="list-style-type: none"> • Dialysis is done in the comfort of your home • Flexibility to choose a time of day for dialysis • More flexibility for activities, including work, school, family, and friends • No need to travel to a dialysis center • Allows for more independence and control • Allows for a more flexible diet • Many people feel their overall health (physical, social, mental) improves with home dialysis 	<ul style="list-style-type: none"> • A care partner may be needed depending on the home hemodialysis machine being used (No care partner is needed for peritoneal dialysis - another type of home treatment) • Training is required • Space is needed to store equipment and supplies

What Is In-Center Hemodialysis

For patients who lack a suitable partner, or who prefer dialyzing in a clinical environment, treatments can be given in a clinical center. Here, a nurse will perform a clinical assessment, and a technician will cannulate the arterial and venous sides of your access and begin your dialysis. You will be checked frequently over the dialysis period, usually four hours. Once your dialysis is completed and the blood from the dialyzer returned to you, the needles will be pulled back out of your access, and sites will be compressed until there is no bleeding. You will then be free to return to your home.



The dialysis is limited in what it can and cannot do. For instance, it is now recommended that no more than 13cc/kilogram per hour be removed in fluid volume. The dialysis machine does a poor job of removing phosphorus, and you will be asked to control your dietary phosphorus, especially process foods that contain excess phosphorus. Several medications are required to control the phosphorus as well as to supplement vitamin needs, vitamin D, iron and erythropoietin (epo). Erythropoietin is a hormone made by the kidneys that controls the production of red blood cells. With kidney failure erythropoietin is decreased, and anemia is present. This is easily controlled by synthetic epo and iron, both given during dialysis.

ADVANTAGES	CHALLENGES
<ul style="list-style-type: none"> • Staff performs all aspects of treatment • Friendships might develop with those dialyzing during your same shift • A care partner may be needed depending on the home hemodialysis machine being used (No care partner is needed for peritoneal dialysis - another type of home treatment) • Training is required • Space is needed to store equipment and supplies 	<ul style="list-style-type: none"> • You may have little control and/or involvement in your treatment as staff performs all aspects of treatment • You must travel to a center at least three times weekly • Treatment days and times are scheduled by the center and may not be accommodating • May not fit your schedule or lifestyle • There may be rules against eating or drinking in the facility

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 allow enough flow of your blood through the dialyzer to receive a cleansing hemodialysis treatment. To prepare for dialysis, you will need surgery to create a reusable, "access" to your blood stream, often called "vascular access."

There are three basic types of accesses: a fistula, a graft or a catheter.

A fistula, or arteriovenous fistula (also called by its initials, AVF), is created by directly connecting an artery and a vein, beneath the skin, usually in the opposite arm than you write with. Studies show that a working fistula produces the best results for dialysis. Once the fistula is made, it might take 2 – 12 weeks to become big enough to use. Therefore, it is very important that a fistula be made at least three months before you suspect you will need to start using dialysis. Because a working fistula depends on the size and flow of blood through your artery and vein, these factors should be determined by a check-up by your surgeon.

Your blood vessels should also be looked at by a Doppler machine (often called “mapping”). Mapping is done with a microphone on top of the skin. It doesn’t hurt and isn’t dangerous. Just as with hemodialysis, there are proven guidelines that rule how a fistula is planned and made. It is okay to make certain you have had Doppler vessel mapping before a fistula is made. It is a good idea to ask your surgeon about his or her success rate with AVFs (how many AVFs heal, mature and allow a proper dialysis).

A graft, or arteriovenous graft, is created by connecting an artery and vein with an artificial tube. The graft is tunneled under the skin to connect the artery and vein. It can be used for dialysis within 3 days but it is often better if it can be allowed to heal for 1 - 2 weeks. Two needles are inserted through the skin into the graft, just like a fistula. Because the artificial graft is already big enough to allow access to your blood stream, it can be used for dialysis sooner than a fistula. However, because the graft is artificial it may become plugged by a blood clot that prevents the graft from allowing a proper dialysis treatment. If this happens, the clot must be removed by someone trained to do so.

Because the graft is artificial, it is more prone to become infected. If a graft becomes infected, the graft usually must be surgically removed. Then a different access to your blood stream must be made. Therefore if you have a graft instead of a fistula, you are likely to have more surgery done on your arm and more hospitalizations than if you dialyzed with a fistula. Therefore the graft is considered the second best choice, often used only when a fistula can’t be made. Another possible benefit of a graft is that while it is working properly, the veins in the upper part of the arm often get big and thick-walled enough to allow a fistula to be made in the upper arm if and when the graft clots.

