



KidneyBeginnings

A PATIENT'S GUIDE TO LIVING
WITH REDUCED KIDNEY FUNCTION

aa kp
*American Association
of Kidney Patients*

aakp Resources



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

AAKP Patient Plan® – This educational series provides comprehensive information on kidney disease and is available in four phases. It features detailed discussions on the treatment of kidney disease, medications, social concerns and much more. Phase 1 in the series contains a book and Phases 2, 3 and 4 each contain a book and a newsletter.



Kidney Beginnings: A Patient's Guide to Living With Reduced Kidney Function

– This educational piece addresses the concerns of those at risk for kidney disease. The book features information on the kidneys, how the kidneys work, diabetes, hypertension, medical tests, emotional issues, common medications and much more. It provides patients and family members with answers to questions about the health of their kidneys, diet and overall lifestyle.



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



AAKP My Health™ – This is a unique section of the AAKP Web site, www.aakp.org, dedicated to helping you take charge of your healthcare. **AAKP My Health** allows you to monitor your lab values, record valuable health contact information, store information about your medications and learn more about kidney disease and its impact on you anywhere Internet access is available.

Dietary Booklet – AAKP provides this pocket-size brochure as a guide to eating healthy with kidney disease. It contains the amounts of sodium, potassium, phosphorus, calories and protein in standard sizes of everyday foods. This brochure is also available in Spanish.

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

For more information or to request copies of any of the above materials, contact the AAKP National Office.



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Introduction

One in nine adult Americans has chronic kidney disease (CKD). However, many don't realize they have reduced kidney function. Therefore, they don't know they can take steps to protect their kidneys from further damage. If your doctor has diagnosed you with CKD, this book was written specifically for you and your family. Take the time to read through all the information and write down any questions you have in the spaces provided. At your next doctor's appointment, take this book with you and discuss your concerns with your doctor. You are the most important member of your healthcare team, and it's up to you to take a leadership role.

At this point, you most likely have a lot of questions, the largest one being, "What is CKD and why have I been given this book?" CKD means decreased function of the kidneys. Over time, the condition may progress and your kidneys may fail. The purpose of this book is not to scare you, however, it's to provide you with the information you need to take control of your healthcare and do what is necessary to preserve and protect your kidney function. There are many health conditions, which are discussed later in this book, that lead to CKD. If you've been diagnosed with one of these health conditions, there are many things you should know about your health that will impact your kidney function.

One common misconception about CKD is that it's something you don't have to worry about right now. Your kidneys are functioning and everything is fine, so that means kidney failure won't happen to you. This is a false hope that causes many people not to maintain their health and therefore increase the damage to their kidneys. Don't let this happen to you. There are things you can do to maintain or improve your health, and there are things you can do to protect your kidneys from further deterioration.



A Friendly Note: My name is Sam and I'll be your guide through this book. I'm like you. I have CKD. I used education to make myself more aware of my condition. I learned what I needed to do to protect my kidney function. As I'm sure you know, CKD doesn't go away. This isn't something you can watch for awhile and then suddenly everything becomes "normal" again and you never have to worry about CKD. CKD means you're at greater risk for kidney failure. If you do nothing, chances are your kidneys will fail. Take it from me, becoming involved in your healthcare, learning and doing what is needed makes a difference in your overall health.

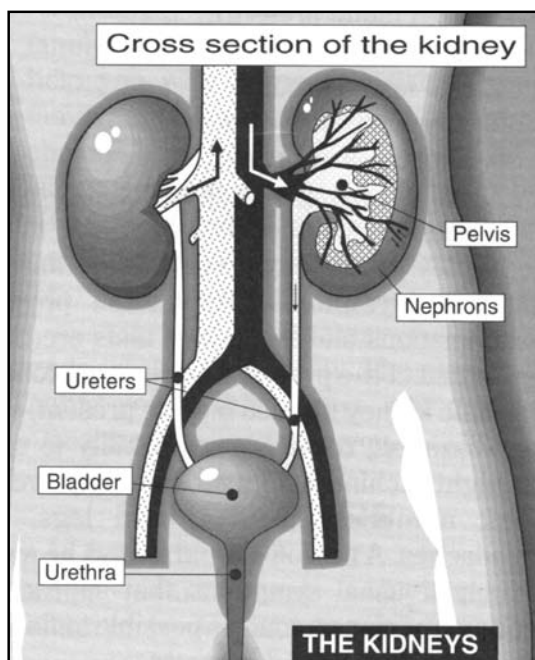
Kidneys 101

A Friendly Note: Before we can begin explaining CKD, you need to understand the role of your kidneys. The information below may have some medical terms with which you aren't familiar. We tried to explain everything, but sometimes it's difficult when we're dealing with medical terms. If you find something you're unclear about, jot down a note in the margin and ask your doctor about it on your next visit. Taking an active role means knowing what questions to ask when. Our doctors are here to help us and they don't mind when we ask questions. After I first found out about CKD, I kept a notebook with me at all times. Every time a question arose, I wrote it down and asked the doctor at my next visit. It really helps.



What are the kidneys and what do they do?

Kidneys are like a 24-hour cleaning machine for your blood. Kidneys are twin organs shaped like kidney beans. They're located below the rib cage in the middle of your back. In adults, each kidney is about the size of a closed fist. The kidneys are joined to your bladder by tubes called ureters. These tubes carry urine from the kidney to the bladder.



The kidneys filter your blood and make 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 near normal life with as little as 20 percent of their total kidney function.

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

- **Remove waste products from the blood.** As your body works, it builds up waste products that need to be removed. The kidneys are the “garbage collectors” that remove the waste from your body in the form

of urine. If it were not for the adequate removal of toxic substances in the urine, as well as in the stool, we would become ill.

- **Remove extra fluid.** Kidneys get rid of the extra water in your body.
- **Adjust levels of minerals and other chemicals.** The kidneys balance important minerals and chemicals in your body like sodium, potassium, calcium and phosphorus. For example, if you eat a lot of salt, the kidneys will get rid of the extra you do not need. It's important that these chemicals remain balanced in order for your cells to function correctly.
- **Produce hormones.** Kidneys make hormones (chemical substances that get in the blood stream) that help control your blood pressure. They also help to make red blood cells that carry oxygen to your whole body. The kidneys produce a hormone called erythropoietin (EPO) that stimulates red blood cell production by the bone marrow. Without EPO, red blood cell production declines. This results in a condition known as anemia. Anemia causes extreme fatigue and overall weakness. Kidneys also make vitamins needed for strong bones.

Chronic Kidney Disease



A Friendly Note: The phrase “chronic kidney disease” may sound foreign to you. This section will answer some of the most commonly asked chronic kidney disease (CKD) questions. However, this section doesn’t answer everything. You’ll find other valuable information throughout this book. Be sure to read through it thoroughly and ask your doctor any questions you may have.



Will I know if I start to have kidney problems?

Not necessarily. The early signs of CKD can be subtle and therefore many people do not realize they have symptoms of the condition. The symptoms can include high blood pressure, blood in the urine and swelling in the legs, feet or hands. The only way to know for sure if you’re starting to have kidney problems is a simple test which detects protein in the urine. Do not wait for signs of kidney damage to have your urine tested. Talk to your doctor and ask what type of tests you should have performed.

A Friendly Note: You play an important role in your healthcare. Actually, you ARE the most important player. And, as the most important player, you need to be informed and involved. Not only do you need to have an understanding of the tests being performed and the measures you should take to preserve your kidney function, but you need to realize it’s OK to ask questions, share insight and keep track of your own health.



What’s the best way to be an active member in my healthcare?

The answer is simple. Get involved with your healthcare. No one knows your body better than you. By understanding the various tests performed to measure kidney function, you can become active in monitoring your health. By doing this, you will also become more aware of the activities that can slow down the progression of kidney disease. If you take an active role in your healthcare and understand your condition, whatever challenges you face will be less complicated to adjust to.

What should I do when my doctor recommends a new test?

When your doctor prescribes a test to gauge your kidney function, there are several questions you should ask. When you ask the questions, make sure you write the answers on a piece of paper. Some people like to keep a journal in which all of their important information is kept. This will help you later when you’re trying to digest everything the doctor has told you.

Whenever you deal with a subject that's new or unfamiliar to you, it's easy to become overwhelmed and confused. It's important to remember that the healthcare team is there to help you. Don't become frightened because you don't understand something. Instead, ask questions.

Sample Questions to Ask:

- What is the name of the test?
- Why do I need this test?
- Could the test results change the treatment of my condition? If so, how?
- How accurate is the test? Is there a chance for a false-positive or a false-negative result?
- Is there anything I should do to improve the accuracy of the test?
- Is there anything special I need to do before the test, such as limiting food intake, fasting, not taking medications, exercising, etc.?
- Is this test covered by my insurance?
- Are there any consequences if I delay or avoid having this test done?
- Are there any health risks associated with this test? If so, what are they?
- When and how will I receive the test results? What will the results mean?
- What is the next step if the results are normal or abnormal?



*A Friendly Note: After you have a test performed, when the doctor calls or when you meet with the doctor to discuss the results, you should be prepared with a pen and paper. Try to write down as much as you can. This will help you remember what your doctor has told you. You may also want to take someone to the doctor appointment with you. With another person there, you have the advantage of hearing with two sets of ears. This will help you if you have questions later on about what your doctor said. Another helpful tool is **AAKP My Health™** located on the AAKP Web site, www.aakp.org. I use it. **AAKP My Health** allows you to track your lab results, information about your medications, doctor visits, prepare information for upcoming doctor visits and store your healthcare team contact information. This is a FREE service provided by AAKP.*

When I have tests done, what should I do with the results?

Keeping track of your own results puts you in control of your healthcare. The more you know about CKD, your percentage of kidney function, your hemoglobin and other important results, the better you can take care of yourself. In the Appendix, there are three sample tracking charts to help you keep a history of important test results.

You should also take an active role in monitoring your own health. Purchase a blood pressure cuff and learn to take your own blood pressure and track the results. By keeping track of your test results, you'll know what questions to ask your doctor during the next visit.

