



A Patient's Guide to Chronic Kidney Disease

Normal Kidney Function

The kidneys are located in the middle of the back, below the rib cage. On average, they are the size of a closed fist. The main function of the kidneys is to remove toxic waste products and extra body fluids. Most people are born with two kidneys, but a single kidney can often function as well as two. They are also important in regulating other body functions such as blood pressure, maintaining healthy bones and red blood cell production.

Chronic Kidney Disease

Chronic Kidney Disease, or CKD, is a term used to describe a permanent loss of kidney function or kidney injury. Most people don't know they have CKD because they feel fine. Some symptoms of the early stages of CKD include high blood pressure, swelling of the hands, legs or feet and blood in the urine. Early signs of CKD may not be detected until blood work is drawn by their family doctor. A urine test may also be done to determine if the kidneys are functioning properly.

When kidney function is reduced, certain substances begin to build up in the bloodstream. Blood and urine tests will help the doctor determine how well the kidneys are working. The following are common tests performed to determine how well the kidneys are functioning.

Complete Blood Count (CBC): this is a count of all the components of the blood: red blood cells, white blood cells and platelets. When kidney function is reduced, the CBC level may be low.

Creatinine: this is a waste product of muscles and is normally eliminated by the kidneys. When kidney function is reduced, the creatinine may be elevated.

Blood Urea Nitrogen (BUN): urea is a waste product that is eliminated by the kidneys. Nitrogen is a byproduct from urea, also eliminated by the kidneys. When kidney function is reduced, the BUN may be elevated.

Creatinine Clearance: this test is a more accurate measure of how well the kidneys are functioning. It measures how well the creatinine is removed by the kidneys. It involves



A Patient's Guide to Chronic Kidney Disease

a blood test and a 24 hour urine collection. When kidney function is reduced, the creatinine clearance may be low.

Blood electrolyte tests: also known as chemistries. Electrolytes are filtered out of the blood by the kidneys. Abnormal levels may indicate reduced kidney function. Some electrolyte testing may include potassium, sodium, phosphate, calcium and magnesium.

Kidney Biopsy: this test involves a needle puncture of one of the kidneys to obtain kidney tissue. It is performed during a Renal Ultrasound, a test which examines the kidneys. The tissue is examined closely under a microscope to determine the exact cause of CKD. This procedure is performed only if the nephrologist determines it is necessary to guide the treatment of CKD.

Hemoglobin A1C: this test measures how well blood sugar (glucose) is controlled during the three months prior to testing. An elevation indicates that blood sugar is not well controlled, which may contribute to reduced kidney function.

Glomerular Filtration Rate (GFR): this is a calculation of the creatinine clearance. It is calculated from the creatinine, age, body size and sex of the patient. It is expressed in a percentage (ie. 30%) and is considered the best measure of kidney function. The GFR determines the "stage" of Kidney Disease. The higher the numbers of the GFR, the better the kidneys are working.

There are five stages of CKD based on GFR:

- **Stage 1:** GFR is 90 or higher. There may be slight kidney damage.
- **Stage 2:** GFR is 60-90. There is a mild decrease in kidney function.
- **Stage 3:** GFR is 30-60. Moderate decrease in kidney function.
- **Stage 4:** GFR is 15-30. There is severe decrease in kidney function.
- **Stage 5:** GFR is 15 or less. This is considered kidney disease. Treatment is necessary to sustain life.

Urine Dipstick: a test performed on urine to determine if there is any protein in the urine. Protein in the urine (proteinuria) may show something is wrong with the kidneys' ability to filter the blood properly. Many diseases may cause proteinuria, such as diabetes and hypertension.



A Patient's Guide to Chronic Kidney Disease

Causes of CKD

Several conditions and diseases can cause CKD. Diabetes (high blood sugar) and Hypertension (high blood pressure) are the two most common causes.

Diabetes: this is a disease caused by not enough insulin in the body, or the body's inability to use insulin. The lack of insulin causes blood sugar (glucose) levels to rise. Without treatment, it can be fatal. High blood sugar can damage the makeup and function of blood vessels, including the small blood vessels of the kidneys. High blood sugar can also weaken the kidney's nephrons (filters). When kidney blood vessels and filters are damaged, kidney function worsens. As kidney function worsens, protein leaks out of the kidneys and into the urine (proteinuria). This may be one of the first signs of CKD.

