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Living Well with Chronic Kidney Disease



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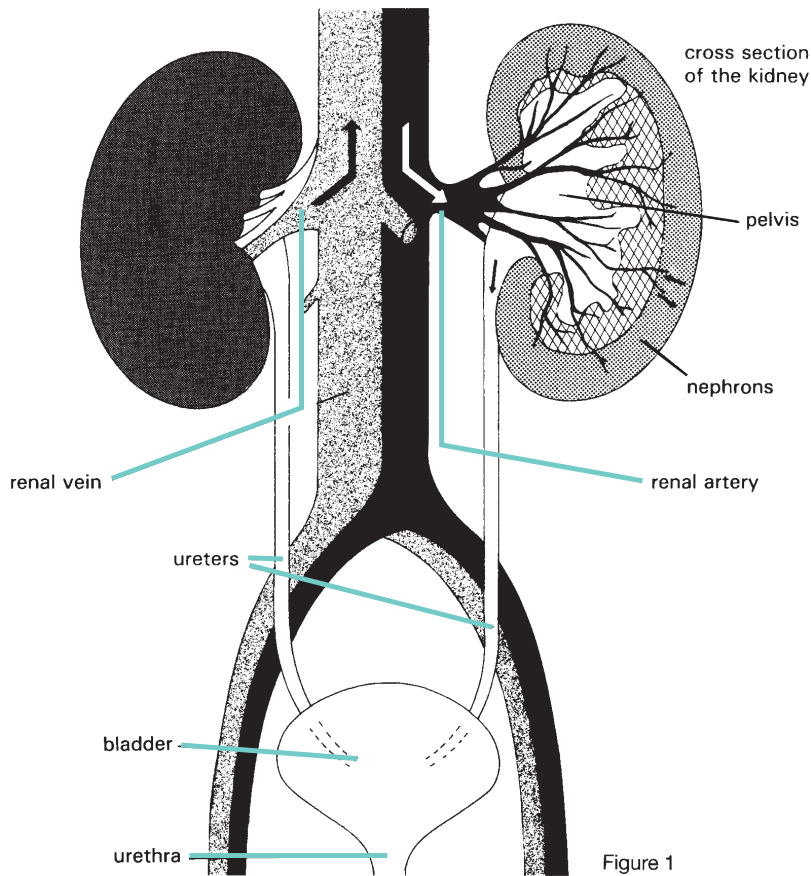
Living Well with Chronic Kidney Disease

Your doctor has just told you that your kidneys are not working as well as they should. Your condition is called chronic kidney disease or CKD. You probably have a lot of questions. You may be wondering what you can do now to help your kidneys stay as healthy as possible. With early treatment, kidney disease can be slowed and kidney failure (the need for dialysis or transplant) may be avoided. This brochure will:

- Introduce you to kidney disease
- Tell you about the possible complications of kidney disease, and how you can control them
- Let you know about changes in your diet that may help
- Introduce you to the health care team you will meet during your treatment

While reading this brochure, you may see a word you don't know. If so, turn to page 28 and look for the word in the glossary. We realize it is not possible to answer all of your questions about CKD. Read this brochure carefully. Write down any questions you have. Discuss them with your health care team.

The Kidneys



This is how normal kidneys work.

The Kidneys

What do your kidneys do?

Your kidneys filter wastes and extra water from your blood to make urine. Your kidneys also:

- **Keep the chemical balance in your body**
- **Help control your blood pressure**
- **Help your bones and teeth stay strong**
- **Direct your bones to make red blood cells– which deliver oxygen through your body**

Your life depends on your kidney function!

How do your kidneys work?

1. The renal (kidney) artery takes blood from your heart and brings it to your kidneys.
(An artery is a blood vessel that carries blood away from your heart and through the body.)
2. Once the blood reaches your kidneys, wastes and extra fluid are filtered out of your blood and made into urine.
3. Your urine then goes to your ureters (large tubes that carry urine from your kidney to your bladder).
4. The clean blood is circulated back to your heart through the renal vein.
(A vein is a blood vessel that carries blood from your organs back to your heart.)

