



**Nebraska**  
Kidney Association

# KIDNEY PATIENT

## RESOURCE GUIDE

PROVIDED AS A PUBLIC SERVICE BY THE  
**NEBRASKA KIDNEY ASSOCIATION**  
FOR NEWLY DIAGNOSED KIDNEY PATIENTS AND THEIR FAMILIES.



[kidneyne.org](http://kidneyne.org)

**The Nebraska Kidney Association (NKA) has been helping Nebraska kidney and transplant patients for more than 40 years. The NKA is committed to improving the quality of life for all Nebraskans by:**

- Advocating for better health policies
- Funding research
- Supporting legislation for better health care
- Providing information and education to the general public, professional community, and those impacted by kidney disease or organ donation
- Conducting free early disease detection screenings throughout the state
- Providing services to kidney and transplant patients and their families

The Nebraska Kidney Association achieves its mission through a number of programs and services including:

- **Kidney Early Detection Screenings (KEDS)** – Free kidney health evaluation programs for individuals at increased risk of developing kidney disease. Free screenings are conducted periodically throughout the state.
- **Annual Patient/Family Celebration Day** – Each year, kidney and transplant patients are invited to participate in a day-long program designed to inform patients and their families about the latest treatment methods, as well as provide entertainment and fun for everyone. There is no charge for patients who choose to attend the event.
- **Medic-Alert Jewelry** – Free medic-alert jewelry for kidney and transplant patients is available through the NKA. Your social worker has all the information. A form for requesting medic-alert jewelry is located in this brochure.
- **Emergency Financial Aid** – Emergency financial aid for kidney and transplant patients is available through the NKA. Your social worker has all the information.
- **Access** - The NKA offers a toll-free phone number for Nebraska patients and families to contact the association. In addition, a website is available at [kidneyne.org](http://kidneyne.org) with information designed to inform and educate the kidney or transplant patient, as well as the general public.
- **Doctor to Doctor** - Written by Doctors for Doctors, Nurse Practitioners and Physician Assistants.

*For more information, visit our website at [www.kidneyne.org](http://www.kidneyne.org) or call NE Toll Free 800-642-1255*



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## FOREWORD

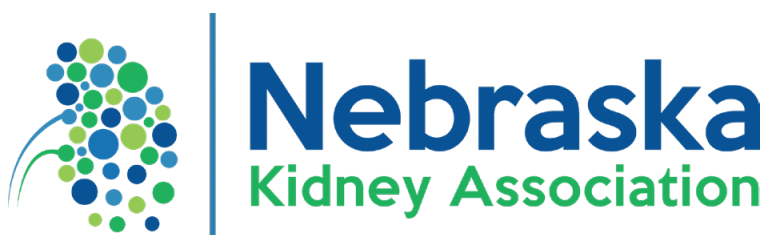
The information in this guide was compiled from a number of sources that offer additional valuable resources for kidney patients and their families. Referenced sources can be found throughout this guide.

The Nebraska Kidney Association knows the many varied resources available to kidney patients and families can seem overwhelming. Newly diagnosed patients with Chronic Kidney Disease face a myriad of decisions on treatment, physical restrictions and dietary restraints.

The purpose of this guide is to consolidate the resources available to CKD patients into one document that provides a quick reference for the patient based on subject. Patients and family will be referred to websites, organizations, resources, and agencies that can expand on the information provided in this guide.

Your specific condition may require treatment or diagnostic advice beyond that included in this guide. Please consult with your medical team on all issues involving treatment for your specific case.

All information in this guide was reviewed by the Nebraska Council of Renal Dietitians, the Nebraska Council of Nephrology Nurses and Technicians, and the Nebraska Council of Nephrology Social Workers



For additional copies of the ***Kidney Patient Resource Guide***, please contact our office. Guides are provided at no cost to kidney or transplant patients as well as to medical professionals who treat kidney or transplant patients.

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## CONTENTS

Page 5 ..... Terms from A to Z

Page 7 ..... Your Kidneys

Page 10 ..... Your Healthcare Team

Page 11 ..... Medications

Page 13 ..... Healthy Lifestyle

Page 14 ..... Nutrition

Page 16 ..... Emotional Health

Page 17 ..... Anemia

Page 18 ..... Treatment Options

Page 23 ..... Resources

Page 26 ..... Medic-Alert Jewelry Form





## TERMS FROM A TO Z

**ALBUMIN:** A water soluble blood protein. Found in the blood, it helps to maintain blood volume and blood pressure.

**ANEMIA:** A decrease in the number of red blood cells.

**ANURIA:** A condition in which the body stops making urine.

**ATHEROSCLEROSIS:** A hardening or thickening of the arteries.

**BLOOD UREA NITROGEN (BUN):** Waste product of the kidneys. At increased levels, it may signal early kidney damage.

**CHRONIC KIDNEY DISEASE (CKD):** A condition which does not require dialysis currently; however, the kidneys are not functioning effectively. Red blood cells may not be produced, blood pressure is not being controlled, and there may be an inability to rid the body of waste through urination.

**COMPLETE BLOOD COUNT (CBC):** A test that includes counts for red blood cells, white blood cells, platelets, and hemoglobin level.

**CREATININE:** A substance found in the blood and urine that is measured in both blood and urine tests to determine the level of kidney function.