It is extremely important to control blood sugar levels. This can be done by following the diet prescribed by the doctor, taking antidiabetic medications (sugar pill or insulin), and exercising several times a week.

Hypertension (High Blood Pressure): blood pressure is the force (pressure) of the blood on the walls of the blood vessels. Over time, high blood pressure can damage the blood vessels and nephrons (filters) in the kidneys. If blood pressure becomes extremely high, it can restrict (narrow) the blood vessels which supply the kidneys. This reduced blood flow to the kidneys result in reduced kidney function. High blood pressure can also damage other organs such as the heart, brain and eyes.

It is extremely important to keep blood pressure under good control. Generally, good control means the blood pressure should be 130/80 or less. To help control blood pressure, take medications as prescribed by the doctor, check blood pressure readings at home daily, eliminate sodium in the diet and exercise several times a week.

Glomerulonephritis: this is known as an inflammation (swelling) of the nephrons (filters) inside of the kidneys. Sometimes it may be due to an infection. Damage to the kidneys from Glomerulonephritis generally occurs over a long period of time.

Nephrotic Syndrome: this is a condition in which large amounts of protein is lost in the urine (proteinuria). It causes swelling (edema) in the legs, hands, feet.

Polycystic Kidney Disease (PKD): PKD is a condition in which a large number of cysts develop in the kidneys. It is typically an inherited disease. The cysts grow large and can block the ability of the kidneys to filter waste products out of the blood. However,



A Patient's Guide to Chronic Kidney Disease

the kidneys are still able to produce normal amounts of urine. Reduction of kidney function from PKD generally occurs over a long period of time.

Systemic Lupus Erythematosus (Lupus): a disease which causes inflammation (swelling) in all organs of the body. It can cause CKD.

Chronic Pyleonephritis (Kidney Infection): this is an inflammation or infection of the nephrons (filters) inside of the kidneys. When left untreated, it can cause kidney failure.

Kidney Stones: kidney stones can form anywhere within the urinary tract, including the kidneys. They cause blockage of the urine drainage to the bladder. The kidneys can be damaged due to the pressure of urine backing up into the kidneys or from infections.

Prostate Obstruction (Enlarged Prostate): a disease limited to only men, an enlarged prostate may cause reduced kidney function if urine drainage is blocked.

Anemia and CKD

Anemia is a condition in which the body doesn't have enough red blood cells. Red blood cells are needed to carry oxygen throughout the body. Lack of oxygen to muscles and organs can cause extreme fatigue (feeling tired), weakness and exhaustion.

The kidneys play an important role in the production of red blood cells. The kidneys produce a hormone called erythropoietin (EPO) which stimulates the bone marrow to produce red blood cells. When kidney function is reduced, not enough EPO is produced, thus causing anemia. Symptoms of anemia include fatigue, tiredness, shortness of breath, headache and inability to concentrate.

Anemia of CKD is treated with medications which help produce red blood cells. Oral iron is one medication used to treat anemia and can be taken without a prescription. It should be taken between meals, not with a meal. It should not be taken with antacids or phosphate binders. Iron can cause GI upset such as nausea, feeling of fullness or constipation. Stool softeners help avoid constipation.

If oral iron doesn't improve the anemia, or if it isn't tolerated, iron can be given intravenously (IV). This is given once a week for 4-8 weeks and is given in our Infusion Clinic. The infusion generally lasts about an hour. Most patients tolerate the infusion just fine.



A Patient's Guide to Chronic Kidney Disease

Blood is drawn once every three months to analyze iron stores. Based on the iron levels, the physician prescribes the type of iron (oral versus IV) and the amount to be used to treat anemia.

Another medication used by the UNC Kidney Center to treat anemia is Aranesp. Aranesp is a form of erythropoietin, the hormone produced by the kidneys to produce red blood cells. It is an injection (shot) given by the nurse in our Anemia Clinic. The dose and how frequently it is given depends on the patient's CBC (complete blood count). The CBC is checked at least once a month, the result is reviewed by the physician who then orders the Aranesp dose. Typically, Aranesp is tolerated well by patients.

