

# LIVING WITH KIDNEY FAILURE

A Guide For Patients and Their Families



## Southeastern Kidney Council, Inc.

Improving the lives of people with, or at risk for, End Stage Renal Disease by promoting and advancing quality of care.

1000 St. Albans Drive, Suite 270

Raleigh, NC 27609

Phone: (919) 855-0882

Toll free for patients and family members: (800) 524-7139

Fax: (919) 855-0753

E-mail: [info@nw6.esrd.net](mailto:info@nw6.esrd.net)

DEVELOPED BY THE CONSUMER COMMITTEE  
OF THE SOUTHEASTERN KIDNEY COUNCIL

---

## THE SOUTHEASTERN KIDNEY COUNCIL

---

The Southeastern Kidney Council, also known as End Stage Renal Disease Network 6, is located in Raleigh, North Carolina. The Council is one of eighteen Network organizations in the United States under contract with the Centers for Medicare & Medicaid Services. The territory for Network 6 is Georgia, North Carolina and South Carolina. Like the other seventeen Networks, the Southeastern Kidney Council monitors the quality of care provided by Medicare-approved kidney dialysis and transplant centers. The goal of the Council is to make sure all patients receive the quality care they are entitled to through their Medicare benefits.

### NETWORK STAFF

Jenna Krisher	Executive Director
Leighann Sauls RN, CDN	Director, Quality Improvement
Sammy Bailey LMSW, CACII	Patient Services Specialist
Amy Williams	Administrative Manager
Christine Gevertz PHR, MBA	Director, Operations
Margo Clay MIS	Director, Information Management
Deborah Jackson	IM Specialist
Dee Tyburski	Information Systems Specialist
Wanda Boddie	IM Specialist

This manual was originally developed under contract 500-88-0019 and revised under contract HHSM-500-2006-NW006C with the Centers for Medicare & Medicaid Services, Baltimore, MD. For additional copies, contact the Southeastern Kidney Council.

## ACKNOWLEDGMENT

The Southeastern Kidney Council would like to thank the members of the Consumer Committee for all their hard work in developing this manual in 1988:

Danny Allen  
Judy Anderson RN  
Sammy Bailey LMSW, CACII  
Chuck Brown  
Jim Cain, MD  
Pat Dunkerley MSW

Priscilla Godfrey RN  
Fred Greiner  
Pearl Magovern MSW  
Frances Sullivan PhD  
Ann Thomas MSW  
Preston Turner



The 2005-2006 Consumer Committee members revised this manual in 2006:

Sammy Bailey LMSW, CACII  
Carl Brooks BA  
Jennifer Graves  
George Harper M.Ed, Ed.S  
John Haynes CPA  
Barbara Haynes  
W. Merrill Hicks MD  
Pearl Fu Magovern MSW  
Mary Claire Montilus MA

Omega Powell  
John H. Robinson  
Richard Rogers  
Noreen Rogers  
Elizabeth Simmons  
Thomas Taylor  
Willoughby Taylor  
Wayne Welborn