Chronic Kidney Disease (CKD)

Who gets CKD?

Anyone can develop kidney problems. Some people are more likely to have problems with their kidneys than others. These are people who have:

- **Diabetes**
- **High blood pressure**
- **A family member with kidney failure**
- **Are over 60 years old**

Diabetes is the leading cause of CKD. High blood pressure is the second leading cause. CKD runs in families. You may be more at risk if your mother, father, sister or brother has kidney failure. Some racial and ethnic groups are also more likely to get CKD. These include:

- **African Americans**
- **Hispanics/Latinos**
- **Native Americans**
- **Asian and Pacific Islanders**



How Do I Know if I Have CKD?

Early CKD usually has no symptoms. The only way to find out if you have CKD is to have some simple medical tests. Your doctor may use one of these tests:

Urine Test

Kidney damage can cause protein to leak into your urine. This protein is called "albumin". Your doctor may test your urine in their office or ask you to collect your urine for 24 hours at home. If too much protein shows up in your urine, it is called proteinuria. Proteinuria is often a sign of early kidney disease.



Blood Test

Your doctor will test your blood for creatinine. Creatinine is a waste created in your muscles. When the kidneys are damaged, they have trouble removing enough creatinine from your blood. Too much creatinine in your blood may show kidney damage. Talk to your doctor if your blood (serum) creatinine is higher than 1.2.

GFR

Your doctor or lab may also put your creatinine result, age, race, and sex into a math formula to get your GFR (Glomerular Filtration Rate). GFR can help tell your doctor how fast your kidneys clean your blood.

A GFR *below 60* suggests you may have some kidney damage. This means your kidneys may not be working at full strength. If your GFR is less than 60, make an appointment to see your doctor soon.



GFR is an estimate. The test is not always accurate for GFRs *above 60*. It is important for your doctor to look at other tests to find out if you have kidney disease.

The normal ranges and five stages of CKD are listed on the opposite page.

GFR Level	Stage	Description
90-130, no protein in the urine	Normal	Normal kidney function
90 or more, and protein in the urine	Stage 1	Slightly abnormal kidney function
60 to 89	Stage 2	Mild decrease in kidney function
30 to 59	Stage 3	Moderate decrease in kidney function
15 to 29	Stage 4	Severe decrease in kidney function
Less than 15	Stage 5	Kidney failure (dialysis or transplant will be needed soon) ¹

Without treatment, CKD can become kidney failure with little or no warning. It is very important to know your GFR and understand what your GFR means. **Ask your doctor if you have questions about your GFR.**

¹ From the National Kidney Foundation's Kidney Disease Outcomes Quality Initiative

What Is the Treatment for CKD?

The treatment goal for a person with CKD is to slow down or stop kidney damage. Things you can do to slow your kidney disease may include:

- **Blood pressure control**
- **Diabetes control (blood sugar control)**
- **Avoiding certain medicines**
- **Diet and exercise**
- **Regular doctor visits**
- **Don't smoke or use tobacco**



Blood Pressure Control

Very strict blood pressure control is important now that you have CKD. High blood pressure and kidney disease are related. Uncontrolled high blood pressure damages the blood vessels in your kidneys. This damage can make your CKD worse.

If you have CKD, talk with your doctor a target blood pressure. Ask your doctor if an ACE (angiotensin converting enzyme) inhibitor or ARBs (angiotensin receptor blockers) would be right for you. These medicines are used to stop or slow the progress of your CKD, while keeping your blood pressure controlled. Your doctor may also put you on a diuretic or "water pill."