What tests may be performed to gauge my kidney function?

Kidney disease is diagnosed and monitored by measuring various substances in your blood and urine. There are several tests that may be performed to monitor your kidney function. It's just as important to know the purpose of these tests as it is to keep track of your own test results. By doing this you are taking an active role in your healthcare and becoming more aware of your personal health.

The tests your doctor may order will help him/her evaluate several factors related to your kidney function and overall health. The tests will answer questions such as, what is your current kidney function, what is causing your kidney function to decrease, what treatment options are available to slow the progression of kidney failure, etc.

When kidney function is reduced, certain substances begin to build up in the bloodstream. The following blood and urine tests measure changing levels of these substances in the bloodstream. This will help your doctor determine how well your kidneys are working.

● **Complete blood count (CBC).** A complete blood count is a very common test and can tell your doctor a lot about what's happening with your kidneys. Your blood is made up of three basic types of cells: red cells, white cells and platelets. Red cells carry oxygen to body tissues and remove carbon dioxide. White cells fight infections and harmful substances that invade the body. Platelets help stop bleeding by plugging leaks in blood vessels. It takes all three types, working together properly, to perform vital bodily functions. In order to know if your blood cells are functioning properly, a CBC is commonly performed to measure the levels of the different types of cells in your body.

A CBC is a relatively fast and painless procedure. A healthcare professional will take blood from your vein. The blood sample is then sent to a laboratory for analysis (*see CBC chart on page 54*). This chart will help you learn how to read your own CBC results.

● **Creatinine and creatinine clearance.** Creatinine is filtered out of the blood by the kidneys and then passed out of the body in urine. Creatinine is a waste product of muscle tissue. A creatinine clearance test measures how well creatinine is removed from the blood by the kidneys. Compared to a blood creatinine level, a creatinine clearance test provides a more precise measure of how well the kidneys are working. A creatinine clearance test is performed on a blood sample taken from a vein. Additionally, a sample of urine is collected over 24 hours. If the kidneys are damaged and not functioning normally, the amount of creatinine in the urine decreases while the amount of creatinine in the blood increases. Creatinine levels in the blood can vary, and each laboratory has its own normal range. In many labs the normal range is 0.6 to 1.2 mg/dL.

● **24-hour urine collection for protein in the urine.** In this test, all of the urine produced in 24 hours is collected and the amount of protein in the urine is measured in the laboratory. Normally there is little or no protein in urine. Increased amounts of protein indicate reduced kidney function.

● **Blood urea nitrogen (BUN) level.** Along with an increase in creatinine, an increase in urea nitrogen in the blood (blood urea nitrogen, or BUN) can help estimate how well the kidneys are removing wastes from the bloodstream. Urea is a waste product formed when protein is broken down in the body. Urea is produced in the liver and eliminated from the body in urine. A BUN test measures the amount of nitrogen in the blood that comes from urea. It's done to estimate how well the kidneys are functioning. If the kidneys aren't able to remove urea from the blood normally, the BUN level increases. The test is done from a blood sample. A normal BUN level is between 7 and 20 mg/dL.

● **Blood electrolyte tests.** Electrolytes are also filtered out of the body by the kidneys. If there are altered levels of the following electrolytes in the blood, it may mean the kidneys are not functioning adequately:

- Potassium > 3.5 – 5.0 mEq/L
- Sodium > 135 – 145 mEq/L
- Phosphate > 2.4 – 4.5 mg/dL
- Calcium > 8.5 – 10.5 mEq/L
- Magnesium > 1.5 – 2.0 mEq/L

- **Kidney Biopsy.** A diagnostic test where a small piece of kidney tissue is removed by a needle. The tissue is looked at under a microscope to determine the cause of kidney failure.
- **A1C.** A blood test that gives an estimate of blood glucose control over several months.
- **Serum Creatinine Level.** A blood test used to evaluate kidney function.
- **Glomerular Filtration Rate (GFR).** A measurement of how well your kidneys filter waste products. Determined by calculating the creatinine clearance.

A Friendly Note: These may be a lot of strange sounding tests. Don't be alarmed by the name of the test. When your doctor recommends a test, ask questions to find out more about the test and what the results of the test will tell your doctor.



How is percentage of kidney function measured?

The percentage of kidney function is measured by comparing the amount of waste products in the urine to the amount in the blood stream. The waste product most frequently measured for this purpose is creatinine. Creatinine is a waste product of muscle tissue.

Kidney function is measured by the clearance of creatinine from the blood stream. The term creatinine clearance is used to describe the ratio of the amount of creatinine in the urine to that in the blood plasma. A 24-hour urine collection is also used to calculate kidney function.

A normal creatinine clearance ranges from about 80 to 130. For example, someone with a creatinine clearance of 55 has about 50 percent of normal kidney function. Sometimes a formula is used to estimate the creatinine clearance without measuring creatinine in the urine. Instead the doctor uses a blood value and adjusts for the person's size, age, gender and race. This formula is called the Glomerular Filtration Rate or GFR.

What is GFR and what role does it play in measuring my kidney function?

The MDRD Glomerular Filtration (GFR) is one of the best methods for measuring your kidney function. A GFR tells your doctor how well your kidneys are working. GFR is calculated from your blood creatinine, age, body size and gender.

The equation to calculate the GFR was derived from a large study published in 1994 that looked at how the modification of dietary protein would affect renal disease - hence Modification of Diet in Renal Disease (MDRD). **There are five stages of CKD based on GFR:**

- Stage 1: GFR more than 90, may be slight kidney damage with normal or increased GFR.
- Stage 2: GFR 60-90, mild decrease in kidney function.
- Stage 3: GFR 30-60, moderate decrease in kidney function.
- Stage 4: GFR 15-30, severe decrease in kidney function.
- Stage 5: GFR less than 15, kidney failure. Dialysis, transplant or no treatment using palliative care is necessary at this point. Dialysis or transplant is the usual treatment option.



A Friendly Note: You should always know your GFR number. This helps you understand where things are with your kidney function. When your doctor tells you your GFR stage, keep track of it in the notebook where you're writing down all your questions.

My doctor is watching for protein in my urine. Why is this?

Protein in the urine is called proteinuria. It is often the first sign of kidney disease. Very small amounts of protein in the urine are referred to as microalbumin. If you are a person with diabetes, one of the first signals that you may be experiencing diabetic nephropathy (decreased kidney function) is microalbumin. Consequently, testing urine for the presence of protein should always be a part of a routine medical exam.

A dipstick test (a special strip of paper that's quickly dipped into a sample of urine to test its chemical makeup) may be done. The dipstick test only becomes positive when the amount of proteins, mainly albumin, reaches two to four times the levels normally found in urine. In people with diabetes, the first sign of kidney problems is an even lower level of proteinuria, called microalbuminuria, that is too low to be detected by a dipstick test. There are also new sensitive dipsticks that detect microalbumin.

In diseases affecting the kidneys' filters, proteinuria is a sign of some sort of kidney disease. This may be related to the presence of heart disease. If the leakage is heavy, protein lost may be enough to cause a fall in the level of albumin in the blood. This can cause swelling of the ankles or face and an increase in blood cholesterol levels. This condition is called the nephrotic syndrome.

When the doctor finds proteinuria, further tests are needed to sort out the cause. Is it due to kidney disease? If so, what is the disease? Is it caused by diabetes or some other generalized disease that involves the kidneys? In many cases, it may require a kidney biopsy to determine the cause of the proteinuria.

After a diagnosis is made, treatment is aimed at reducing leaked protein. This may include dietary advice to restrict protein intake. Various drugs can be used, depending on the diagnosis. These may include ACE (angiotensin converting enzyme) inhibitors, angiotensin receptor blockers (ARBs), steroids, cytotoxic agents and other drugs. In addition, other treatments may be required when the cause of the proteinuria is a more generalized disease such as diabetes. Much research is taking place at this time to find out what are the best treatments for the various diseases that can affect the kidneys and cause proteinuria.

How often should I see my doctor when it's related to CKD?

Your doctor will work with you to determine a schedule for follow-up visits. However, you should see your doctor right away if you get a bladder or kidney infection. Signs of a bladder or kidney infection include cloudy or bloody urine, pain or burning when you urinate and frequent urination. Back pain, chills and fever are also signs of a kidney infection.

What can I do to protect the function of my kidneys?

You can do things to slow the progression of CKD. The sooner you change your habits, the better!

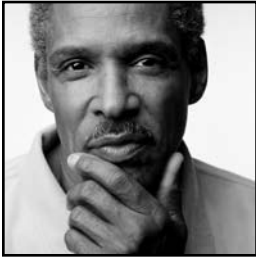
- **Control high blood pressure (hypertension).** Even if your doctor has prescribed medication for you, there's still a lot you can do to lower your blood pressure. Changes in your lifestyle and reducing salt in your diet, along with diet and/or behavior changes can help control high blood pressure. A blood pressure reading of 120/70 is considered normal for an adult. It is very helpful to check your blood pressure at home at least several times each week, record the results and bring your record with you to the doctor's office. Your doctor can teach you how to measure your blood pressure. Discuss your target blood pressure with your healthcare team.

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- **Keep your blood sugar level in a safe range**, especially if you have diabetes. An A1C blood test can tell you and your doctor if your blood sugars have been within a normal range for the past two to three months. A normal range is between 4.5 percent and 6 percent. If your blood sugar is not within this range, talk to your doctor or diabetes educator and find out what you need to do to maintain your blood sugar level. The optimal goal for A1C is less than six, but less than 7.0 is acceptable in advanced CKD to minimize the risk of hypoglycemia while maximizing slowing progression.
 - **Reduce the amount of protein you eat.** Your doctor may recommend you meet with a dietitian to restrict the amount of protein in your diet. For more information about protein, see the “Nutrition” section of this book.
 - **Maintain healthy levels of fats** (known as lipids), such as cholesterol and triglycerides, in your blood. See the Appendix for normal values of cholesterol, as well as a cholesterol tracking chart.
 - **Quit smoking.** If you do not smoke, do not start. If you smoke, discuss cessation efforts/techniques with your doctor.
 - **Exercise.** Consistent physical activity and/or exercise will have a profound affect on your blood pressure and sugar levels. A few proven benefits include: increased energy, strengthening heart and other muscles, weight control and self esteem. Talk to your doctor before beginning a new exercise routine.
 - **Medications.** Take all of your medications as prescribed. Do not skip or leave out doses.