Bone Disease and CKD

Kidneys play an important role in maintaining good bone health. Bones need a balanced level of calcium and phosphorus in the blood in order to stay strong. When kidney function declines, phosphorus may build up in the blood, causing calcium levels in the blood to become too low. When this happens, the parathyroid gland (located in the neck) releases too much parathyroid hormone (PTH) into the blood. The purpose of PTH is to keep calcium levels normal in the blood. When calcium levels are low, PTH moves calcium out of the bones. Over time, as more calcium leaves the bones, the bones become brittle and break easily.

Bone disease in CKD can happen in its earliest stages. Most patients do not have symptoms of bone disease in the early stages. But as phosphorus builds up, patients may experience itching. Other symptoms may include bone pain, muscle weakness, fractures and joint pain.

The best treatment for bone disease is prevention. Our nephrologists routinely screen CKD patients for early stages of bone disease. The screening involves a blood test which includes calcium, phosphorus, PTH and sometimes Vitamin D levels. If the results are abnormal, the patient will be advised to follow a low phosphorus diet (see Nutrition). In advanced stages of CKD, the patient may also have to take certain medications, phosphate binders, to help eliminate the excess phosphorus in their blood (see Medication). The patient may also be advised to take a calcium supplement or Vitamin D. These medications should be taken only at the advice of the nephrologist.

Exercise is another way to improve bone health. Any weight bearing activity, such as walking, will increase the strength of the bones. The physician should be consulted prior to beginning any exercise program.



A Patient's Guide to Chronic Kidney Disease

Medications

CKD can affect the way in how the body regulates many functions such as blood pressure, bone health, fighting infections or other illnesses. Medications are given to help the CKD patient with these functions. It is important to take the medication as prescribed and to report any side effects experienced. It is also important to know HOW to take the medications. For example, some medicines should be taken with a meal and some should not. The pharmacist is a good resource and should be informed if the patient has CKD. The pharmacist can inform the patient if there could be side effects when certain medications are combined. Lastly, the patient should inform the nephrologist of all medications he/she is taking, including over the counter medications or herbal medications.

Some of the most commonly prescribed medications used in treating CKD are listed below:

- **Iron:** used to help produce red blood cells. It can be given by mouth or intravenously (IV). See section on Anemia.
- **Erythropoietin (EPO):** a hormone to stimulate red blood cell production. There are several forms of erythropoietin used. Aranesp is the medication most commonly used at UNC Kidney Center. See Anemia.
- **Blood Pressure medications:** there are many different BP medications used. It is important to take it as prescribed by the physician to prevent heart failure, stroke or further damage to the kidneys. See Hypertension.
- **Corticosteroids (steroids):** these medications are used to treat certain illnesses, provide relief from pain and reduce inflammation.
- **Vitamins and minerals:** used to enhance health and supplement the diet. They should be taken as directed by the physician.
- **Calcium tablets:** these medications are used to keep bones strong and heart muscle healthy. They should be taken as directed by the nephrologist. See Bone Disease
- **Phosphorus Binders:** these medications help “bind” excess phosphorus that can build up in the body with CKD. They should be taken WITH meals and snacks. They should be taken only as prescribed by the nephrologist. See Bone Disease.
- **Antibiotics:** antibiotics are used to help the body fight infections. However, not all antibiotics are okay for persons with CKD and can cause harm. It is important to check with the nephrologist when another



A Patient's Guide to Chronic Kidney Disease

physician prescribes an antibiotic to see if it is okay to take or if the dose should be adjusted.

There are some medications that should be avoided for persons with CKD. Some of the most common are:

- **Alka Seltzer:** baking soda or other “bubbling” type of medications. These are usually high in sodium which can elevate the blood pressure and cause edema.
- **Milk of magnesia:** or other antacids which contain magnesia. When kidney function is reduced, excess magnesium can build up in the blood. This can cause neurological problems such as seizures.
- **Aspirin:** should only be taken if prescribed by the physician. Aspirin has an effect on the clotting system of the blood and may cause bleeding.
- **NSAIDs:** these are anti-inflammatory medications which can cause further damage to the kidneys. Some examples of NSAIDs are: Advil, Nuprin, Motrin, Ibuprofen, and Aleve.
- **Enemas or laxatives:** consult with physician before using.
- **Vitamins or food supplements:** some may contain high amounts of potassium and magnesium. It is best to seek physician advice before beginning any dietary supplement.
- **Over the counter (OTC) medicines:** some multi symptom cold medicines may interact with other medications prescribed by the physician. Some may increase blood pressure. It is best to seek physician advice before using any OTC medications.
- **Herbal medications:** should be avoided for CKD patients. Herbal medications are not regulated by the government the same way that prescription medications are. Some may contain pesticides, heavy metals or poisonous plants. Some herbal medications may boost or decrease the effectiveness of prescribed medications. It is important to inform the physician if herbal medications are being used.