For more information on high blood pressure, order the American Kidney Fund's brochure *High Blood Pressure and Your Kidneys*. Call (866) 300-2900 or visit <http://www.kidneyfund.org>

Diabetes Control (blood sugar control)

If you have diabetes, you should try to keep your blood sugar as close to normal as possible. This will help you slow down kidney damage and help prevent other problems such as heart disease, stroke, amputation and blindness. Good control will also help you feel better. You can control your blood sugar by:

- **Staying on your diet**
- **Exercising regularly**
- **Taking your medicine**
- **Checking your blood sugar often**

You may also benefit from taking an ACE inhibitor or ARB (as mentioned above) even if your blood pressure is normal. **Ask your doctor about these medicines.**

How will you know if your blood sugar is well-controlled?

A blood test called “hemoglobin A 1C” can tell if your blood sugar has been well-controlled over the past 2 to 3 months. This test is a type of ‘report card’ of your blood sugar levels. The test should be done 4 times a year. The result to try for is about 4.5% to 7.0%. **Do you know what your percentage is? If not, ask your doctor.**

For more information on diabetes, order the American Kidney Fund’s brochure Diabetes and Your Kidneys. Call (866) 300-2900 or visit <http://www.kidneyfund.org>

Avoid certain medicines

There are several medicines that you should not take, or should take in lower doses if you have CKD. Be sure to check with your kidney doctor before taking ANY drugs, including over-the-counter medicine. And be sure to tell your pharmacist and other doctors that you have CKD.

Diet

When your kidneys are not working well, wastes from what you eat and drink build up in your blood instead of being removed by your kidneys. That’s why a special diet is important for you to follow. Some foods may need to be changed in your diet now that you are living with CKD. These may include limits on protein, carbohydrates, fat, fluid, sodium, potassium, and phosphorus in your diet. You will also need to watch your calories. A dietitian who specializes in kidney disease can help you with a meal plan that is right for you. **Ask your doctor to refer you to a renal dietitian.**

Ask your doctor or dietitian if you should change any of these parts of your diet:



Protein

Urea is a waste product that comes from the breakdown of protein. Normally, urea is removed from the blood by your kidneys. The extra urea leaves your body in your urine. If you have CKD, eating too much protein makes your kidneys work harder. This can cause more kidney damage. Since your body needs some protein, a careful

balance is needed to keep your nutrition at its best. Many people eat more protein than they need. Most kidney doctors recommend that people with CKD avoid extra protein. **Be sure to ask your doctor how much protein you should eat.**

Here is a list of foods to help you if your doctor recommends that you limit the protein in your diet:

1 egg =	7 grams protein
1 chicken thigh =	14 grams protein
8 ounces milk =	8 grams protein
1 slice bread =	2 grams protein
1/2 cup corn =	2 grams protein
1 cup cooked rice =	4 grams protein
1 cup black beans =	15 grams protein
1 ounce cheddar cheese =	7 grams protein
3 ounces ground beef =	22.5 grams protein
3 ounces flounder =	21 grams protein
2 tablespoons peanut butter =	8 grams protein
8 ounces yogurt =	11 grams protein

Once you enter stage 3 or 4 of CKD, some doctors might tell you to eat a low-protein diet. Pages 11 and 12 show a sample low protein menu.

Sample Menu

This is a sample low-protein menu. You should discuss your diet with your dietitian.

**Sample Menu for a 50 year old Non-Diabetic Patient with Chronic Kidney Disease (stage 4)
40-50 grams Protein**

BREAKFAST	EXAMPLE OF FOOD CHOICE
1 serving of fruit	1/2 cup orange juice or 1/2 fresh banana
2 servings of bread/starch	1 English muffin or 2 slices toast or 1 cup oatmeal
Fat and sweet choices	1 Tbsp margarine*, jelly, jam
Beverage	Coffee or tea with non-dairy creamer, sugar
MORNING SNACK	
1 serving of fruit	2 canned pear halves in heavy syrup
LUNCH	
1 ounce of protein	1 hard boiled egg or 1 ounce of meat (such as a chicken leg without thigh)
2 servings of bread/starch	2 slices of bread
1 serving of fruit	2 canned peach halves in heavy syrup
Extras	Mustard, small piece lettuce
Beverage	Lemon-lime soda or lemonade