A Friendly Note: There's a lot you can do to protect your kidney function. If you're feeling like I first did, you may feel like there's not much you can do. Whatever's going to happen is going to happen and that's it. That thinking couldn't be further from the truth. You have a lot of control over your health. The doctors can guide you, but you're the one who can make the ultimate difference. Don't just skim over this list. Read it carefully, and make the changes you need to make. Ask questions and do not be satisfied until you understand the answers.

CKD Risk Factors



There are several conditions and diseases that can eventually lead to CKD. Two of the most common conditions are diabetes and hypertension (high blood pressure). Diabetes is the single leading cause of kidney failure in the United States, accounting for about 44 percent of the people who start treatment for kidney failure each year, and about 38 percent of all Americans being treated for kidney failure. Twenty-six point five percent have high blood pressure as causes of kidney disease. The remaining 29.8 percent lost kidney function due to another condition. Because diabetes and hypertension are two of the main causes of kidney failure, these conditions are explained in further detail in the next section. Most people with kidney disease have hypertension.

A Friendly Note: If you have one of the below mentioned conditions it doesn't mean you WILL develop kidney failure, however, it does mean you're at greater risk and it's in your best interest to understand your condition and do what's necessary to maintain your health. You're also at greater risk if you are African American and/or have a first degree relative (mother, father or sibling) with kidney disease.



Diabetes - Diabetes is a disease of high blood glucose (sugar) levels caused by either a reduction or lack of insulin or resistance to it in the body. High glucose can disrupt the structure and function of blood vessels. Most people with type 2 diabetes do not have a reduction in insulin but the body does not react to insulin in a normal fashion. This is often associated with obesity and occurs after the age of 30. People with diabetes have an insulin deficiency, which results in abnormal metabolism of carbohydrates, fat and protein. Over time, the small vessels of the kidneys are affected, causing destruction of the filters of the kidneys.

Diabetes has become the most common single cause of end-stage renal disease or kidney failure in the United States and Europe. People with diabetes constitute over half of those currently starting dialysis.

Hypertension (high blood pressure) - 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 - Glomerulonephritis is an inflammation of the filters of both the kidneys. This is sometimes due to infection. It results in slow, progressive damage. Early diagnosis is difficult because there are minimal symptoms in the early stages of this disease.

Nephrotic Syndrome - Nephrotic syndrome occurs when excess amounts of protein pass from the blood into the urine. Nephrotic syndrome results from massive losses of protein, large amounts of water stay in your body. This causes overall swelling in your body, called edema.

Polycystic Kidney Disease - Polycystic kidney disease (PKD) is an inherited disease in which abnormal sacs, called cysts, develop in the kidneys. These cysts usually contain fluid, gas or tissue. As these cysts grow, they block normal kidney function. Cysts may be painful because of the blockages. Cysts can get infected and can bleed. If you have polycystic kidney disease, you'll still urinate in normal amounts, but the harmful waste products are not removed from the body.

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

Chronic Pyleonephritis or Kidney Infection - Kidney infection is an inflammation of the tissues of the kidneys surrounding the filters. Infection and other forms of inflammation, if left untreated, can cause kidney failure. There is no evidence that kidney infections alone (i.e. without structural abnormalities like obstruction or scarring) can cause kidney failure.

Kidney Stones - 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.

Prostate Obstruction - As men age, the prostate can grow, blocking normal urine drainage.

Family Connection - If you have a family member who's on dialysis or who's had a kidney transplant, you may be at an increased risk of developing kidney disease.

Diabetes and Hypertension



A Friendly Note: Don't be alarmed with these statistics. Instead, use this information to understand what you should do to protect your kidneys.



If I don't watch my blood sugar levels, what can happen to my kidneys?

If you have diabetes, it's because your body does not make enough insulin or cannot properly use the insulin it does make. Your body uses insulin to convert sugar into energy. If your body doesn't have the insulin it needs to do this, the sugar stays in your blood and damages parts of your body. The high blood sugar can damage (weaken) your kidney's glomeruli – the filtering system for your kidneys. To protect your kidneys, it's important you control your sugar levels.

How else can diabetes damage my kidneys?

When kidneys are working well, the filters keep protein inside your body. You need the protein to stay healthy.

High blood sugar (described above) and high blood pressure damage the kidneys' filtering system. When the kidneys are damaged, the protein leaks out of the kidneys into the urine. Damaged kidneys don't do a good job of cleaning out waste and extra fluids. So not enough waste and fluids go out of the body as urine. Instead, they build up in your blood.

An early sign of kidney damage is when your kidneys leak small amounts of a protein called albumin into the urine. This is called microalbuminuria.

With more damage, the kidneys leak more and more protein. This condition is called proteinuria. More and more wastes build up in the blood. This damage gets worse until the kidneys fail. When there's protein in the urine, it increases the chance of heart disease.

How can I prevent diabetic kidney problems?

- Keep your blood sugar as close to normal as you can. Ask your doctor what blood sugar numbers are healthy for you.
- Keep your blood pressure below 130/80 to help prevent kidney damage. Ask your doctor what blood pressure is best for you. If you take blood pressure pills, take them as your doctor tells you. Keeping

your blood pressure under control will also slow damage to your eyes, heart and blood vessels.

- Follow the healthy eating plan you work out with your doctor or dietitian. Change your meal plan as suggested by your doctor and/or dietitian. In particular, reduce the salt in your diet.
- Have your kidneys checked at least twice a year by having your urine tested for small amounts of protein.
- Have any other kidney tests that your doctor thinks you need.
- See a doctor immediately if you think you have a bladder or kidney infection. You may have an infection if you have any of these symptoms:
 - Pain or burning when you urinate.
 - Frequent urge to go to the bathroom.
 - Urine that looks cloudy, reddish or brown.
 - Fever or a shaky feeling.
 - Pain in your back or on your side below your ribs.

HYPERTENSION (HIGH BLOOD PRESSURE)

How does high blood pressure damage the kidneys?

High blood pressure is a condition that can damage your kidneys. Your kidneys act like a filtering system to get rid of excess water and wastes in the blood. Blood pressure is the force, or pressure, of the blood on the walls of your blood vessels. Over time, uncontrolled high blood pressure can damage the blood vessels and nephrons (filtering units) in the kidneys. The damaged nephrons can't do their job of filtering out all of the wastes, sodium and excess fluids from your blood. The excess fluid and sodium stays in your bloodstream putting extra pressure on the walls of your blood vessels - raising your blood pressure even more. This extra pressure leads to further kidney damage. High blood pressure also affects many other organs, slowly destroying them. This includes the heart, brain and eyes.

My doctor told me that controlling my kidney disease means controlling my blood pressure. What does this mean?

Blood pressure is the force of blood inside an artery. The readings are made up of a systolic number (the top number) and a diastolic number

(the bottom number). The systolic blood pressure is when the heart beats and the diastolic blood pressure is when the heart is at rest. A blood pressure reading consists of an upper number and a lower number. As an example, this is stated as “120 over 80 or 120/80.” Blood pressure readings are measured in units called millimeters of mercury or “mm Hg.”

Your blood pressure is considered high if the top number (systolic number) is equal to or greater than 130 mm Hg or the bottom number (diastolic number) is more than or equal to 80 mm Hg. Hypertension can be both a cause and result of kidney disease.

The Joint National Committee on the Prevention, Detection and Treatment of Hypertension states that blood pressure for patients with protein in their urine should be controlled to 130/85 mm Hg or lowered to 125/75 mm Hg. This can help preserve kidney function and protect the kidneys from further damage.

Atherosclerosis is the development of plaque of fatty clots which hardens and narrows the arteries. It is aggravated by hypertension. High blood pressure increases the workload on the heart. It can also affect the heart’s pumping ability and may lead to heart failure. High blood pressure increases the risk of coronary artery disease, aneurysms, stroke, kidney disease and eye problems. Most patients with hypertension eventually develop microalbuminuria.

Are there medicines to slow down kidney damage?

Yes. The strategy to control blood pressure is to use medicines that have additional benefits. Angiotensin is a hormone your body makes that constricts smooth muscles in the vessels of the kidney and in other vessels as well. There are two types of drugs that can block this hormone: angiotensin converting enzyme (ACE) inhibitors and angiotensin receptor blockers (ARBs). ACE inhibitors decrease your blood pressure by opening or dilating blood vessels. ARBs work by blocking the hormone that causes blood vessels to narrow. Both types of drugs have been shown to help reduce the progression of kidney disease, especially in diabetics.

Since the target blood pressure required to help protect the kidneys is often lower than you can achieve with one drug, your doctor may have you take additional medications. Calcium channel blockers are also

useful, but are generally recommended for use once you are already on an ACE inhibitor or ARB. The calcium channel blocker dilates the blood vessels by relaxing the muscles in the vessel walls, thus making it easier for blood to flow through the vessels. Other drugs such as beta blockers are also used.

Your doctor may prescribe a diuretic for you. Diuretics are used to remove extra sodium and fluid from the body. Eliminating excess fluid may lower your blood pressure and assist the other drugs mentioned above.

Blood pressure can also be reduced with diet, especially one lower in salt, and exercise which is very important. But most people with hypertension will also need to take medication over the course of their lifetime in order to achieve optimal blood pressure and slow the progression of CKD.