**CYSTINURIA:** A condition in which urine contains high levels of the amino acid cystine. If cystine does not dissolve in the urine, it can build up to form kidney stones.

**DIABETES:** A condition caused by high blood sugar resulting from the body's inability to use glucose efficiently. In Type One Diabetes, the pancreas is unable to make enough insulin. One of the leading causes of kidney disease is Diabetes.

**DIALYSIS:** The process of cleaning wastes from the blood artificially.

**END STAGE RENAL DISEASE (ESRD):** Total 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.

**GLOMERULAR FILTRATION RATE (GFR):** A test that determines kidney function by measuring creatinine clearance.

**GLOMERULI:** Tiny looping blood vessels in the nephron, where blood is filtered in the kidney.

## TERMS FROM A TO Z

**HEMATOCRIT:** A way of measuring the red blood cell content 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.

**HEMOGLOBIN:** The part of the red blood cell that carries oxygen to all parts of the body.

**HYPERTENSION:** Blood pressure that is above the normal range. This is one of the leading causes of kidney disease.

**HYPOGLYCEMIA:** Low blood sugar.

**INSULIN:** A hormone produced in the pancreas that helps the body use sugar for energy.

**KIDNEYS:** Two fist-sized organs in the lower back that clean wastes from the blood, control blood pressure, and regulate red blood cell production.

**MICROALBUMINURIA:** Protein found in the urine that may signal the early stages of kidney disease.

**NEPHRONS:** Each kidney is made up of about 1 million nephrons, which are the working units of the kidneys that remove waste and extra fluids from the blood.

**PERITONEAL DIALYSIS:** Cleaning the blood by using the lining of the belly as a filter.

**PROTEINURIA:** High levels of protein found in the urine, which could be a sign of kidney disease.

**TRANSPLANTATION:** A surgical procedure placing an organ from a donor into the recipient.

**UREA:** Waste product formed when protein is broken down in the body.

**URETERS:** Tubes that carry urine from the kidneys to the bladder.

**URETHRA:** A thin tube from the bladder to outside the body. Urine empties from the bladder through the urethra.

**URINE:** Liquid waste product filtered from the blood by the kidneys.

## YOUR KIDNEYS

### A Primer

Everyone writes songs about the heart, but no one gives the kidneys the respect they deserve. The truth of the matter is that unless your kidneys are functioning properly, no other organ in your body can work.

Kidneys are structurally and functionally very interesting organs. They rid the body of waste materials, but they also do so much more. Kidneys are responsible for balancing the body's fluids, releasing hormones which regulate blood pressure, synthesizing vitamins that control growth, and controlling the production of red blood cells.



There are two kidneys, each about the size of your fist, located on either side of your spine at the lowest level of your rib cage. Each kidney contains about one million units called nephrons. Nephrons consist of a filtering unit called a glomerulus, which has been called the kidney's colander. Each hour, the amount of salt in 700 cans of beef soup and the sugar contained in 333 chocolate bars is filtered by your kidneys.

Kidney problems can range from a minor urinary tract infection to progressive kidney failure. As with any disease, early diagnosis is often the key to successful treatment.

### Chronic Kidney Disease

You may not know if you have the early stages of chronic kidney disease (CKD). A simple test to detect protein in your urine can alert your doctor to problems with your kidney function. If you have experienced high blood pressure (hypertension) or suffer from Diabetes, you are at greater risk for developing kidney disease than others.

Always ask your doctor if he or she is monitoring your kidney function and whether you are at risk for developing kidney disease. Never assume your doctor is scheduling the kidney function tests.

### Symptoms of kidney disease include

- Burning or difficulty during urination
- More frequent urination, particularly at night
- Puffiness around the eyes, swelling of hands and feet
- Passage of bloody-appearing urine
- High blood pressure
- Pain in the small of the back below the ribs

## YOUR KIDNEYS

**Some of the tests your doctor may perform to monitor or stage your kidney disease include:**

- **Complete Blood Count (CBC):** This is a very common test, which gives your doctor Your Kidneys information on the levels of red and white cells and platelets and whether they are functioning properly. Blood is drawn from a vein and sent to a laboratory for analysis. The results are forwarded to your doctor.
- **Creatinine Level:** Creatinine is a chemical filtered out of the blood by the kidneys and eliminated from the body in urine. A simple blood test identifies the Creatinine Clearance Level and tells your doctor whether the kidneys are functioning properly. If the kidneys are damaged, the amount of creatinine in the urine decreases, while the amount of creatinine in the blood increases.
- **Protein in Urine:** In this test, your urine is collected for a 24-hour period, and the amount of protein in the urine is measured. Normally, there is little or no protein in the urine. Increased amounts of protein can indicate reduced kidney function.
- **GFR:** One of the best methods for determining whether or not your kidneys are functioning properly is checking your Glomerular Filtration Rate (GFR). Your GFR is calculated based on a formula that takes into consideration your blood creatinine levels, age, body size and gender. The GFR can stage your kidney disease and help determine the proper treatment.

*Additional tests your doctor may order include blood urea nitrogen (BUN), blood electrolytes, serum creatinine level, and in some cases, a kidney biopsy where a small piece of kidney tissue is removed by a needle and examined to determine the cause of kidney failure. Always ask your doctor what the test is for and what would be considered normal or abnormal results.*

### Five Stages of CKD

There are five stages of CKD based on your GFR.