# TABLE OF CONTENTS

<b>INTRODUCTION</b>		<b>6</b>
<b>CHAPTER 1</b>	<b>TREATMENT OPTIONS FOR KIDNEY FAILURE</b>	<b>8</b>
	<ul style="list-style-type: none"><li>• Hemodialysis</li><li>• Peritoneal Dialysis</li><li>• Kidney Transplant</li><li>• The Treatment Team</li></ul>	
<b>CHAPTER 2</b>	<b>MEDICINES AND KIDNEY FAILURE</b>	<b>21</b>
	<ul style="list-style-type: none"><li>• General Information</li><li>• Commonly Prescribed Medications</li></ul>	
<b>CHAPTER 3</b>	<b>ROUTINE TEST AND CHECKS</b>	<b>29</b>
	<ul style="list-style-type: none"><li>• Adequacy</li><li>• Anemia</li><li>• Dialysis Facility Compare</li></ul>	
<b>CHAPTER 4</b>	<b>CHANGES IN YOUR DIET</b>	<b>34</b>
<b>CHAPTER 5</b>	<b>REHABILITATION</b>	<b>37</b>
	<ul style="list-style-type: none"><li>• Emotions</li><li>• Vacation and Travel</li><li>• Jobs and Education</li><li>• Exercise</li></ul>	
<b>CHAPTER 6</b>	<b>PATIENT RIGHTS AND RESPONSIBILITIES</b>	<b>44</b>
	<ul style="list-style-type: none"><li>• Rights and Responsibilities</li><li>• Complaint and Grievance Procedure</li><li>• Reuse</li><li>• Advanced Directives</li></ul>	
<b>CHAPTER 7</b>	<b>DISASTER PREPAREDNESS</b>	<b>49</b>
<b>CHAPTER 8</b>	<b>WHERE TO TURN FOR HELP</b>	<b>51</b>
	<ul style="list-style-type: none"><li>• Paying For Your Treatment</li><li>• Medicare Part D</li><li>• Resources by State</li></ul>	

<b>CHAPTER 9</b>	<b>REVIEW QUESTIONS</b>	<b>68</b>
<b>CHAPTER 10</b>	<b>COMMONLY USED WORDS</b>	<b>73</b>
<b>CHAPTER 11</b>	<b>SUGGESTED READING AND REFERENCES</b>	<b>83</b>

## ***INTRODUCTION***

Having kidney failure does not mean that your "world has come to an end." Your attitude toward life with kidney disease and treatment will make the difference. There will be some big changes in your lifestyle. However, once you and your family adjust to these changes and settle into a routine, you can lead a fairly normal lifestyle.

Reading this handbook can help you to better understand the many things you need to know about kidney failure and its treatment. It has been written by doctors, nurses, social workers, other health care professionals, and people like you who have also faced kidney disease. Those of us who are patients and family members want to share with you how we have adjusted with this illness. All of us want to help you to live a good life.

You've probably already heard your doctors and nurses use many strange words such as "end-stage renal disease (ESRD)." This is simply the medical term for kidney disease that requires dialysis or a kidney transplant for a patient to stay alive. Normal healthy kidneys act as the body's filtering or cleansing system. When they fail, you must either have a healthy kidney transplanted from someone else, or you must have dialysis treatments. These terms will be more clearly explained in this handbook.

First, what causes end-stage renal disease or kidney failure? High blood pressure, diabetes, kidney infections, and inherited diseases are some of the main reasons. Sometimes the exact cause may not be known. When your kidneys fail, waste products and fluid build up in your blood stream causing you to feel sick. When this happens, you must begin treatment.

There are three types of treatment options for you to know about: hemodialysis, peritoneal dialysis and kidney transplantation. If you have a transplant, the kidney can come from a living related or unrelated donor or a deceased donor. Together with your family and doctor, you can choose the best treatment for your special needs.

Read the information in this handbook carefully. It has been divided into sections explaining the different aspects of kidney failure. However, don't try to read it all at once. There is a lot to learn! If you don't understand something you are reading, don't be afraid to ask a staff member to explain it to you. You owe it to yourself and your family to know as much as you can about your disease and treatment.

Before reading on, remember two very important keys to your successful living with kidney failure: **keep a positive attitude and learn as much as possible about your illness. The keys to successfully living with kidney failure are knowledge, attitude and control.**



## **CHAPTER 1**

# **TREATMENT OPTIONS FOR KIDNEY FAILURE**



When your physical condition and disease permits, treatments should be tailored to meet your lifestyle. Once you start a form of treatment, you can try another if it's not going well for you. What works for one person might not work for another. Treatment options are chosen according to medical condition, lifestyle and preference.

## **HEMODIALYSIS**

A normal kidney is the body's main filter. It cleans your blood and keeps your body balanced for normal functioning. When your kidneys fail, dialysis, along with medications, diet changes and exercise, will keep this balance going.