***A Friendly Note:** Don't let this information overwhelm you. Education is the key to living a healthy life and knowledge is power! Having diabetes or hypertension doesn't mean you'll experience kidney failure. In fact, only three percent of all diabetics today have complete kidney failure. But, it does mean those with diabetes and high blood pressure must be extra alert about their kidney health.*

Side Effects of CKD



A Friendly Note: Having CKD doesn't just mean you're at risk for kidney failure. However, it means you may also experience other problems with your health as well. As it has been explained earlier, the kidneys do a lot more than create urine. I learned early that I'm the one who knows my body best. I knew something wasn't right when I constantly felt tired and worn out. I talked to my doctor and found out I was anemic. Luckily, I'm now taking iron and erythropoietin and I feel a lot better. Anemia is explained in this section.



ANEMIA

CKD may make you feel extremely tired, weak or exhausted. This is called fatigue. You may find it hard to do some of your normal daily tasks or activities. If you've been feeling especially tired since you developed kidney problems you might have a condition called anemia. Anemia is a condition in which the body doesn't have enough red blood cells. Red blood cells carry oxygen throughout your body. Oxygen acts like fuel for the body, providing energy for muscles and organs to work. It's the lack of oxygen that causes the extreme fatigue.

Normally functioning kidneys make a hormone called erythropoietin (Epo). This hormone helps form red blood cells. When you have reduced kidney function, your body may lack this hormone and cause anemia.

What are the symptoms of anemia?

One of the more common side effects of anemia is fatigue, or excessive tiredness. Other symptoms include:

- Dizziness
- Headaches
- Loss of sex drive
- Inability to concentrate
- Shortness of breath

The fatigue you're feeling is real, and may be a direct result of your condition. It's not just feeling tired after a bad night's sleep or needing a nap once in awhile. Fatigue is an extreme level of exhaustion and it interferes with your daily life. How you describe fatigue will depend on your lifestyle and how fatigue is affecting it. You may have trouble focusing at work; household chores may become overwhelming; or a walk may feel like a 10-mile run. So, talk to your doctor or nurse about your condition. Ask if anemia is causing it.

Use This Form to Monitor Your Activity Status and Share the Answers with Your Doctor to Help Evaluate if You Have Symptoms of Anemia

(For a tear-out form to take to your doctor, please see the Appendix.)

- 1** Since you started having trouble with your kidneys, have you had to cut back on everyday activities (grocery shopping, walking the dog, etc.)?
 Yes No Somewhat
- 2** Is it more difficult for you to walk up stairs without becoming tired or short-of-breath?
 Yes No Somewhat
- 3** Is it hard for you to stand in line for a long time because you feel weak?
 Yes No Somewhat
- 4** List two or three activities you can no longer do.
- 5** Can you no longer perform these tasks because of weakness or tiredness?
- 6** Which daily activity do you enjoy doing the most?
- 7** Please rate your ability to do this activity now:
 1 = Equally Able, 5 = Not Able

1 2 3 4 5
- 8** Are you frustrated by not being able to do the things you want to do?
 Yes No Somewhat
- 9** Please rate the impact tiredness/weakness has had on your ability to lead a "normal" life:
 1= Very Little Impact, 5 = Tremendous Impact

1 2 3 4 5
- 10** I am content with the quality of my life right now:
 1 = Very Content, 5 = Not Content

1 2 3 4 5
- 11** Do you know your hemoglobin (red blood cell) count?
 Yes No

If yes, enter it here: _____

If no, ask your doctor.

What can be done to prevent or control anemia?

As a person with CKD, you may not be making enough erythropoietin and your doctor may prescribe a special medication. This medication is a man-made form of erythropoietin called erythropoietin stimulating agents or ESAs. It may be given by injection into your vein, called an intravenous or IV injection. It can also be given by a very small injection under your skin, called a subcutaneous or S.C. injection.

Taking iron by mouth (oral iron) is important while taking ESAs. As new red blood cells are being formed, they need iron to support their growth and this is why oral iron is needed. Some patients taking ESAs need to receive iron through the vein. The amount of iron your body keeps stored won't be enough to make all the new red blood cells you need.

How will my doctor know if I'm anemic?

A blood test will give your doctor a picture of how many and healthy your red blood cells are. It will show if you are anemic.

There are other blood tests that show how your red blood cells are doing and there are blood tests that show where the iron is in your body and how it's being used.

The red blood cell tests are:

- **Hemoglobin:** This is the amount of the substance that carries oxygen to your body tissues. It contains iron.

Normal Hemoglobin Ranges

Male	14-18 g/dL
Female	12-16 g/dL

Hemoglobin Target Range for CKD Patients Receiving ESAs

10-12 g/dL

(Hemoglobin is measured in grams (g) per deciliter (dL).)

- **Hematocrit:** This is the fraction of the blood, which consists of red blood cells and plasma, that is red blood cells. The target hematocrit range for CKD patients receiving ESAs is 30-36 percent.

The iron blood tests are:

● **Ferritin:** This is a protein that keeps iron in “storage” until it’s needed. To optimize blood cell production, your serum ferritin should be maintained greater than 100 ng/ml if you have CKD not on dialysis or peritoneal dialysis and greater than 200 ng/ml if you’re on hemodialysis. Your doctor will know when to start iron and when to stop it. When you have a serious infection, it’s possible that your body will hold onto the iron in storage. In this case, you may have a high ferritin level but the body cannot use it even though you don’t have enough iron in your blood cells. If this happens to you, you should receive treatment for your infection before continuing to receive your supplemental iron therapy.

● **Transferrin saturation:** Transferrin is a protein that takes the iron from the storage protein (ferritin), or the iron that you’re being treated with, and takes it to the bone marrow where it may be used to build healthy red blood cells. This blood test measures the amount of iron on the transferrin protein. If your transferrin saturation is less than 20 percent, it means you do not have enough iron for your red blood cells. The normal transferrin saturation range should be between 20 and 50 percent.

What type of iron may my doctor prescribe?

There are two ways of taking iron if diet alone is not enough. Your doctor may first prescribe oral iron pills that you may buy without a prescription. Oral iron is usually given three times a day between meals. How and when you take oral iron is very important.

- Take iron one hour before or two hours after a meal.
- Do not take with antacids.
- Do not take with phosphate binders.
- Avoid alcohol.

If you begin to get constipated, have nausea or a feeling of fullness; try increasing your iron dose slowly.

If you’re not able to reach a good blood count with oral iron, your doctor may prescribe intravenous (given as an IV) iron.

Erythropoietin and iron work together to help your body make more healthy red blood cells.

How can I monitor my energy level?

This chart will be an excellent reference for both you and your doctor to track your activity and energy levels, as well as your hemoglobin level. A longer chart can be found in the Appendix. You may find that you're feeling more energetic when your hemoglobin level is high and less energetic when your hemoglobin level is low. To use the chart, record the date and your hemoglobin level and then place an "X" in the box that corresponds best to your energy level.

You can obtain your hemoglobin level each time you visit your doctor by asking for the results of your Complete Blood Count (CBC). Look for Hb, the symbol for hemoglobin on your results.

Date:	Ex 5/15					
Hb Level	12					
5 - Can do most normal activities	X					
4 - Can do less than normal activities						
3 - Can do some normal activities						
2 - Can hardly do any activities						
1 - Cannot do any activities						

Your Emotions



When you first learned about your condition, whether it was diabetes, high blood pressure, polycystic kidney disease, etc., you most likely dealt with a variety of emotions. At some point while you were adjusting to the change in your health you probably felt anger, depression, confusion, frustration to name just a few. Everyone reacts differently and finding out you may be at risk for kidney failure is likely to cause another rollercoaster of emotions. You may experience emotions shortly after you're told about CKD or you may experience them much later. Either case, it's important to know your healthcare team is available to answer your questions.



A Friendly Note: No one benefits when you keep emotions bottled up inside of you. 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 embarrassed to share your fears and concerns. When you talk about these things, many times it helps to ease those anxieties.

What emotional changes might I experience?

● Depression and Anxiety

Depression and anxiety are two common feelings you may experience. These feelings are normal when a person is facing a change in his/her health. Sadness, anger, loss of appetite, trouble sleeping, lack of interest in sex or daily living can be signs you're 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.

● Anger

Anger is also a normal response to learning you have a chronic health condition. This is a time when you'll have a lot of questions about your condition and the future. You may be angry because you feel like you're losing control. However, education and involvement in your care can help you regain some of that control.

● Despair

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. Becoming involved and understanding your health can ease the feeling of despair.

● Isolation

Isolation is when you pull back from the people in which you usually depend. 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 condition. Remember, your family and friends want to help you. It's OK to lean on someone for support.

Your feelings may change. Just because you feel one way today, doesn't mean you'll feel the same way tomorrow. And, you're not the only one who may be experiencing emotional changes. Your family and friends may have similar feelings. Many times it helps to share your feelings and learn what others are thinking. This strengthens the support system for you and your family/friends.

How do I tell my family and friends?

Deciding who to talk to and who to tell you've been diagnosed with CKD is an individual decision. How did you tell people about other chronic diseases you may have such as diabetes? If that process worked well for you then, it should work well for you again. People often ask how to tell family and friends. There are no "cookie cutter" phrases that work for everyone. Sharing the information in an honest, open and direct way is the best approach. This can be challenging. Our natural instincts cause us to 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 important to be open when explaining your CKD with young and old alike. Remember, your family and friends may experience many of the feelings you did when you found out. It's OK for them to feel sadness, fear, despair and isolation.

Sharing about your CKD with your family is also important to their health since relatives can have a higher incidence of kidney disease. You should suggest they also get tested for CKD.

A Friendly Note: : It's important not to block out your family and friends during this time. They're a great support network and can help you watch your health. I know this is scary and a lot of times we try to be strong for our families. It's the "I can handle anything" philosophy. I'm not saying you can't handle this, but I am saying it's a lot easier when you let someone help you.



What else should I do?