AFTERNOON SNACK

1 serving of fruit Fresh apple (medium size)

DINNER

2-3 ounces of protein	2-3 ounces ground beef, weighed after cooking
1 serving of bread/starch	1 small boiled potato with margarine*
2 servings of vegetable	1/2 cup green beans or carrots AND one small green salad made of lettuce, cucumbers, onions, green pepper
Fat choices	Salad dressing made of 2 Tbsp olive oil with vinegar or lemon
1 serving of bread/starch	1/8 wedge of apple or cherry pie
Sweet choice	1/2 cup fruit sorbet
Beverage	Iced tea with sugar or coffee with non-dairy creamer and sugar

EVENING SNACK

2 servings of fruit 1 small whole banana

1 serving of bread 10 small vanilla wafers

** Select a reduced-fat or "healthy fat" margarine with no trans fatty acids.*

The success of your treatment depends on everyone working together. It is very important to keep in contact with your dietitian to prevent you from losing weight. You need to have good nutrition.

Calories

Eating the right amount of calories a day is more important than ever. Calories are found in carbohydrates, proteins, fats, and alcohol. Your dietitian can help plan your diet to make sure you are getting enough calories. You and your family need to keep close contact with your dietitian for advice and follow up. The total amount of calories you need each day depends on your size, sex, activity level and age. People under the age of 60 probably need about 15.9 calories per pound of desired weight per day. People over the age of 60 years may need about 13.6 calories, per pound, per day. It is very important to discuss your calorie intake with your dietitian to make sure you are eating the right amount of calories each day.

A 50-year-old man 5'7" tall and 150 pounds (70 kilograms) needs:

15.9 calories x 150 pounds = 2,385 calories per day

Carbohydrates

Carbohydrates are found in breads, cereals, rice, potatoes, fruits and vegetables, as well as sugar, honey, cookies and cakes, hard candies and sugared drinks. If you are diabetic and on a low protein diet, you may need more calories from carbohydrates, even if it means taking more medicine to control your blood sugar. **Be sure to ask your doctor before changing how you take your medicine.**

Fats

Fats include foods like margarine, mayonnaise, and oil. Fats are also ingredients in other foods. Fats contain twice the calories as carbohydrates or proteins. Fats that are called polyunsaturated fats are better for you than saturated fats. Cholesterol is a fatty substance found in the body. Your liver makes some cholesterol and the rest comes from the foods you eat. High cholesterol can cause kidney damage and heart disease. To control your cholesterol:



- **get a cholesterol screening (from a blood test)**
- **eat foods low in saturated fat and cholesterol**
- **keep a healthy weight**
- **exercise regularly**
- **follow all your health care team's suggestions.**

Four Ways to Avoid "Bad" Fats:

1. Avoid margarine with "trans-fat" which is also not good for you.
2. Use corn oil or olive oil instead of lard or butter when cooking.
3. Trim the fat on meat, and remove the skin on chicken or turkey to reduce needless fat.
4. Learn to read food labels to see how much fat and what kind of fat is in the foods you eat.

Fluids

Usually there is no fluid limit during early CKD. This is because you still make urine, although your urine may not have all the wastes that are in normal urine. The amount of urine may eventually decrease and then fluid may be restricted.

Sodium

Sodium is a mineral found naturally in almost all foods. It is the main ingredient of table salt. Too much sodium in the diet can cause high blood pressure and swelling. Learn to read food labels so you can choose foods that are low in sodium. Here is a list of some high-sodium foods to limit:

- **Salt**
- **"Chinese" food**
- **Sausage**
- **Cheese**
- **Pizza**
- **Ham**
- **Pickles**
- **Bacon**
- **Fast food**
- **Lunch meats**

Potassium

Potassium is a mineral also found in many foods. Foods that are high in potassium are not restricted at first. However, as CKD gets worse, potassium-rich foods will probably be limited. Too much potassium in the body can be serious. In case you need to change the amount of potassium in your diet, here is a list of high potassium foods:

- **Bananas**
- **Potatoes**
- **Prunes**
- **Chocolate**
- **Tomatoes**
- **Beans**
- **Nuts**
- **Peaches**
- **Oranges**
- **Orange juice**
- **Milk**
- **Raisins**

Phosphorus

Phosphorus is another mineral found in many foods. When you have CKD, phosphorus may start to build up in your blood. Your phosphorus may need to be limited. Here are some foods high in phosphorus:

- Milk (any kind)
- Desserts made with milk
- Chocolate
- Cheese
- Liver
- Beans
- Sardines
- Nuts

Sometimes your doctor will prescribe a medicine called a “phosphate binder.” This medicine binds the extra phosphorus from food so that it will be removed in your bowel movements.

Vitamins and Minerals

Special vitamins are often recommended for people with CKD. They contain the right amounts of vitamins B and C. They also contain folic acid which is needed for making red blood cells. **Be sure to talk to your doctor and pharmacist about any vitamins or supplements you may be taking.**



My Health Care Team

It takes a health care team to help you stay healthy– you are the captain of the team. Write the names and phone numbers of your health care team in this chart.

Name and Phone Numbers

Primary Doctor _____

Nephrologist _____

Nurse _____

Endocrinologist _____

Social Worker _____

Dietitian _____

Pharmacist _____

Hospital _____

Does CKD Affect Any Other Part of the Body?

Your kidneys play an important role in your overall health. Your kidneys are vital organs. When they are not working as well as they should, you may have health problems related to your CKD. You can talk to your health care team about possible health problems you may face due to CKD. We will discuss a few possible effects CKD may have on your body.

Anemia

Having too few red blood cells is called anemia. Anemia is a problem that can be caused by kidney disease. Healthy kidneys make a hormone called erythropoietin (EPO) that directs the bone marrow to make red blood cells. Your kidneys may not make enough of this hormone. Anemia can make you feel weak and tired because not enough oxygen is getting to all parts of your body. Your doctor may prescribe a shot of EPO or a similar product. This shot works just like the hormone normally made by the kidneys. The shot stimulates red blood cell production. This shot should help you build red blood cells. Along with this shot, you may be told to take iron. You need both the EPO and the iron to make red blood cells.



Hemoglobin and hematocrit are tests for anemia. They are part of a complete blood count or CBC. Guidelines for normal levels are:






- **Hemoglobin —**
Men: at least 13 g/dL
Women: at least 12 g/dL
- **Hematocrit —**
Men: 41-50%
Women: 36-44%

Your doctor should tell you what is normal for you.

Source: The National Kidney Foundation's Dialysis Outcomes Quality Initiative

Do you know what your hemoglobin and hematocrit are?

This chart is a good way for you and your doctor to track your activity and energy levels. You may find that you have more energy when your hemoglobin or hematocrit is high and less energy when your hemoglobin or hematocrit is low.

DATE															
Hb LEVEL															
 5 Can do most normal activities.															
 4 Can do less than normal activities.															
 3 Can do some normal activities.															
 2 Can hardly do any activities.															
 1 Can not do any activities.															

Charting Your Energy Level

If you have kidney disease and feel weak and tired, you may be anemic. Here are a few questions to ask yourself. Fill out the quiz and bring it with you to your next doctor's visit.

1. Since you started having trouble with your kidneys, have you cut back on everyday activities?
 Yes **No** **Somewhat**
2. Does walking up the stairs exhaust you more than it used to?
 Yes **No** **Somewhat**
3. Do you often find yourself out of breath?
 Yes **No** **Somewhat**
4. Do you feel too weak to wait in line for long periods of time?
 Yes **No** **Somewhat**
5. Do you have difficulty concentrating when reading the newspaper?
 Yes **No** **Somewhat**
6. How much of an impact has tiredness had on your ability to lead a normal life?
 Very little **Somewhat** **Substantial**
 Tremendous Impact
7. Do you know your hemoglobin level?
 Yes **No**

If yes, please enter it here: _____

If no, ask your doctor.