- **Stage One** – GFR greater than 90 may indicate slight kidney damage.
- **Stage Two** – GFR 60-90 signals a mild decrease in kidney function.
- **Stage Three** – GFR 30-60 indicates moderate decrease in kidney function.
- **Stage Four** – GFR 15-30 means severe decrease in kidney function.
- **Stage Five** – GFR less than 15 means kidney failure. Dialysis or a transplant is necessary.



## YOUR KIDNEYS

### Good Kidney Health

There are things you can do to slow the progression of kidney disease, and your health care team will provide you with the information you need. At a minimum, you should consider the following:

- **Control high blood pressure (Hypertension)** – Even if you're on medication to control your blood pressure, changes in your lifestyle and diet can make a big difference. You should try to keep your blood pressure less than 120/80 range which is considered normal for an adult. Make sure you discuss your target blood pressure rate with your healthcare team.
- **Maintain a safe range for your blood sugar level** – If you have diabetes, this is an extremely important rule. Your doctor will probably do an A1C test, which can tell you whether your blood sugar level stays within a normal range. Talk to your healthcare team or diabetes technician and find out what you need to do to maintain your levels.
- **Watch protein consumption** – You may be asked to restrict the amount of protein in your diet. Consult with your dietitian for more information.
- **Maintain healthy levels of fats** – Fats, also known as lipids, are responsible for cholesterol and triglycerides in your blood. Your doctor will tell you what are considered normal levels for your specific body makeup.
- **Quit Smoking** – There is nothing good attributable to smoking, and the habit becomes even more dangerous if you suffer from CKD. If you don't smoke, don't start. If you do smoke, quit.

#### ***Recommended additional reading:***

*"Kidney Beginnings - A Patient's Guide to Living With Reduced Kidney Function," published by the American Association of Kidney Patients, [www.aakp.org](http://www.aakp.org)*

*Additional information for this section provided by David Petzel, Ph.D., Professor of Physiology, Creighton University*

## YOUR HEALTHCARE TEAM

Once diagnosed with CKD, you may find yourself facing an entirely new healthcare team. There are many people who will be involved with your health care. This “team approach” is designed to make sure all of your needs are met. The most important member of the team is you, and to some degree, your family. You will need to take an active role in your healthcare, and your team will involve you in every decision at every stage of your treatment. Your job is to make sure the team is kept informed on how CKD is impacting you and your family. Full disclosure is necessary for your healthcare team to make accurate decisions about your treatment. Some of the people involved in your care and treatment are:

- **Nephrologist** – The head of your healthcare team is the nephrologist, a doctor with special training in kidney disease and internal medicine. The doctor will develop your treatment plan and oversee its implementation. Constant monitoring will enable your nephrologist to make adjustments as you progress through your treatment.
- **Nephrology Nurse** – A registered nurse (RN) or licensed practical nurse (LPN) with special experience in caring for patients with kidney disease or kidney failure who will work with you and your family and sometimes can provide in-home training for home dialysis treatments.
- **Nephrology Technician** – The individual who is trained to start your dialysis treatment and monitor you through the length of the dialysis.
- **Nephrology Social Worker** – Typically, a nephrology social worker is a licensed professional with an advanced degree trained to help you and your family cope with the changes CKD can bring to your lifestyle. The social worker has information on financial and other resources available to you and he or she can explain hard to understand information in easy to understand terms. Your social worker will be a key member of your healthcare team as you continue treatment for CKD.
- **Renal Dietitian** – A dietitian with special training will help you develop a diet program that incorporates what you like to eat with what you should eat. Most importantly, the dietitian will outline a personalized plan for you that will help keep you healthy.

You may have additional members of your healthcare team depending on your specific treatment program or condition.

### ***Recommended additional reading:***

*Visit the National Institute for Health, National Kidney Disease Education Program web site at [www.niddk.nih.gov/health-information/communication-programs/nkdep](http://www.niddk.nih.gov/health-information/communication-programs/nkdep).*

## MEDICATIONS

### Medications

When you have CKD your doctor may prescribe medications to control your blood pressure, help your body make red blood cells, eliminate phosphorus, guard against infection, help replace vitamins and minerals, and more.

**Don't** be alarmed by the number or volume of medications prescribed or over-the-counter treatments recommended.

**Do** ask questions about the drugs and their reaction or interaction with your body. Make sure your healthcare team and your pharmacist are aware of other medications you may be taking both prescription and over-the-counter. Depending on your specific case, you may be prescribed:

- **Iron Supplements** – To help your body make red blood cells.
- **Erythropoietin (epoetin alfa)** – To help stimulate red blood cell production.
- **Blood pressure medication** – High blood pressure is one of the leading causes of kidney disease. Keeping your blood pressure under control helps maintain good kidney health.
- **Steroids** – In some cases, you may have inflammation or pain in your kidneys. Corticosteroids are prescribed to relieve the pain and swelling. Make sure you discuss the side effects of steroids with your healthcare provider.
- **Vitamins and minerals** – CKD can cause vitamin and mineral loss. The addition of these diet supplements can help you maintain a healthy life style.
- **Phosphorus binders** – These help your body control the phosphorus that builds up, which can lead to long-term bone disease.
- **Antibiotics** – To help your body fight infections. A word of caution: If you have CKD, antibiotics need to be monitored carefully. If you are prescribed antibiotics by another doctor, make sure your nephrologist is aware of the prescription before you begin taking the drug.