During any health condition, there will be difficult times when the support of others can influence you. Keep communication open with your family so they can understand and feel a part of decisions, too. Dealing with a chronic illness can be scary for spouses and children, but knowledge is power and often provides strength. Scheduling a weekly or biweekly family meeting is an ideal way to keep the lines of communication open. It's a perfect opportunity to check how everyone is doing – not only regarding the diagnosis of CKD, but life in general. Even though you've been diagnosed with CKD, there are still life issues not necessarily related to CKD that will need addressing. You may also want to join a support group or attend a patient educational seminar. Check with the American Association of Kidney Patients (AAKP) for a program in your area.



A Friendly Note: When I first found out about CKD, my family and I started to hold a weekly family meeting. At first, we talked a lot about my health and this was very helpful for my children, but soon we started talking about other things. We still hold the weekly family meetings. I like them because my children feel comfortable asking me questions about my health and I learn about things that are going on in their lives.

Your Healthcare Team



I'm facing a new team of healthcare professionals. What are their roles?

There are many people who will be involved with your care. This “team approach” is helpful to make sure all your needs are met. Although helpful, it can be confusing sorting out “who is who” and “who does what.” Each of these “team members” is responsible for certain areas of your care. You, however, are the expert on you and your family. You need to be part of the team to help everyone understand what you need. You need to let the team know how CKD affects you and your family. Working together as a team will help you receive the treatment and care that will work best for everyone. Below is a summary of some of the members of your healthcare team.

- **Specialist** - A specialist is usually a kidney doctor - nephrologist, but could also be a cardiologist, diabetologist and others. Whether you have high blood pressure, diabetes, lupus or any condition that put you at risk for kidney failure, currently you are most likely seeing a specialist for this primary condition. This specialist is aware of your health condition and your CKD. He or she will work with you to help you preserve your kidney function and maintain your health. The specialist 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. Remember to take notes of your doctor's answers.
- **Primary Care Physician** - A doctor who delivers basic or general care that is intended to be the patient's first level of contact with the medical care system. Primary care physicians are trained in every major area of medicine, they serve as the primary source of a patient's healthcare throughout life.
- **Nurses** - The experienced registered nurse (RN), licensed professional nurse (LPN) or nurse practitioner (ARNP) is an excellent person to answer questions about CKD and daily care. Most nurses realize that answering your questions now will help you make healthy choices. If you have a question, don't hesitate to ask it.
- **Dietitian** - Your doctor may refer you to a dietitian. Since one way to preserve kidney function is to modify your diet, a dietitian will help you make good food choices. Watching what you eat and drink may

be one of the hardest changes you make. A dietitian can help you make meal choices, which will help keep you healthy. Dietitians aren't there to "police" you, but to work with you to make the best choices possible. If your doctor hasn't recommended a dietitian and you're interested in finding one in your area, visit the American Dietetic Association's Web site at www.eatright.org.

- **Social Worker** - If you're referred to a social worker, he or she can provide you with a great deal of information, from financial resources to coping and support systems. The social worker can explain hard to understand information in easy to understand words. They can help you with work, insurance and rehabilitation issues. The social worker can help you adjust to the feelings you're experiencing.

- **Nephrologist** - You may be referred to a nephrologist. The nephrologist is a doctor who has had special training on how to treat kidney disease. Your nephrologist will work with you and the rest of the healthcare team. A plan to treat your disease and manage your health will be developed. You'll see your nephrologist on a regular basis. Your nephrologist will monitor your health. He will make changes as needed to help you stay healthy.

- **Diabetes Educator** - Diabetes educators are health professionals, nurses, dietitians, pharmacists, exercise specialists, doctors and social workers, who specialize in the treatment of people with diabetes. They help you learn to live a healthier, more productive life with diabetes. Diabetes educators work in a variety of settings. You will find many of them in hospitals teaching patients in group classes or they may work with patients individually. They also may be found in doctor's offices, nursing homes or neighborhood clinics.

- **Pharmacist** - A professional who fills prescriptions, and in the case of a compounding pharmacist, makes them. Pharmacists are familiar with medication ingredients, interactions, cautions and hints. Pharmacists are trained to prepare and distribute medicines and to give information about them. Let your pharmacist know you have CKD. Many medications, including over-the-counter medications are cleared from your body by your kidneys. Your pharmacist can check each medication and ensure their use with CKD is appropriate.



A Friendly Note: That's a lot of healthcare people to remember. It should also make you feel safer. Look at how many people are available to help you maintain your health. The important factor to remember is that you should always feel comfortable asking your healthcare team questions. The more questions you ask, the more informed you become.

How do I talk to my healthcare team?

Many people find it helpful to have a notebook where they write down questions for their healthcare team. If you're like most people, you have questions you think of at home, and then when you see the team it's hard to remember those questions. A notebook that you carry with you can be a good way to make sure your questions are answered. 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 chronic kidney disease is a learning process, too.

A Friendly Note: It's important to remember that you can ask more than one healthcare professional the same question. If you ask someone a question and aren't satisfied with the answer, you should ask someone else. It's OK to get a second opinion.



What questions should I ask at my doctor visits?

To keep yourself as healthy as you can be, it's important to understand your condition and how it affects your health. The following is a list of some questions many people have. You can use this list to check off the questions you would like to have answered.

Checklist

- What has caused me to develop CKD?
- What are the stages of CKD and what is their significance?
- What stage am I?
- Am I going to need dialysis or a transplant soon?
- What medical tests have I had done?
- What medical tests can I expect to have done in the next three months?
- What medicines have I been prescribed? What does each one do? What side effects might I have?
- What medicines, vitamins and/or herbs should I avoid?
- Should I be following a special diet?
- Should I be exercising? What types of exercises can I do?
- How often should I be seeing my nephrologist?
- Who do I contact in an emergency?
- How will CKD affect my sex life?

- Who can I talk to about the emotions I'm having?
- What Web sites, books and other resources can I use to learn more about my health?

You may find it helpful to have a list of phone numbers and medications posted by the phone and on the inside of your “question 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 medicines must I take?

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. Always let your pharmacist know you have CKD and be sure to ask if there is anything you should know about the medication. Stopping or changing medicines may affect other areas of your treatment. Talk to your doctor if you have financial problems with purchasing needed medicines. When you have CKD, 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 fully and treat infection or other illnesses you may have.

Some common medications you may be prescribed include:

- **Iron** is used to help your body make red blood cells.
- **Erythropoietin (epoetin alfa)** is a hormone that helps stimulate red blood cell production. It's identical to the naturally occurring erythropoietin manufactured in the kidney.
- **Blood pressure medicine** is used to keep your blood pressure under control. If it's not controlled, you could have heart failure, a stroke or cause further damage to you kidneys.
- **Corticosteroids (steroids)** are often given to reduce inflammation or provide relief from pain. When your kidneys aren't working as well as they should, you may have some pain or swelling of the kidneys. Discuss any side effects of corticosteroids with your healthcare provider.
- **Vitamins and minerals** enhance your health and supplement your diet.
- **Calcium** helps keep your bones strong and your heart muscles healthy.
- **Phosphorus binders** help your body "tie up" the phosphorus in your stomach so it cannot build up in your body. Not taking your binders can lead to long-term bone disease.
- **Antibiotics** help your body fight infections. However, when your kidneys aren't working as well as they should, antibiotics dose and blood levels need to be carefully monitored. Thus, if another doctor gives you an antibiotic, be sure to ask your nephrologist if the dose is OK.

What medicines should I avoid?

Many people take over the counter medicine, herbal remedies, vitamins or supplements, to help them to feel better. When you have CKD, some of these medicines or remedies may actually 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.
- **NSAIDs** are anti-inflammatory medications like Advil, Nuprin, Ibuprofen or Aleve can damage the kidneys.
- **Enemas and laxatives** should be avoided, unless suggested by your doctor.
- **Vitamins or food supplements** may have potassium and magnesium in them.
- **Any "cure all" remedies and over-the-counter medicines** that have not first been discussed with your doctor.
- **Herbal medicines.**

What is alternative or complementary medicine?

In recent years, there has been a growing trend to use alternative 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 doctor.

Are there any herbal products that may cause further damage to my kidneys?

It's important to understand that pharmaceutical drugs and herbs are not regulated in the same way. Herbs and a number of other biologically active substances are classified as dietary supplements. Regulations of

these supplements are based solely upon adverse events, i.e., they are considered safe until proven harmful. Unfortunately, since herbs are not regulated they can be potentially very dangerous. In contrast, drugs must prove they are safe through clinical trials before they are allowed on the market. As a result, herbals can contain pesticides, heavy metals and/or poisonous plants.

Another aspect of herbal supplementation use to consider is drug interaction. People with CKD are on a number of medications. Herbals can boost or decrease the effectiveness of prescribed medications. For instance, Ephedra, often used in weight loss products, causes an increase in heart rate and blood pressure and should not be used in patients with hypertension, congestive heart failure and/or diabetes. It's critical to mention to your doctor any herbals, over-the-counter medications and products purchased from health food stores you may be using.

Other herbs that may be problematic are those with diuretic properties. A diuretic is a drug that reduces the amount of water in your body. Goldenrod, parsley, uva ursi and juniper berries fall into this category. Other herbals may affect electrolyte balance. Alfalfa and dandelion contain high levels of potassium, of particular concern for those taking potassium-sparing diuretics.

Some herbs have been found to be extremely dangerous. Between 1990 and 1992, the herb Aristolochia, innocently used as a weight loss product, was found to be highly carcinogenic and a direct cause of irreversible kidney failure.

People with any form of kidney disease, should exercise caution when using herbal products. Be sure to tell your healthcare team if you are using any products containing herbs.

Nutrition



What is a CKD diet?

Much research has been done to determine if low protein diets will help delay the progression of kidney disease. The results are not conclusive. However, strict blood pressure control (125/75) and a low protein diet may help in some kinds of kidney disease. Reducing salt in your foods is extremely helpful if you have CKD. The watchful eye of a dietitian is also very important and helpful.

Seeing a renal dietitian will help you develop and maintain a healthy diet. If you don't have access to a dietitian, learn as much as you can about the diet you should follow and if you have questions, ask your doctor.