Nutrition

One goal in the treatment of CKD is to reduce the workload of the kidneys in order to preserve their function as long as possible. One way in which to do this is to follow a healthy diet. A diet low in fat, sodium and protein will be helpful. Diabetics should continue to follow the diet prescribed by their physician to help control blood sugar levels. A low sodium diet is extremely important for patients with CKD and high blood pressure. The nephrologist will prescribe the proper diet for the CKD patient. A



A Patient's Guide to Chronic Kidney Disease

nutritionist may also be involved and is a good resource when developing a diet plan. Medicare will now pay for three nutrition counseling sessions per year.

Here are a few important CKD diet facts.

Low Protein: limiting protein in the diet may help reduce the workload of the kidneys. There is some thought that a diet low in protein may help with certain kinds of kidney disease. More research is needed to determine how helpful it is in treatment of CKD. The nephrologist will prescribe a diet tailored for the patient with CKD.

Calorie Intake: persons who are overweight will need to reduce the amount of calories consumed daily. A nutritionist can develop a good diet plan for the CKD patient.

Limit Salt Intake: too much salt (sodium) in the diet can lead to high blood pressure, swelling and thirst. Generally, do not salt while cooking or at the table. Do not use a salt substitute. Avoid canned and processed foods such as bacon, sausage and lunch meats. They contain "hidden" salts. Avoid salty snacks such as chips, pretzels and popcorn. Always read the food label to determine if there is any hidden salt in the product. Generally, any food whose label contains the word "sodium" as a key ingredient, should be avoided.

Phosphorus: many foods contain the mineral, phosphorus. If the kidneys are not functioning properly, phosphorus can build up in the blood and lead to bone disease. Foods to avoid include all dairy foods (such as milk and cheese), beans, nuts, colas and chocolate.

Potassium: this is another mineral found in foods. When kidney function is reduced, potassium can build up in the blood and may cause fatal heart arrhythmias. Foods to avoid include all citrus fruits and their juices, bananas, milk, nuts, prunes, spinach and tomatoes. Consult with the nephrologist to determine when it is best to limit potassium in the diet.

Limit fluids: as kidney function worsens, fluid may build up in the body. If unresponsive to treatment, the patient will have swelling of the extremities and may become short of breath. The nephrologist may restrict fluids drastically to help control the swelling. Like sodium, there are "hidden" fluids in some foods such as jello, gravy, ice cream and watermelon. Generally, any food that becomes liquid at room temperature is considered a fluid and should be limited. Ways in which to control thirst are to suck on ice, a wet wash cloth or hard candy (diabetics should use sugar-free candies). To determine how much ice will make an ounce, let it melt and measure it.



A Patient's Guide to Chronic Kidney Disease

Then add up the number of ice cubes used per day as part of the daily fluid allowance. Consult with the nutritionist for additional tips.

Exercise

There is an association between muscle wasting and CKD. Muscle wasting may be due to decreased nutrition and inactivity. Weight bearing activities and weight training may help increase muscle mass. Additionally, exercise can improve cardiovascular disease by helping to lower cholesterol. It can also improve stamina, blood pressure control, emotional well-being, sleep habits and weight control. CKD patients are encouraged to increase daily activity but should consult with their physician before beginning an exercise program.

Symptoms of Kidney Failure

As kidney function worsens, patients may experience some or all of the following symptoms:

- Change in color and frequency of urination
- Blood in the urine
- Decreased urine output, or lack of urine
- Swelling which is unresponsive to treatment (medication)
- Increased tiredness
- Itching
- Decreased appetite
- Metallic taste in the mouth
- Nausea or vomiting
- Shortness of breath
- Memory impairment (difficulty remembering things)
- High blood pressure unresponsive to medication
- Headache

Our nephrologists will work closely with the patient as kidney function worsens. Generally speaking, treatment will involve close monitoring of labs and symptoms, medications, diet and fluid restrictions. Our CKD nurse will educate the patient and their families about preserving kidney function. When it becomes necessary, treatment options for kidney failure will be discussed (see below). The patient and their families are involved in deciding which treatment option best fits their lifestyle.