*Note: Financial assistance for medications may be available at Partnership for Prescription Assistance at 888-477-2669 or Nebraska Renal Disease Program at 402-471-0925.*

*Contact your social worker for additional information.*

## MEDICATIONS

### Should I avoid some medications?

The short answer to that question is “yes.” Some over-the-counter medicines, herbal remedies, even vitamins and supplements may actually worsen your CKD or have the opposite effect on you. That is why it is critically important that you inform your healthcare team about every medicine and remedy you’re taking.

There are some common medicines that you should avoid:

- **Alka Seltzer, baking soda** or other fizzy remedies. These are high in sodium.
- **Milk of Magnesia** or any antacid containing magnesium. Magnesium can build up in your system and cause problems.
- **Aspirin**, unless ordered by a doctor. Aspirin can cause bleeding and interfere with the clotting action of your blood.
- **NSAIDs** or anti-inflammatory drugs. Some trade names include Advil, Nuprin or Aleve.
- **Enemas** and **laxatives** should be avoided unless your doctor recommends them.
- **Vitamins** or **food supplements** that contain potassium or magnesium.

Many over-the-counter herbal medicines have drug interaction problems with prescription medication. Prior to taking any supplement, discuss with your healthcare team the possible side effects or interaction with your CKD medications.



## HEALTHY LIFESTYLE

### Small Steps Lead to Large Successes

Simple, and often small, lifestyle changes can help control high blood pressure and Diabetes, the two leading causes of kidney disease.

- **Maintain a healthy weight** – Diet and exercise are critical to your health, and this is especially true when kidney disease invades your system. Find out what is considered a healthy weight for your age and body frame. Have your BMI (Body Mass Index) measured and develop a routine exercise program that neither overtaxes your physical strength, nor sets the bar too low to be effective.
- **Be physically active** – Beyond an established and regular exercise program, remain active throughout the day. Take the stairs and not the elevator or escalator whenever possible. Park in the far reaches of the store’s parking lot, rather than right at the door. If your lifestyle is somewhat sedentary, find out about exercises you can do while sitting at your desk.
- **Follow a healthy eating plan** – Work with your dietitian to establish a plan that meets your nutritional needs without sacrificing flavor. Most importantly, follow the plan.
- **Reduce salt and sodium in your diet** – Add sugars to that list also. Control of your salt and sugar intake is critical to your treatment as a kidney patient.
- **Drink alcohol only in moderation** – The sugar content in alcohol can have a devastating effect on Diabetes and kidney patients. Alcohol can also cause chemical reactions in your kidneys that may counter the effect of your medications.
- **Quit smoking** – Don’t just cut back. Don’t switch from cigarettes to cigars. Stop all tobacco use in any form. If you need help quitting, talk to your health care team.
- **Control your blood sugar if you have diabetes** – Keep track of your blood sugar. Know what’s normal for you and how to react if the readings are outside the normal range.
- **Take prescribed medicine as directed** – Medicines are effective only if you take them when and how the doctor prescribes them. Skipping a day or waiting to refill a prescription three days after you’ve run out of the drug can cause major problems for you. If your schedule of medications seems to be too complicated to follow, work with your healthcare team to make it simpler.



## NUTRITION

### Diet and Dialysis

Chronic Kidney Disease often means the kidneys stop working. When this happens, your doctor will probably recommend some type of dialysis treatment, which will require you to make many changes in your life. One of those changes will be to closely monitor the foods you eat. A renal dietitian will help you develop a diet that keeps you healthy. Your specific needs will be addressed by the dietitian, but some of the considerations will include:

- **Protein** – Needed for growth and repair of body tissue, fighting infection and healing wounds, adequate protein intake while on dialysis is essential. Protein is lost in the dialysis process. Meat, poultry, fish, and eggs are excellent sources of high-quality protein. It is very important that you eat the amount of protein recommended by your dietitian and physician.
- **Sodium** – Sodium is found naturally in foods, but the greatest amount of sodium in our diet comes from salt added to foods prepared at home or commercially. Do not use salt in cooking or at the table. Too much sodium may lead to fluid retention, rapid weight gain, or high blood pressure, and must be controlled in your diet.
- **Phosphorus** – A mineral to be kept at normal levels in the blood, as excessive amounts may cause calcium to leave the bones, leaving them weak and brittle. Milk, foods made from milk, dried beans and peas, whole grain cereals, nuts, chocolate, cocoa, and cola-carbonated beverages are high in phosphorus.
- **Potassium** – Your potassium intake will be individualized based on your blood levels. Potassium intake may or may not need to be limited. Potassium influences muscle activity, which includes the heart. Fruits and vegetables are two major sources of potassium. Salt substitutes are high in potassium, and should not be used. Not all products list potassium counts, so always check with your dietitian when in doubt.
- **Fluids** – Controlling your intake of fluids is critical to your health. Your kidneys may not be able to remove enough fluid from your body. Excess fluid can collect in your lungs, hands and feet, and cause high blood pressure and congestive heart failure. Fluid control is necessary to maintain a balance between fluid intake and fluid loss.