High Blood Pressure (Hypertension)

High blood pressure, also called hypertension, can be both a *cause* **and** a *complication* of CKD. The kidneys play a part in controlling your blood pressure. In addition to keeping the right chemical and fluid balance, the kidneys make a hormone, called renin. Renin helps control blood pressure. If the kidneys are not working well, blood pressure can rise. So, sometimes the kidney disease is the cause of the high blood pressure. There are several kinds of medicines that work in different ways to lower blood pressure. You can work with your doctor to find the one that works best for you. This may mean trying several different medicines or a combination of medicines.



Acidosis

Your kidneys control the amount of acid in your body. When your kidneys are not working well, your body holds onto too much acid. This condition is known as acidosis. Too much acid in your body can lead to many health problems, including muscle breakdown and poor nutrition. There may be no signs of acidosis. **Ask your doctor what your bicarbonate level is. If it's less than 20, ask if you should take a bicarbonate supplement.**

Bone Disease

Your kidneys keep the right levels of calcium and phosphorus in your blood. When your kidneys are not working well, the calcium levels in the bone can be changed. This change in the bone is known as renal (kidney) bone disease or renal osteodystrophy. Osteodystrophy (ahs-tee-oh-dis-tro-fee) slows the growth of bones and causes defects in growing children. In adults whose bones are fully formed, their bones may become thin and weak, and may break more easily. Phosphate binders are often used to reduce the effects of high blood phosphorous levels on the bones. Also, a special form of vitamin D called calcitriol, or similar product, may be needed. It is important not to take your phosphate binders with your iron pills. **Take the iron on an empty stomach and the phosphate binders with food.**



Take Control

The sooner you understand what it means to have CKD, the more likely you are to slow the disease and prevent problems. The basic goals of your health care team should be to:

- **Slow your kidney disease**
- **Treat related problems**
- **Have time to decide the path of treatment**
- **Avoid emergency dialysis**

What if I Still Get Kidney Failure?

We have given you some tools that may slow your CKD. However, even people who are careful with their health may still get kidney failure.

If this happens to you:

- **Talk to your doctor.** Your doctor can tell you about your treatment options and help you prepare.
- **Find out if and when you are eligible for Medicare.** Most patients with kidney failure can get Medicare no matter their age. Ask your healthcare team or call 1-(800) MEDICARE
- **Ask about a kidney transplant.** Ask your healthcare team if you are a good candidate for a kidney transplant.

- **Ask about an access.** The most common kind of dialysis is hemodialysis (see glossary). Blood vessels in your “non-dominant” arm (the one that you *don’t* write with) are usually used for this. Once you enter Stage 4 of CKD (a GFR less than 30), you should protect the blood vessels in that arm by:
 - **Telling every doctor or nurse that you have advanced CKD.**
 - **Don’t have blood pressure taken on that arm.**
 - **Don’t have an IV put in that arm.**
 - **Don’t have blood taken from that arm.**

Fistula

Talk to your doctor about getting a fistula (fish-chuh-luh, see glossary). Fistulas are used for hemodialysis. For most people, a fistula is the best choice. It gives the right amount of blood flow for hemodialysis with the lowest risk of infection. Think about a fistula even if you choose a different kind of treatment. It can help you in an emergency.



Summary of Key Points

We hope that many of your questions have been answered and you feel more informed about CKD after reading this booklet. We urge you to discuss what you have read with your health care team. The more you know about CKD, the more likely you are to help slow and prevent more problems.