Depending on your kidney function and your size, the amount of protein in your diet will be figured. Your doctor will tell you what amounts are good for you. If you have diabetes, be sure to talk to your doctor, as a very low-protein diet may not be recommended for you. A person with diabetes needs to eat enough protein to reduce the risks of tissue breakdown and infection. The secret of the diet is **THE SIZE OF THE PORTION**.

Below is a sample of a non-diabetic menu. This will show you where the protein is found in the diet. There are very small amounts of protein in fruits, juices and in non-dairy products, but to make matters easier, the sample menu did not count that protein in the daily allowance. There is no guarantee that a low-protein diet will delay the progression of kidney failure.

This non-diabetic diet has about 40 grams of protein, 2,000 milligrams of sodium, which is about 6,000 milligrams of salt, and is low in phosphorus.

Example – Non-Diabetic diet

Protein	Breakfast
2 grams	4 ounces apple juice. 1/2 cup puffed rice with Polyrich as desired, sugar as desired.
2 grams	1 slice white toast or 1/2 English muffin. Unsalted margarine and jelly as desired. Coffee or tea with Coffeemate or Polyrich as desired.
	Snack
2 grams	4 fresh strawberries and 1" slice angel cake. Cool Whip®. Coffee with sugar and Cremora®.

Lunch	
4 grams	2 slices bread, regular mayonnaise as desired.
7 grams	1 ounce chicken (weight after cooking without skin and bone). Lettuce with onions and cucumbers as desired. Oil and vinegar or special recipe for creamy garlic dressing*.
2 grams	1 small tomato sliced. Fruit cocktail in heavy syrup. 1/2 cup Sprite® or iced tea with sugar and lemon.
Snack (small)	
	Baked apple with honey. Mints or gum drops.
Dinner	
14 grams	2 ounces steak (weight after cooking without bone). You may sauté or fry in allowed oils or unsalted margarine.
4 grams	A medium baked potato (1 cup). Unsalted margarine as desired.
2 grams	1/2 cup canned corn (rinse and drain).
2 grams	Small blueberry muffin. Unsalted margarine. Romaine salad with scallions, wine vinegar and oil dressing. Cranberry juice or 7-Up® or Hawaiian Punch®.
Snack	
	1/2 cup applesauce. Lemonade.
Total: 41 grams of protein	

You are allowed to use 1/2 teaspoon of salt per day. Use additional sugars and sweets allowed if your weight is below desired weight and your dietician advises you to do so. Always weigh meat or equivalent after cooking without bone or shell.

***Creamy Garlic Dressing**

Ingredients: 2/3 cup oil, such as corn oil or olive oil; 1/3 cup vinegar, such as garlic, cider, wine or tarragon; 1 or 2 cloves garlic, peeled and chopped; 1 teaspoon Dijon Grey Poupon® Mustard; ground black

pepper. Preparation: Combine ingredients in blender for about 30 seconds. Analysis per one cup: 1,282 calories, 0.3 grams protein, 16 milligrams phosphorus, 35 milligrams sodium, 100 milligrams potassium.

This diabetic diet has about 40 grams of protein, 2,000 milligrams of sodium and is low in phosphorus.

Example – Diabetic diet

Protein	Breakfast
4 grams	8 ounces apple juice. 1 English muffin. 1 tablespoon unsalted margarine. Diet jelly. Coffee or tea, sugar substitute. Cremora® or Polyrich.
	Snack
	1/4 cup cantaloupe. 1 cup grapes. Diet 7-Up®.
	Lunch
7 grams	1 ounce unsalted tuna fish. Chopped celery, chopped onions. 1 tablespoon regular mayonnaise.
4 grams	2 slices white bread. Tossed salad with cucumbers, romaine lettuce. 1 tablespoon oil (or creamy garlic dressing), vinegar or lemon as desired. 2 diet peach or pear halves. Iced tea or diet Sprite® or coffee.
	Snack
	A small raw apple.
	Dinner
14 grams	2 ounces chicken (1 thigh = 2 ounces after cooking with the bone). You may broil, bake or you may fry in part of your fat allowance.
4 grams	A medium baked potato (1 cup). 2 tablespoons unsalted margarine.
2 grams	1/2 cup fresh asparagus.
2 grams	6 fresh strawberries. 1" slice angel cake. Iced tea with sugar substitute and lemon.

	Snack
2 grams	3 graham cracker squares. 1/2 cup grape juice. 1 small fresh pear.
Total: 41 grams of protein	
<i>You are allowed 1/4 teaspoon of salt per day. Always be sure you weigh meat, fish, poultry or seafood without bone or shell after cooking.</i>	

If I have diabetes what else should I keep in mind?

If you have diabetes and have been diagnosed with CKD you should also remember:

- You may have problems with your blood glucose control and will need to monitor it more frequently. Discuss with your healthcare provider what your goals for blood glucose levels should be.
- You need to avoid treating hypoglycemia with orange juice due to its high potassium content.
- Talk to your doctor about your insulin dosages as they may be decreased or changed now that you have CKD.

How else can proper nutrition help me?

One goal of proper nutrition is to reduce the workload of the kidneys and allow the best environment for optimal kidney function. Below are a few health tips. Discuss these issues with your physician and refer to this list frequently.

● Have a Healthy Heart:

Cardiovascular complications often accompany kidney disease - this is preventable. Limit total fat, especially saturated fat (such as butter and trans fat) and know your total cholesterol and potassium levels.

● Eat an Appropriate Amount of Protein:

Limiting total protein intake may decrease the workload of the kidneys. Eating too much protein will make your kidneys work much harder, which can cause more damage to your kidneys. Albumin and total protein in the blood should be monitored to prevent malnutrition. Utilizing portion control will be helpful in controlling protein. One trick: three ounces of meat is about the size of a deck of cards.

● Activity:

Consistent aerobic exercise, such as walking, will help to control weight and improve cardiovascular function. Strength training exercises may

prevent muscle breakdown. Discuss your exercise program with your physician. If you haven't exercised regularly before being diagnosed with CKD, don't start a new program until you discuss it first with your physician.

● **Calorie Intake:**

Make sure you're eating the right amount of calories each day. Talk to your doctor or dietitian and find out if you're receiving enough calories. If you're overweight, talk to your healthcare team about ways to reduce calories.

● **Limit Salt:**

Too much salt can lead to hypertension, swelling and thirst. Read food labels and become aware of hidden sodium in foods, especially processed foods, snack foods, frozen foods and restaurant fare. Be careful of salt substitutes as they can contain high levels of potassium.

● **Limit Phosphorus:**

When your kidneys aren't working properly, phosphorus will begin to build up in your blood. Phosphorus is a mineral found in foods. You'll need to limit the amount of phosphorus-containing foods you eat. Foods that have a lot of phosphorus include: beans, cheese (except cream cheese), chocolate, custard, meats, fish, milk (all kinds) and nuts.

● **Take Care of Your Bones:**

Know your phosphorus level. Excessive levels of phosphorus can cause calcium to be leached out of the bones, leading to weak and brittle bones. High amounts of phosphorus are found in beans, nuts, liver, milk and other dairy products, such as cheese.

● **Understand Potassium:**

Potassium is a mineral found in many foods. Initially, this will not be restricted in your diet, however, if your CKD becomes worse your doctor will most likely tell you to watch your potassium. Foods high in potassium include: bananas, beans, chocolate, milk, nuts, oranges, prunes, spinach and tomatoes.

● **Watch Your Fluids:**

If your doctor has restricted your fluid intake, talk to your dietitian about ways to control your thirst. Remember fluid is found in such unexpected things as jello, watermelon, gravy, sherbet and many other places. Decreasing salt in your diet also helps control thirst.

● Help Yourself to a Wealth of Information:

Contact a registered dietitian in your area for more personalized information. You can also order various dietary guides from AAKP.

A Friendly Note: Watching what I ate was probably the hardest adjustment I had to make. Working with a dietitian to better understand the diet was extremely helpful. I learned a lot about nutrition and how it can affect my kidneys and my body. My family also learned about what foods were healthy and what foods were harmful.

**Is a dietitian helpful?**

A dietitian is an active part of the medical team. The dietitian can enable and empower you to feel in control of your own health. With a little help from the dietitian, a little moderation and a little planning, you can feel in control of your diet and still enjoy meals by making good food choices.

Experts on the psychology of eating explain that when restrictions are placed on anything, including food, what a person will want most is this forbidden food. You should not have to deprive yourself of your comfort foods or favorite foods. With this in mind, discuss the foods you like with your dietitian. He or she can assist you in planning a menu to fit your likes and lifestyle. With the knowledge of appropriate portion sizes, rarely is there a forbidden food.

It's essential to know your lab values to make good food choices. Pay special attention to potassium, phosphorus and protein levels. It's just as important to become well versed in the amounts of potassium, phosphorus, protein and sodium found in the foods you eat. Make an effort to know and understand your potassium level and how much potassium is in certain fruits and vegetables. With this knowledge, you can work with the dietitian to schedule a cheat-time for your favorite high-potassium food. Your dietitian has many tricks-up-the-sleeve, such as using nondairy creamers as a substitute for milk on cereal. Discuss your degree of dietary flexibility with a dietitian.

What other activities should I avoid?

Everyone, even if they don't have CKD, should not smoke. Smoking accounts for more than 430,000 deaths each year and it's the leading avoidable cause of death in the United States. For individuals with CKD, smoking can impair kidney function and put you at greater risk of kidney failure.

Exercise



Anemia is one reason why people with CKD might feel more tired than a person without CKD. This might lead to a tendency to cut back on physical activity. After time, you might have difficulty climbing a flight of stairs or walking around the block. If this happens to you, your healthcare team can assist you in beginning a physical activity program or can further encourage you if you've already begun a program. Remember, do not start a physical activity program without first consulting your doctor. Start exercising slowly and consistently. This is the key to doing enough exercise.

Developing and sticking to an exercise program can help you in the following areas:

- Improve physical functioning.
- Increase physical stamina.
- Improve blood pressure control and reduce the risk of coronary artery disease.
- Improve emotional well-being.
- Lower levels of cholesterol and triglycerides.
- Results in a better night's sleep.
- Better control of body weight.