## NUTRITION

### Calorie Counting

Calories provide energy for your body. If your doctor recommends it, you may need to cut down on the calories you eat. A dietitian can help you plan how to cut calories in the best possible way.

Some people on dialysis need to gain weight. You may need to find ways to add calories to your diet. Vegetable oils, such as olive oil, canola oil and safflower oil, are good sources of calories. Use them generously on breads, rice and noodles.

Butter and margarines are also rich in calories, but contain saturated or trans fats that can clog your arteries. Limit your consumption, and use soft margarine in tubs rather than stick margarine.

Sweets can also add calories, but if you have diabetes, you need to watch your blood sugar levels.

### Renal Dietitian

A renal dietitian is an important part of your healthcare team. Your dietitian can help you feel in control of your diet, while still enjoying meals, by making good food choices.

You should not have to deprive yourself of comfort foods or any of your favorites. Your dietitian will work with you to plan a menu that matches your lifestyle and your food preferences. Controlling portion sizes is one way to continue to enjoy all of your favorites.

The American Association of Kidney Patients recommends that you know your lab values in order to make good food choices. Pay special attention to potassium, phosphorus, protein and sodium found in the foods you eat.

Your dietitian can also recommend recipes for healthy eating.

### ***Information for this section provided by:***

*Nebraska Council on Renal Nutrition, "Nutritional Guidelines for the Dialysis Patient"*

*American Association of Kidney Patients, "A Patient's Guide to Living with Reduced Kidney Function"*

*National Institute of Diabetes and Digestive and Kidney Diseases, "Eat Right to Feel Right"*

## EMOTIONAL HEALTH

There's an old saying that "misery loves company," but don't believe it. The fact that one in nine Americans suffers from kidney disease doesn't provide any comfort to those who have it.

When you were first diagnosed with Chronic Kidney Disease, you probably went through a range of emotions from anger to depression. The fact that all kidney patients suffer from these emotions doesn't mean we all react the same. Faced with the possibility of a lifetime of dialysis and deprivation or waiting for a kidney transplant, we all react differently.

The most important way to deal with your emotions during this time of treatment is to share them with someone else. Whether it's a family member, your healthcare team, or a close friend, talking about your feelings or concerns is the first step toward helping you and your family better understand what you're going through.

Some of the feelings you may experience include:

- **Depression and Anxiety** – These feelings are normal when someone faces a major change in his or her health. Sadness, anger, loss of appetite, trouble sleeping, and other symptoms can manifest themselves. Anxiety can cause feelings of uneasiness or fear.
- **Anger** – It's normal to be mad about your situation. You could experience anger for any number of reasons. Most people are angry because they feel they have no control over the situation. If you stay involved in your treatment and educate yourself about your condition and the options available to you, you will regain some of that control.
- **Despair** – Sometimes the diagnosis, treatment and prognosis are so overwhelming, you may feel like the situation is hopeless. It's not. Again, you need to let your healthcare team and your family know what you're feeling. Express your concerns that you may not be able to continue doing everything you've always done.
- **Loneliness** – You may pull back from people that you usually depend upon. You may not want to burden friends or family with your condition. You need to remind yourself that friends and family want to help and should be counted on for support during this health crisis.



Remember, your feelings will change over time. Initial reactions of fear, anger, depression, and loneliness will ultimately subside as you and others become more knowledgeable about your situation. There are any number of agencies available to help you deal with your CKD. Your social worker or other healthcare team members can refer you to the proper organization or agency.

## ANEMIA

Anemia is a common problem for people with kidney disease. Healthy kidneys produce a hormone called erythropoietin (EPO), which stimulates the bone marrow to produce the red blood cells needed to carry oxygen to vital organs. Chronic Kidney Disease keeps your kidneys from making the proper amount of EPO, and as a result, the bone marrow makes fewer red blood cells.

### Treatment

Anemia tends to worsen as kidney disease progresses. Nearly everyone with end-stage kidney failure has anemia. There are ways to treat anemia, and your healthcare team will go over your options with you before you begin dialysis. Treatment may include:

- **EPO** – Anemia can be treated with a genetically engineered form of the EPO hormone. This is injected under the skin two or three times per week. Hemodialysis patients who can't tolerate the EPO shots may receive the hormone intravenously during dialysis. This method requires a larger and more expensive dose of the hormone.
- **IRON** – Many patients will also need an iron supplement in addition to EPO treatments. The iron will raise your hematocrit levels to a satisfactory level. If your iron levels are too low, EPO won't help, and you'll continue to experience the effects of anemia. You may start with iron pills, but studies have shown that the pills are not as effective as iron given intravenously. You will be constantly monitored when receiving iron treatments to make sure you have no adverse reaction to the treatments.
- **VITAMINS** – In addition to EPO and iron, a few people may also need vitamin B12 and folic acid supplements. A special "kidney vitamin" may be recommended.

Anemia keeps many people with kidney disease from feeling their best. EPO treatments help most patients raise their hemoglobin, feel better, live longer, and have more energy.