A Patient's Guide to Chronic Kidney Disease

Treatment Options

When kidneys fail, treatment is necessary to replace the work that they normally do. This includes eliminating waste products and excess fluids, regulating blood pressure, maintaining healthy bones and creating red blood cells. There are four treatment options from which patients can choose to replace kidney function.

Hemodialysis:

Hemodialysis is a term that means to “filter the blood”. It does so by using a machine to run a few ounces of blood to a filter for removal of waste products and excess fluid. The blood is filtered continuously over a 3-5 hour period, depending on severity of kidney failure. The blood never leaves the patient’s body completely, only a few ounces at a time. The treatment typically occurs three times a week. Most patients are awake during the procedure, or they may nap, watch TV, read a book or other lap type hobbies.

Ideally, patients and their families are given education about hemodialysis well in advance of their needing it. One of the advantages of this is that the vascular access needed for the hemodialysis procedure is created several months before it’s time to start. A vascular access is surgically created in the skin to get the blood from the patient to the dialysis filter. There are three types of vascular access: a catheter, fistula or graft. Our Vascular Access Nurse will work intimately with the patient in deciding the type of access, scheduling the surgery appointment and teaching them how to take care of it.

Peritoneal Dialysis:

Like hemodialysis, peritoneal dialysis removes waste products and excess fluid from the body. It does it by using the lining of the abdomen, the peritoneal membrane. It is performed daily, in the comfort of the patient’s home. And like hemodialysis, an access needs to be placed well in advance of needing to start dialysis. This access is called a Peritoneal Dialysis (PD) catheter, sometimes known as a Tenckhoff catheter. Our Vascular Access Nurse will work intimately with the patient in deciding the type of access, scheduling the surgery appointment and teaching them how to take care of it.

Peritoneal dialysis solution, a special solution containing minerals and sugars, is drained into the abdomen through the PD catheter. It is clamped and allowed to dwell in the abdomen for a short period of time, and then the clamp is opened and allowed to drain out of the abdomen. This is called an “exchange”. Several exchanges are required during the course of the day. The patient may choose if he/she would prefer exchanges



A Patient's Guide to Chronic Kidney Disease

during the day or during the night. The patient is taught how to do these exchanges by the PD nurse at the dialysis unit.

Transplantation:

Kidney transplantation is another treatment choice for CKD patients. A kidney is placed in the patients' abdomen and does the work of the two failed kidneys. The patient's kidneys are not removed during transplant unless there is a medical condition which requires it.

There are two sources of kidneys: deceased donor kidney (the donor has died and the family has agreed to donate his/her organs) or live donor kidney from a family member or friend. Regardless of type of donor, the patient must go through an extensive evaluation to determine if he/she is in the best health possible for transplantation.

The advantage of kidney transplantation is that it allows the patient to live a more normal life without dialysis. There is a higher chance of living a longer life too. The disadvantage of transplantation is that it requires major surgery and the need to take anti-rejection medications for a lifetime. There is always a chance of rejection of the kidney despite taking anti-rejection medications.

Deciding Not to Start Treatment for CKD:

Patients have the right to decide what kind of treatment they want to treat their CKD. For most patients, choosing dialysis or transplantation will improve their quality of life. Other patients may view treatment for CKD as prolonging their life unnecessarily. This is especially true for those who suffer from other serious ailments.

Deciding not to treat CKD is a decision that should be made after careful discussion with the nephrologist and family members. Patients should understand that without treatment, they will ultimately die. How long it will take depends on the patient's medical condition and kidney function. It may take a few days, several weeks or even months. Death from kidney failure is usually painless. The nephrologist will prescribe medications to make the patient as comfortable as possible. Hospice can also be involved in the patient's care.

If the patient decides not to undergo treatment for CKD, an Advance Directive (Living Will) should be completed. It should detail the patients' wishes for end of life treatment. A Power of Attorney should be appointed to execute the Advance Directive. The Power of Attorney should be someone willing to carry out the patient's wishes when the patient is unable to.