A Friendly Note: Exercise is beneficial for everyone – whether or not you have CKD. Because you didn't exercise before, doesn't mean you shouldn't start now. I never really exercised before I found out about CKD. Getting started was the biggest challenge. Once I got started, however, I became hooked. I noticed how much better I felt and I now look forward to my daily walks.

I have CKD and I continue to work. How will exercise help me?

Many CKD patients are able to continue working. With any person, it can sometimes be difficult to schedule exercise into a busy work and family schedule. However, this is something you will want to strive to add to your daily routine. Something as simple as walking 20-30 minutes per day will have a remarkable positive effect on your well-being. In addition, maintaining your physical strength, which also helps improve your emotional well-being, is useful in promoting job retention.

Are there things I should know if I have diabetes and want to exercise?

Yes. First, be sure to talk to your doctor about exercising. Changes in your metabolism may change your blood glucose and cause different needs with your medicines. General guidelines to keep in mind are:

- Be sure you have good shoes and practice proper foot care.
- To reduce the risk of hypoglycemia, you should exercise 30 to 60 minutes after eating.
- Follow a regular routine of exercising, eating meals and taking medicines.
- Be careful starting a long or strenuous activity such as marathon running, heavy weight-lifting, etc., as these can cause your body to produce adrenaline and other hormones. Such activity may change the effects of insulin and cause blood glucose to rise, thus your insulin needs would change. Talk to your physician prior to starting such activities.
- The saying, “No pain, no gain,” can be hazardous. Stop any exercise that causes pain.
- Test your blood glucose before and after you exercise. If it is 100 mg/dL or lower before you start exercising, be sure to first eat a snack. If your blood glucose is 300 mg/dL or higher before starting, do not exercise.

Why is it a good idea for me to exercise? I never did it before I had CKD.

Exercise is a very important part of any program to stay healthy.

Cardiovascular disease is a major cause of hospitalization and death in kidney disease and dialysis patients. Endurance exercise training, such as running, swimming and bicycling, has been shown to improve HDL cholesterol (good cholesterol) in the general population.

Cardiovascular fitness is a predictor of mortality. Of course, patients who exercise regularly should have their doctor’s approval. Patients with CKD need only to look to the sports pages for inspiration. In 1999, Sean Elliott helped the San Antonio Spurs to win four out of five playoff games over the New York Knicks for the NBA Championship. A few weeks later, he underwent a kidney transplant. It’s evident that he had chronic kidney disease during the most illustrious time in his career. He never missed a game and scored double digits in most games! But you don’t have to be a superstar. Simple activities, such as walking, can be beneficial.

Chronic kidney disease (CKD) can be associated with muscle wasting, but this may be related to decreased nutrition and inactivity. Although it's recommended that patients with chronic kidney disease limit their intake of protein (or at least not increase protein consumption), there is controversy as to how much. In the later stages of CKD, patients lose their appetite and may experience muscle wasting as a secondary complication of decreased kidney function. It has been shown resistance training (weights and exercise machines) increases muscle mass and helps patients on protein restriction better use what protein they do ingest. But, remember to check with your doctor first.

Above all, exercise makes one feel good. This is true regardless of the underlying condition. Patients with heart failure also benefit from cardiac rehabilitation. In the past, poor nutrition and anemia decreased exercise capacity. Now, we are aware of both of these problems and can focus on avoiding them.

Rehabilitation and Employment



How will CKD impact my ability to work?

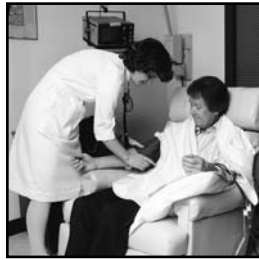
A CKD diagnosis may have no affect on your ability to continue to work. Some patients continue to work even after their CKD has progressed on to Stage 5. As someone with CKD, you can continue to work and spend time doing the things you enjoy, such as gardening, volunteering, canoeing, etc.

CKD will cause you to make a few changes to your lifestyle, however, you don't need to let it stop you from doing the things you enjoy. Continuing to work and staying active will help to keep you healthy.

A Friendly Note: I remember when I first heard the words, chronic kidney disease. Right away I was worried what it was going to do to my livelihood. Was I going to be able to continue doing the things I enjoyed? Was I going to be able to continue working? Was I going to be able to continue caring for my family? I quickly found out that the answer to my questions was "yes, yes, yes." There are changes in your life that you'll need to make to adapt to CKD, such as diet and exercise, but you don't have to let CKD take over your life. You're still in control and you are still capable of doing the things you enjoy. Maintain your health and be aware of your CKD, but don't live in fear.



When and If My Kidneys Fail



If my kidneys begin to fail, what are some of the signs?

Being aware of changes to your body can help your healthcare team give you the treatment you need to feel your best. Below is a brief outline of some of the most common symptoms. Remember, many of the symptoms we describe can also be related to other health conditions. Only your doctor can give you an accurate diagnosis. We encourage you to discuss this list and any of our similarities with your doctor.

- Swelling in the legs, ankles, feet, face and/or hands
- Change in urination– changes in color and frequency, presence of blood, increased difficulty
- Chills
- Lower back pain
- Unexpected rash or itching of skin
- Lack of energy– fatigue
- Decreased appetite
- Metallic taste in your mouth
- Nausea and vomiting
- Problems breathing– a shortness of breath
- Difficulty concentrating, dizziness and problems with your memory
- Waking at night more often
- Decreased urine output
- Weight gain or loss
- Headaches
- High blood pressure

What types of treatment options are there?

Hemodialysis, peritoneal dialysis and transplantation. Dialysis is a medical word that means cleaning the blood by “artificial means.” During dialysis, wastes and extra fluid that build up with kidney failure are removed from the blood.

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

To learn more about kidney failure or end-stage renal disease and the treatment options, call the American Association of Kidney Patients at (800) 749-AAKP and request Phase 1 of the AAKP Patient Plan.

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 responsibility to understand CKD and the treatments available to you. Remember, you aren't alone! There are people along the way who'll 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.

A Friendly Note: It could be years before you need dialysis or simply a matter of months. Don't despair. My father is on dialysis – has been for several years – and he plays golf twice a week. As someone with CKD, I am very active. I work, coach my son's baseball team and have a great tomato garden. Remember, a good attitude and being the leader of your healthcare team can keep you healthy, whether you're a CKD patient, on dialysis or have a transplant.



As a patient with a chronic illness, it is vital you keep track of all your medications, doctor visits and conversations you've had with your healthcare team. AAKP has made it easier for you to do so with the development of *AAKP My Health*[™]. *AAKP My Health* is an online resource that allows you to monitor your healthcare.

AAKP My Health allows you to keep track of:

- your doctor visits
- names of your specialists and nurses
- the medications you are taking and what they treat
- your laboratory test results
- your activity status
- your overall knowledge of kidney disease and its side effects.

This complete record of your healthcare is stored in a safe, secure location that is accessible to you anywhere there's an internet connection, at to you. Visit the AAKP Web site, www.aakp.org, to register.

Appendix

My Activity Status

Use this form to let your doctor know how you're feeling. This will help him or her determine if you are anemic.

- 1 Since you started having trouble with your kidneys, have you had to cut back on everyday activities (grocery shopping, walking the dog, etc.)?

Yes ___ No ___ Somewhat ___

- 2 Is it more difficult for you to walk up stairs without becoming tired or short-of-breath?

Yes ___ No ___ Somewhat ___

- 3 Is it hard for you to stand in line for a long time because you feel weak?

Yes ___ No ___ Somewhat ___

- 4 List two or three activities you can no longer do.

- 5 Can you no longer perform these tasks because of weakness or tiredness?

- 6 Which daily activity do you enjoy doing the most?

continued on next page

-
- 7** Please rate your ability to do this activity now:
1 = Equally Able, 5 = Not Able
1 2 3 4 5
- 8** Are you frustrated by not being able to do the things you want to do?
Yes ___ No ___ Somewhat ___
- 9** Please rate the impact tiredness/weakness has had on your ability to lead a
"normal" life:
1 = Very Little Impact, 5 = Tremendous Impact
1 2 3 4 5
- 10** I am content with the quality of my life right now:
1 = Very Content, 5 = Not Content
1 2 3 4 5
- 11** Do you know your hemoglobin (red blood cell) count?
Yes ___ No ___

If yes, enter it here: _____ If no, ask your doctor.

My Kidney Function Chart

% Kidney Function

Test Date				
35% or above				
30%				
25%				
20%				
15%				
10%				
5%				

Serum Creatinine

Test Date	Serum Creatinine

Creatinine (CR)

Normal value = less than 1.4 MG/DL for adult males and less than 1.2 MG/DL for adult females.
 Creatinine is a waste product of muscle breakdown. Healthy kidneys remove creatinine from the blood. With CKD, creatinine builds in the blood.

<u>Symptoms of abnormal levels include:</u> - Itchy skin - Numbness or tingling in toes	<u>Causes of abnormal levels can mean:</u> - Reduced kidney function - Increase in body mass
---	--

About My Cholesterol

Blood Cholesterol Levels

Your blood cholesterol level is determined by a simple blood test. The blood is drawn the same way it is for a Complete Blood Count (CBC). When you get your results back, you will be given two numbers, one is for HDL-cholesterol (“good” cholesterol) and the other is LDL-cholesterol (“bad” cholesterol). In order to determine your LDL-cholesterol your doctor will ask you to fast nine to 12 hours before the test.

Below are guidelines for determining your cholesterol levels. This information is for people who do not have heart disease.

Total Cholesterol Level	Category
Less than 200 mg/dL	Desirable level that puts you at lower risk for heart disease. A cholesterol level of 200 mg/dL or higher raises your risk.
200-239 mg/dL	Borderline high cholesterol.
240 mg/dL and above	High blood cholesterol. A person with this level has more than twice the risk of heart disease as someone whose cholesterol is below 200 mg/dL.