*Your healthcare team is your best source for information on anemia, but we also recommend:*

*National Institute of Diabetes and Digestive and Kidney Diseases, "Anemia in Kidney Disease and Dialysis."*



## TREATMENT OPTIONS

### The Right Treatment for You

When your kidneys fail, you need treatment to replace the work your kidneys normally perform. The choice of treatment will ultimately be made by you after consultation with your nephrologist and healthcare team. You may choose to forego treatment altogether, but before you make that decision, make sure you are aware of the consequences. If you choose to receive treatment, your choices include:

- **Hemodialysis** – This process uses a machine to filter your blood outside your body.
- **Peritoneal Dialysis** – Usually done at your home, this treatment method uses the lining of your belly to filter your blood inside the body.
- **Transplantation** – A new kidney, either from a deceased or living donor, is placed inside your body to take over for your diseased or damaged kidneys.
- Each treatment has advantages and disadvantages. Your choice of treatment will have a big impact on your day-to-day lifestyle.

### Hemodialysis

Hemodialysis cleans and filters your blood using a machine to temporarily remove harmful wastes, extra salt and extra water. Hemodialysis helps control blood pressure and helps your body maintain the proper balance of important chemicals, including potassium, sodium, calcium and bicarbonate.

Hemodialysis uses a special filter called a dialyzer that functions as an artificial kidney. During treatment, your blood travels through tubes into the dialyzer, which filters out wastes, extra salt, and water. The cleaned blood then flows through another set of tubes back into your body.

Hemodialysis is usually done three times per week. Each treatment lasts from three to five hours. During treatment, you can read, write, sleep, talk, or watch TV.

Hemodialysis is most often done in a dialysis center by nephrology technicians and supervised by nurses. If you choose in-center treatments, you will have a fixed time slot three times per week.

Home Hemodialysis could also be an option, and one you should discuss with your healthcare team.



## TREATMENT OPTIONS

Each person responds differently to different situations. What may be a negative factor for one person may be a positive one for another. There are advantages and disadvantages to all treatment methods.

### In-Center Hemodialysis

#### Pros

- Facilities are widely available.
- Trained professionals are with you at all times.
- You get to know other patients.
- You don't have to have a partner or keep equipment in your home.

#### Cons

- Treatments are scheduled by the center.
- You must travel to the center for treatment.
- You will need to take more medications.
- It may take a few hours to feel better after treatment.

Please discuss the pros and cons of home hemodialysis with your healthcare team.

### Peritoneal Dialysis

Peritoneal Dialysis is another procedure that removes wastes, chemicals, and extra water from your body. This type of dialysis uses the lining of your abdomen to filter your blood. This lining is called the peritoneal membrane, and acts as the artificial kidney.

In peritoneal dialysis, a solution containing a mixture of minerals and sugar travels through a catheter into your belly. The solution draws wastes, chemicals, and extra water from the tiny blood vessels in your peritoneal membrane into the dialysis solution. After several hours, the used solution is drained from your abdomen through the tube, taking the wastes from the blood with it. Your abdomen is then refilled with fresh dialysis solution, and the cycle is repeated. The process of draining and refilling is called an exchange.

There are three types of peritoneal dialysis:

- **Continuous Ambulatory Peritoneal Dialysis (CAPD)** – CAPD requires no machine and can be done in any clean, well-lit place. With CAPD, your blood is always being cleaned.
- **Continuous Cycler-assisted Peritoneal Dialysis (CCPD)** – CCPD uses a machine called a cycler to fill and empty your abdomen three to five times during the night while you sleep. In the morning, you begin one exchange with a dwell time that lasts the entire day.

## TREATMENT OPTIONS

- **Combination of CAPD and CCPD** – If you weigh more than 175 pounds, or if your peritoneum filters wastes slowly, you may need a combination of CAPD and CCPD.

Both types of peritoneal dialysis are usually performed by the patient without help from a partner. The most common problem with peritoneal dialysis is peritonitis, a serious abdominal infection. Peritonitis can occur if the opening where the catheter enters your body becomes infected. Infection can also happen if contamination occurs as the catheter is connected or disconnected from the bags. Peritonitis requires antibiotic treatment by your doctor.

Peritoneal dialysis requires a diet that is slightly different from an in-center hemodialysis diet. Your renal dietitian will help you plan your meals based on the dialysis treatment you are receiving.

There are pros and cons associated with both CAPD and CCPD. Your healthcare team will review your options at the time you choose your dialysis method.

Remember that dialysis is not a cure for kidney disease. Hemodialysis and peritoneal dialysis are treatments that help replace the work your kidneys did. These treatments will help you feel better and live longer, but they don't cure kidney failure. Although patients with kidney failure are now living longer than ever, kidney disease can cause problems over the years such as heart disease, bone disease, arthritis, nerve damage, infertility, and malnutrition. These problems won't go away with dialysis. You should discuss your complications and their treatments with your doctor and other members of your healthcare team.

## ACCESS

Several months before your first hemodialysis treatment, an access to your bloodstream will need to be created. This access provides an efficient way for blood to be carried from your body to the dialyzer and back without causing discomfort. You may need to stay overnight in the hospital for this, but many patients have their access created on an outpatient basis. The two main types of access are a fistula and a graft.

- **Fistula** – A surgeon makes a fistula by using your own blood vessels. An artery is connected directly to a vein, usually in your forearm. The increased blood flow makes the vein grow larger and stronger, so it can be used for repeated needle insertions. This kind of access is the preferred type. It may take several weeks to be ready for use.
- **Graft** – A graft connects an artery to a vein by using a synthetic tube. It doesn't need to develop as a fistula does, so it can be used sooner after placement. A graft, however, is more likely to have problems with infection and clotting.