1. It takes a health care team to help you stay healthy and slow the disease. This team is made up of many different professionals. Remember to ask your team questions when you have them. Take control of your health—YOU are the captain of the team.
2. Your kidneys filter waste and extra fluid from your blood to form urine. Your life depends on your kidney function.
3. Early CKD usually has no symptoms. The only way to know for sure is to get tested. By the time symptoms appear, the disease is at a late stage and dialysis or a kidney transplant may be needed.
4. The goal of treatment for a person with CKD is to slow down or stop the disease. This is done by strict blood pressure control, strict blood sugar control, and following a prescribed diet.
5. You can also manage common problems caused by CKD, like anemia, high blood pressure, poor nutrition and bone disease.

Glossary of Key Terms

Amputation: Removing a body part (like a foot, hand, arm) through surgery.

Anemia: A condition in which the body does not have enough red blood cells. A low hemoglobin level is a sign of anemia.

Bicarbonate: A substance in the blood that helps balance the acid levels in the body.

Bone marrow: The tissue that fills the middle of the body's bones. The kidneys cause bone marrow to make red blood cells.

Chronic Kidney Disease: A progressive condition where the kidneys are not working well. The kidneys may be unable to make red blood cells, control blood pressure, or rid the body of waste through urination.

Diabetes: A condition in which the body has problems processing glucose (a simple sugar) and problems making or using insulin. Diabetes is the leading cause of kidney failure.

Dialysis: The process of cleaning wastes from the blood artificially. This job is normally done by the kidneys. If the kidneys fail, the blood must be cleaned artificially with special machines.

Endocrinologist: A doctor who specializes in the endocrine glands (parts of the body that make and release hormones).

Erythropoietin: A hormone made in the kidneys that helps form red blood cells.

Fistula: A connection between an artery and a vein. The connection can be made by a doctor during surgery. For most people, a fistula is the best way to get the right amount of blood flow for hemodialysis.

Glomerular Filtration Rate (GFR): A good test for how well your kidneys are working. It is a calculation your doctor will do based on your lab work, your age, your weight, your sex and race.

Hemodialysis: The most common type of dialysis. A person's blood flows through an artificial kidney machine and back into the body. The blood is slowly cleaned during the treatment.

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

Hemoglobin A1c (HbA1c): A “report card” for your diabetes. It is a test that estimates blood sugar control over the previous three months.

Hormone: A natural chemical made in one part of the body and released into the blood. Hormones cause or control certain functions of the body.

Hypertension: High blood pressure. Uncontrolled hypertension (high blood pressure) is one of the leading causes of kidney disease.

Kidneys: A pair of organs located behind the lower abdominal area that keep the chemical and water balance in the body, and rid the body of wastes in the form of urine. Kidneys help control blood pressure and red blood cell production.

Nephrologist: A doctor who has had special training on how to treat kidney disease.

Proteinuria: Protein found in the urine, which could be a sign of kidney disease or high blood pressure.

Renal: Relating to the kidneys

Transplant: To transfer an organ from one body to another. A kidney transplant may come from a living donor or from someone who has just died.

Urea: A waste found in the blood. It is made from the normal breakdown of protein in the liver. Urea is normally removed from the blood by the kidneys and then sent out in the urine. Urea builds up in the body of people with kidney failure.

Uremia: The illness linked to the buildup of toxins in the blood. Toxins build up because the kidneys are not working right. Symptoms include upset stomach, vomiting, loss of appetite, and confusion.

Urine: Liquid waste filtered from the blood by the kidneys, stored in the bladder, and sent from the body through urination.

Where Can I Find More Information?

American Kidney Fund

6110 Executive Boulevard #1010
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www.aakp.org



American Diabetes Association

1701 North Beauregard Street
Alexandria, VA 22311
800-342-2383 (800-DIABETES)
www.diabetes.org

National Kidney Foundation (NKF)

30 East 33rd Street
New York, NY 10016
Phone: 800-622-9010 or (212) 889-2210
www.kidney.org

National Kidney and Urologic Diseases Information Clearinghouse

3 Information Way
Bethesda, MD 20892-3580
800-891-5390
kidney.niddk.nih.gov

American Dietetic Association

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www.eatright.org



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