Chart courtesy of the American Heart Association.

HDL-Cholesterol Levels

HDL stands for high density lipoprotein. This is considered the “good” cholesterol and is helpful in protecting you a from heart attack. Unlike other cholesterol levels, you want a high HDL level.

HDL Cholesterol Level	Category
Less than 35 mg/dL	A major risk for heart disease.
35-69 mg/dL	The higher your HDL level, the better.
70 mg/dL and above	This range is considered protective against heart disease.

Chart courtesy of the American Heart Association.

LDL-Cholesterol Levels

LDL stands for low density lipoprotein. This is the bad cholesterol that is harmful to your heart. A high level of LDL means there’s a greater risk of heart disease or a heart attack. For your LDL level, you want a lower number.

LDL Cholesterol Level	Category
Less than 100 mg/dL	Optimal – perfect range
100-129 mg/dL	Near or above optimal
130-159 mg/dL	Borderline high
160-189 mg/dL	High
190 mg/dL and above	Very high

Chart courtesy of the American Heart Association.

Triglyceride Levels

Triglycerides will also be measured when you have a cholesterol test. Most of your body fat comes from triglycerides. Foods that contain triglycerides include: butter, margarine and vegetable oil. High triglycerides can be from being overweight, drinking a lot of alcohol, having diabetes or having another condition that affects your triglyceride levels.

Triglyceride Level	Category
Less than 150 mg/dL	Normal
150-199 mg/dL	Borderline High
200-499 mg/dL	High
500 mg/dL	Very High

Chart courtesy of the American Heart Association.

When your doctor gives you the results from your cholesterol test, keep track of them in the chart below. Keeping track of your test results helps you to monitor your health.

Date	Total Cholesterol Level	HDL Cholesterol Level	LDL Cholesterol Level	Triglyceride Level

My Important Medical Information

Use this chart to keep track of your medications. Be sure to take this chart with you whenever you visit your healthcare professional in case there are changes in your medicines.

MEDICATIONS

Medication	Strength	Instructions	Started	Stopped	Special Instructions

My Important Medical Information

IMPORTANT MEDICAL INFORMATION	
<p>Primary Doctor</p> <p>Name: _____</p> <p>Phone number: _____</p>	<p>Specialist</p> <p>Name: _____</p> <p>Phone Number: _____</p>
<p>Nurse</p> <p>Name: _____</p> <p>Phone Number: _____</p>	<p>Emergency Contact</p> <p>Name: _____</p> <p>Phone Number: _____</p>
<p>Pharmacy</p> <p>Name: _____</p> <p>Phone Number: _____</p>	<p>Insurance Plan</p> <p>Name: _____</p> <p>Phone Number: _____</p> <p>Policy Number: _____</p>
<p>Dietitian</p> <p>Name: _____</p> <p>Phone Number: _____</p>	<p>Other</p> <p>Name: _____</p> <p>Phone Number: _____</p>

Questions To Ask Your Healthcare Team

- ✓ What has caused my kidneys to fail?
- ✓ What medical tests should I have done or already have had done?
- ✓ What medicines have I been prescribed?
- ✓ What does each medicine do?
- ✓ What medicines or herbs should I avoid?
- ✓ Should I be following a special diet?
- ✓ Should I exercise? What types of exercise should I do?
- ✓ How often should I see my doctor?
- ✓ Who can I talk to about the emotions I am having?
- ✓ I'm having difficulties becoming sexually aroused, what is wrong?
- ✓ Why am I feeling tired all the time?

Additional Resources

American Association of
Kidney Patients (AAKP)
(800) 749-2257
www.aakp.org

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

American Association of
Diabetes Educators (AADE)
(800) 338-3633
www.aadenet.org

National Kidney and Urologic
Disease Information
Clearinghouse (NIDDK)
www.niddk.nih.gov

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

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

American Heart Association
(AHA)
(800) 242-8721
www.americanheart.org

Nephron Information Center
www.nephron.com

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

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

National Kidney Cancer
Association (NKCA)
(800) 850-9132
www.kidneycancerassociation.org

Glossary

Glossary

Albumin: One of a simple group of water soluble blood proteins. In the blood, albumin acts as a carrier and helps to maintain blood volume and blood pressure. A blood test for albumin helps to determine if a patient has kidney disease or if the body is not absorbing enough protein.

Anemia: A decrease in the amount of red blood cells that are needed to carry enough oxygen to meet the body's needs.

Anemic: Condition in which someone has anemia.

Atherosclerosis: A thickening or hardening of the arteries caused by a formation of fatty plaques.

Blood Urea Nitrogen (BUN): Waste product of the kidneys normally excreted by the kidneys. Increased levels in the blood may signal early kidney damage.

Chronic Kidney Disease (CKD): A progressive condition, not requiring dialysis, in which the kidneys are not functioning effectively and may be unable to produce red blood cells, to control blood pressure or to rid the body of waste through urination.

Complete Blood Count (CBC): A test that includes red blood cell count, white blood cell count, hemoglobin level and platelet count, among others.

Creatinine: A substance found in the blood, urine and muscle tissue. It is measured in blood and urine tests to determine the level of kidney function.

Creatinine Clearance Test: A diagnostic test for kidney function. It measures the rate at which creatinine is cleared from the blood by the kidneys.

Diabetes: 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. Diabetes is the leading cause of kidney disease.

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.

End-Stage Renal Disease (ESRD): Total chronic kidney failure, in which a person 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.

Ferritin: A form of storage iron.

Glomerular Filtration Rate (GFR): A test that determines kidney function by measuring creatinine clearance or other substances' clearance.

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

Hematocrit: A way of measuring the red cell content of the blood. It's measured as a percentage of the total blood volume.

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.

Hemoglobin: The substance in red blood cells that carries oxygen to all parts of the body. Hemoglobin is measured in grams (g) per deciliter (dL).

Hypertension: Blood pressure that is above the normal range. Uncontrolled hypertension is one of the leading causes of kidney disease.

Hypoglycemia: Low blood glucose. Most cases occur when there is too much insulin and not enough sugar in your body.

Insulin: A hormone that helps the body use glucose (sugar) for energy.

Kidney Biopsy: A diagnostic test where a small piece of kidney tissue is removed by a needle. The tissue is looked at under a microscope to determine the cause and status of the disease.

Kidneys: Two organs in the lower back that clean waste and poisons from the blood. The kidneys are shaped like two large beans and they act

Glossary

as the body's filter. They also control the level of some chemicals in the blood such as sodium, potassium and phosphate. Kidneys also control blood pressure and regulate red blood cell production.

Kidney Transplantation: The surgical procedure of placing a kidney from a donor to the recipient.

Microalbuminuria: A small amount of protein found in the urine that may signal the early stages of kidney disease in people with diabetes.

Myeloma: A cancer of the bone marrow.

Nephrons: A tiny part of the kidney. 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.

Peritoneal Dialysis: 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.

Protein: One of the three main classes of food. Proteins are made of amino acids, which are called the building blocks of the cells. Protein is found in many foods such as meat, fish, poultry, eggs, vegetables, milk and nuts.

Proteinuria: Abnormally high levels of protein found in the urine, which is a sign of kidney disease or hypertension.

Transferrin: A protein in the blood that carries iron.

Transferrin saturation: Measures the amount of iron that is immediately available to produce red blood cells.

Urea: A waste product formed when protein is broken down in the body.

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

Urine: The liquid waste product filtered from the blood by the kidneys.

AAKP Membership

AAKP IS THE ONLY NATIONAL ORGANIZATION DIRECTED BY KIDNEY PATIENTS FOR KIDNEY PATIENTS.

Benefits of Membership:

- A membership packet filled with some of our most popular publications and your very own member ID card.
- Subscriptions to AAKP's magazines: *aakpRENALIFE*, *Kidney Beginnings: The Magazine* and *aakpDelicious!*
- Opportunity to subscribe to AAKP's five FREE electronic newsletters.
- Access to *AAKP My Health*TM (an online resource for patients who want to be more proactive in managing their healthcare).
- Advanced updates of upcoming programs and events.
- Access to relevant and updated public policy information.
- Affiliation with an organization that shares your commitment to making a difference.
- Assurance that your voice is heard and your interests are represented in Washington, DC.

3 Easy Ways to Become a Member...

1. Web site: Visit the Membership section of our Web site, www.aakp.org, to join instantly.
2. Mail: Complete the membership application below and mail it to us at the address on the bottom of the application.
3. Phone: Give us a call at (800)749-AAKP.

Please allow 4 to 6 weeks to receive your membership packet.



Membership Application

Member Information

Name: _____

Address: _____

City: _____ State: _____

ZIP: _____ Phone: () _____

Email: _____

Choose a Membership Category:

- Patient/Family Member.....\$25/annually
- Professional Member.....\$45/annually
- Physician Member.....\$100/annually
- Institutional Member..... \$200/annually
- Life Member..... \$1,000*

*or four payments of \$250 every six months for two years

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

Payment Method

- Check (enclosed and payable to AAKP)
- Visa American Express
- MasterCard Discover

Account number: _____

Name on Card: _____

3 or 4-Digit Security Code: _____

Expiration Date: _____

I am not interested in membership at this time, but please send me a complimentary package of information.

Mail completed form & payment to: American Association of Kidney Patients, 3505 E. Frontage Rd, Ste. 315, Tampa, FL 33607

www.aakp.org

The American Association of Kidney Patients (AAKP) wishes to thank all the patients, family members and professionals who gave generously of their time and resources in order to provide Kidney Beginnings: A Patient's Guide To Living With Reduced Kidney Function.

The Kidney Beginnings Team spent numerous hours developing this book. Their devotion to the book ensured its success. The Team members included Rosa Rivera-Mizzoni, MSW, LCSW (professional); Ellie Durrett (patient); Judy Weintraub, MS (patient); and Bonny Wilburn (patient).

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To our sponsor, Ortho Biotech Products, L.P., thank you for the generous sponsorship that provides patients with this very important resource.

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



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American Association of Diabetes Educators

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