## TREATMENT OPTIONS

A catheter – a small soft tube inserted into a vein in your neck, chest, or leg near the groin – can also be used as a temporary access. If your kidney disease has progressed quickly, you may not have time to get a permanent vascular access before you start hemodialysis treatments. Therefore, you may need to use a catheter as a temporary access. Some people use a catheter for long-term access as well. Catheters that will be needed for more than about three weeks are designed to be placed under the skin to increase comfort and reduce complications.

### Kidney Transplantation

Kidney transplantation surgically places a healthy kidney from another person into your body. The donated kidney does enough of the work formerly done by your two failed kidneys to keep you healthy and symptom-free.

A surgeon places the new kidney inside your lower abdomen and connects the artery and vein of the new kidney to your artery and vein. Your blood will flow through the donated kidney, which makes urine just like your old kidneys did. Unless your old kidneys are causing infection or creating other problems, they are left in place.

Transplantation is not for everyone. You could have a condition that would make transplantation dangerous or unlikely to succeed. If you are a candidate for kidney transplantation, you may receive a kidney from a deceased donor or from a living donor. A living donor may be related or unrelated. The wait time for a kidney from a deceased donor could be several years.

A key concern in the transplant process is whether your body will accept the new kidney. Your transplant team uses a number of factors to match kidneys with potential recipients.

Transplantation is the closest thing to a cure, but no matter how good the match, your body may reject your new kidney. One cause of rejection is not taking medication as prescribed. Your doctor will give you medicines called immunosuppressants to help prevent your body's immune system from attacking the new kidney. You will need to take these drugs for as long as the transplanted kidney is functioning. Sometimes, however, even with immunosuppressant medicines, your body may reject the new kidney. If this happens, you will probably return to dialysis and perhaps wait for another transplant.

There are a number of complications associated with immunosuppressant drugs including changes in your appearance, weight gain, acne, facial hair, and more. Not all patients have these problems, and diet and makeup can help.

## TREATMENT OPTIONS

### Maintaining Your Lifestyle

Many patients with Chronic Kidney Disease are able to maintain their lifestyle even after beginning dialysis. If you were working before CKD struck, you will likely have to make some changes to your work schedule for your dialysis regimen or access to a dialysis center.

Maintaining an active lifestyle is important to your overall health. Volunteer work, regular exercise, hobbies, or even a part-time job could be the key to your overall mental and physical well-being. Talk to your doctor about your capabilities and whether maintaining employment will enhance or exacerbate your condition.

### Refusing or Withdrawing from Treatment

For many people, dialysis and transplantation not only extend life, but also improve the quality of life. For others who have serious ailments in addition to kidney failure, dialysis may seem a burden that only prolongs suffering. You have the right to refuse or withdraw from dialysis. You may want to speak with your spouse, family, religious counselor or social worker as you make this decision.

If you withdraw from dialysis treatments or refuse to begin them, you may live for a few days or for several weeks, depending on your health and your remaining kidney function. Your doctor can give you medicines to make you more comfortable during this time.

An advance directive is the best way to make sure your wishes are carried out. The directive can take the form of a living will or durable power of attorney for health. Your doctor or healthcare team can advise you on where to obtain information on advance directives.

*Information for this section was obtained from the National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC). The NKUDIC is a service of the National Institute of Diabetes and Digestive and Kidney Diseases and is part of the National Institutes of Health of the U.S. Department of Health and Human Services.*



## RESOURCES

### WEB SITES

There are a number of web sites that provide information on kidney disease or transplantation, as well as resources available to the kidney patient. Here are just a few:

#### [www.nedonation.org](http://www.nedonation.org)

More than 104,000 Americans are waiting for a life-saving organ transplant. Sadly, close to 18 of these people die every day because there are not enough organ donors. Give the gift of life. Register to become an organ donor on this website.

#### [www.network12.org](http://www.network12.org)

The Heartland Kidney Network promotes and facilitates high quality care standards for dialysis and kidney transplant patients in Iowa, Kansas, Missouri and Nebraska. Dialysis patients can use the site to plan travel throughout the four-state area.

#### [www.niddk.nih.gov/health-information/communication-programs/nkdep](http://www.niddk.nih.gov/health-information/communication-programs/nkdep)

Learn more about kidney disease, testing and treatment. Find out how to talk to your doctor about kidney disease. View and download brochures and fact sheets.

#### [www.dialysisfinder.com](http://www.dialysisfinder.com)

Locate dialysis centers anywhere in the United States with as little information as a city or state. This site helps dialysis patients make travel plans, regardless of where they're travelling.

#### [www.kidneyschool.org](http://www.kidneyschool.org)

Kidney School is an interactive, web-based learning program in 20 minute modules. It was designed to help people learn what they need to know to understand kidney disease and its treatment, adjust to kidney disease, make good medical choices, and live as fully as possible.

#### [www.pparx.org](http://www.pparx.org)

The Partnership for Prescription Assistance program can give you a helping hand. If you need help paying for medicine, call 1-888-4PPA-NOW (888-477-2669) toll-free or visit the website to see if you may qualify.