A catheter is a sterile plastic tube inserted into a vein in the neck to allow hemodialysis until a fistula or graft is healed and ready for use. A catheter can be used immediately for dialysis. Needles are not required, which may sound pretty good at first. But the problems with a catheter are the same as with a graft, namely they can clot or get infected. Catheters tend to clot or become infected a lot more often than grafts. An infected catheter can be very dangerous and lead to serious infections in your blood stream, on your heart valves, in your back bones, and even in your brain. Hospitalizations and death are more frequent in people who use a catheter for longterm vascular access compared to people who use a fistula.

Therefore, guidelines recommend that if at all possible, catheters only be used on a short term basis, removing them as soon as possible when a better access like a fistula is ready for use.

Your access site is often called 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 enough bloodflow are when there’s a “whooshing” that can be heard with a stethoscope or a “buzzing” (vibrations) that can be felt in your fingers with light pressure applied over the fistula.

If these signs are not present, the access may be clotted and therefore not usable for a dialysis treatment. You should call your nephrologist and dialysis unit immediately if you think your access is clotted. Clotting and infection are easier to treat when they’re found early. Early signs of infection include pain, tenderness to the touch, drainage through a previous needle hole, redness, swelling or warmth to the touch. Keep your access clean and dry between treatments.

Before needles are placed in your access site, wash the skin over your access. Anyone placing the needles into your access should wash their hands and put on gloves immediately before they touch your arm to place the needles. 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 the skin over 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, unless it is a life-threatening emergency . 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.

Regardless of the type of access used, the tubing connected to your access, carrying your blood to and from dialysis machine, must always be in plain sight, rather than covered by blankets or clothes. This is to prevent accidental blood loss if the needles or tubing become loose or dislodged.

For further information about hemodialysis access options, visit www.aakp.org to download a copy of the “Understanding Your Hemodialysis Access Options” brochure or call 1-800-749-2257 to order a copy by phone or download at www.aakp.org.

- 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 health care 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 health care 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 health care 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.

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. 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.

- 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 determine the right treatment option for you (dialysis or transplantation), 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 and hardening of the arteries, in turn leading to heart attacks, strokes and extremity amputation.
- 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 okay.

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.

- PAYING FOR TREATMENT -



Your health is the most important asset you have, and health insurance coverage is a close second. When you have good health insurance you are more likely to go see your doctor when you are ill. In turn, you have a better chance of staying healthy.

If you don't have health insurance and are worrying about how to pay for treatment and medicines, there are many options available to help pay for your dialysis treatment including Medicare, 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 website 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 or your insurance company. 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.

What is a Advance Health Care Directive?

Every competent adult has the right to make decisions concerning his or her own health, including the right to choose or refuse medical treatment. An Advance Health Care Directive allows you to do so. It is a written or oral statement about how you want medical decisions made should you not be able to make them yourself. Some people make advance directives when they are diagnosed with a life-threatening illness. Others put their wishes into writing while they are healthy, often as part of their estate planning.

Three types of advance directives are:

A Living Will: It is a written or oral statement of the kind of medical care you want or do not want if you become unable to make your own decisions. It is called a living will because it takes effect while you are still living.

A Health Care Surrogate Designation: It is a document naming another person as your representative to make medical decisions for you if you are unable to make them yourself. You can include instructions about any treatment you want or do not want, similar to a living will. You can also designate an alternate surrogate.

An Anatomical Donation: It is a document that indicates your wish to donate, at death, all or part of your body. This can be an organ and tissue donation to persons in need, or donation of your body for training of health care workers.

- THE GOVERNMENT'S ROLE IN HEALTH CARE -



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, health care professionals and patient groups, including the American Association of Kidney Patients, worked together to inform Congress that Medicare should pay for ESRD treatments. They discussed that if someone was on dialysis they could lead a normal life, but without treatment, they would die. They also educated 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. You can find out more about the ESRD Network that oversees your state at www.esrdnetworks.org.

- 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 health care team? Remember, it's to your benefit to ask questions, work with your health care team and take an active role in your health. When you're ready to receive Phase 2, contact the AAKP at 800-749-2257 or visit www.aakp.org to order/download a copy. 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.

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 referred 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.

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

GLOSSARY

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.

Erythropoietin (Epo): 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 autoimmune 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.

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.

GLOSSARY

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.

Polycystic Kidney Disease (PKD): 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.

GLOSSARY

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.

The Independent Voice of Kidney Patients Since 1969™

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