#### [www.pkdcure.org](http://www.pkdcure.org)

Polycystic Kidney Disease affects 600,000 Americans and 12.5 million adults and children worldwide. Learn about living with PKD and catch up on the latest in PKD science, health, and lifestyle news.



## RESOURCES

### Financial Assistance

Treatment for kidney failure is expensive, but Medicare and Medicaid pay much of the cost – usually up to 80 percent. Often private insurance or state programs pay the rest.

In addition to Medicare and Medicaid, there are a number of resources available for the kidney patient. They include:

- **State Children’s Health Insurance Program (SCHIP)** – This program provides health coverage for children whose families earn too much to qualify for Medicaid, but too little to afford private insurance. Find out more by calling 877-KIDS-NOW, or by checking [www.insurekidsnow.gov](http://www.insurekidsnow.gov).
- **Department of Veterans Affairs (VA) Benefits** – If you’re a veteran, the VA can help pay for treatment or provide other benefits. Contact your local VA office for more information or call 800-827-1000 for the national office. If you’re retired military, you can also contact the Department of Defense at 800-538-9552.
- **Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI)** – These benefits help with the costs of daily living. To receive SSDI, you must be unable to work and have earned the required number of work credits. SSI is for low-income people with limited assets. Your social worker can provide information on whether you qualify for either program.
- **Patient Assistance Programs from Prescription Drug Companies** – Medicare pays for erythropoietin to treat anemia from kidney failure and for immunosuppressants, but other self-administered drugs may not be covered. Most drug manufacturers have patient assistance programs, giving discounts to patients who can show that they can’t afford the cost of prescribed medications. The Partnership for Prescription Assistance provides a website that directs patients, caregivers, and doctors to more than 275 public and private patient assistance programs. Find out more at [www.pparxne.org](http://www.pparxne.org).
- **The United Network for Organ Sharing (UNOS)** – UNOS offers a website called Transplant Living, which includes a section on financing a transplant. Go to [www.transplantliving.org/beforethetransplant/finance/finance.aspx](http://www.transplantliving.org/beforethetransplant/finance/finance.aspx).
- **The Nebraska Kidney Association** – NKA provides limited emergency financial assistance to dialysis and transplant patients. Your social worker can provide you with additional information. All requests must be submitted through your social worker.

## RESOURCES

### Help

You can obtain additional information on kidney disease, treatment options, and programs and services through one or more of the following agencies:

#### **Nebraska Kidney Association**

11725 Arbor St., Suite 120A  
Omaha NE 68144  
402-932-7200  
NE Toll Free: 800-642-1255  
Fax: 402-933-0087  
E-mail: [nkaoffice@kidneyne.org](mailto:nkaoffice@kidneyne.org)  
Website: [www.kidneyne.org](http://www.kidneyne.org)

#### **American Association of Kidney Patients (AAKP)**

3505 East Frontage Road, Suite 315  
Tampa FL 33607  
Toll Free: 800-749-2257  
E-mail: [info@aakp.org](mailto:info@aakp.org)  
Website: [www.aakp.org](http://www.aakp.org)

#### **American Kidney Fund**

6110 Executive Boulevard, Suite 1010  
Rockville MD 20852  
800-638-8299  
E-mail: [helpline@akfinc.org](mailto:helpline@akfinc.org)  
Website: [www.kidneyfund.org](http://www.kidneyfund.org)

#### **National Kidney Disease Education Program**

9000 Rockville Pike  
Bethesda MD 20892  
800-860-8747

#### **Medicare Coverage of Kidney Dialysis and Kidney Transplant Services**

U.S. Department of Health and Human Services  
Centers for Medicare & Medicaid Services  
7500 Security Boulevard  
Baltimore MD 21244-1850  
Toll Free: 800-MEDICARE (633-4227)  
TDD: 877-486-2048  
Website: [www.medicare.gov](http://www.medicare.gov)



## ORDER FORM — EMERGENCY MEDICAL NOTIFICATION JEWELRY

### Nebraska Kidney Association

*Dedicated to improving the lives of Nebraska kidney and transplant patients*



The Nebraska Kidney Association offers **ONE FREE** piece of emergency medical notification jewelry to dialysis and post-transplant patients. Either bracelets or necklaces are available. Each is made with a chain and identification tag of high-quality polished stainless steel.

Up to five lines of information with a limit of 18 spaces on each line can be imprinted. Information would normally include patient's name and medical instructions. We recommend that address, telephone numbers, or doctor information not be included in this information as these can periodically change. Should your medical information change, additional jewelry can be ordered at a cost of \$3.99 each, payable with this form.

To obtain your emergency medical notification jewelry, please complete the order form below. Please allow six to eight weeks for delivery of your jewelry.

#### ORDER FORM

PATIENT'S NAME: (please print or type) \_\_\_\_\_

ADDRESS: \_\_\_\_\_

CITY/STATE/ZIP: \_\_\_\_\_

DIALYSIS UNIT: \_\_\_\_\_

I want a: (check one)     Necklace     Bracelet (Only 18 spaces per line)

**Jewelry to be mailed to:**     Home     Dialysis Unit

Line 1																			
Line 2																			
Line 3																			
Line 4																			
Line 5																			

Return completed form by mail or fax to:  
**Nebraska Kidney Association**  
11725 Arbor St., Suite 120A • Omaha, NE 68144  
FAX: 402-933-0087