One type of dialysis is **Hemodialysis**, which simply means, "to cleanse your blood". Your blood goes through an artificial kidney (called the "dialyzer") to remove waste products and extra fluids that have built up in your body. A pre-mixed fluid, called dialysate, is used to adjust the chemistry of the blood back to normal so it passes through the dialyzer. The dialyzer is connected to the artificial kidney machine, which is necessary for hemodialysis to take place.

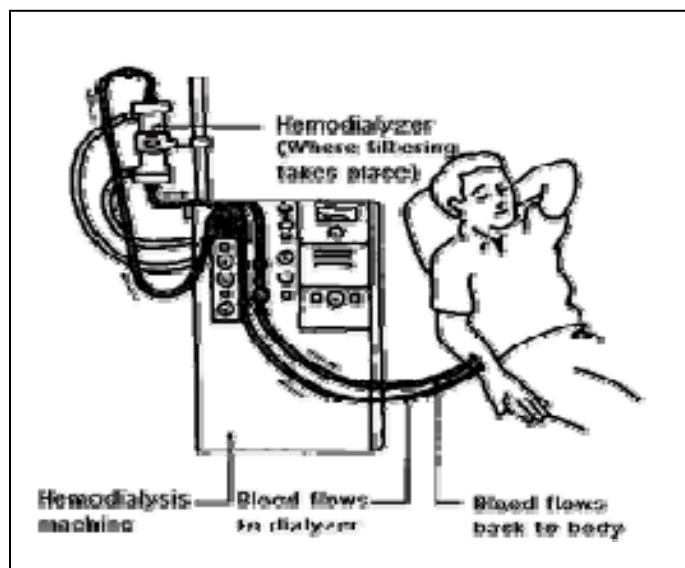
Hemodialysis can take place either in your home or in a dialysis center. If hemodialysis is performed at home, a partner or helper (usually a family member) must train with the patient to set up the dialysis machine. However, in some areas, a trained dialysis staff person may be available to help you at home. Nocturnal hemodialysis, which is performed overnight, is a very successful variation of home hemodialysis. If home hemodialysis is of interest to you, talk with your doctor. He/she may be able to refer you to individuals already on this form of treatment. This way you and your family will have a better idea of what's involved with home hemodialysis. Since patients who do home hemodialysis are relatively rare, home hemodialysis training is not offered in all dialysis centers.

Before starting hemodialysis, a surgical procedure will be done on your arm or leg (although arm is most common) to connect an artery to a vein underneath the skin. This procedure creates a large enough blood vessel to remove and return your blood during treatment. This large blood vessel is called an

"access". When your own artery and vein is used, this is called a "fistula." The fistula is the preferred access because it is less likely to become infected, maintains better flow over time and lasts longer. If a man-made tube or cow artery is put into your arm it is called a "graft".

Usually, you must wait at least six to eight weeks before using a new fistula for treatment, or two to five weeks for a graft. Your doctor or dialysis nurse will give you instructions on how to take care of your access and make it strong for use.

In order to remove your blood for cleansing and then return it to your body, two needles are placed in your access at the beginning of each treatment. These are special needles used just for hemodialysis treatments. If you experience too much discomfort when they are put in, a small amount of medication can be injected or applied first to numb the area in the same way the dentist numbs a tooth before drilling.



If you have to start hemodialysis before your fistula or graft is ready, a catheter will be used. A catheter is a plastic tube that is inserted by a surgeon into the jugular vein or subclavian. There is a risk of a blood vessel being torn upon insertion and it is hard to maintain adequate blood flow over time. The catheter will be removed once your permanent access is ready to be used. In some cases, a catheter is the dialysis access of last resort and must be left in place long-term. **Unless all other options have been exhausted, the catheter should not be used as a permanent access and it is important to remove it as soon as possible.**

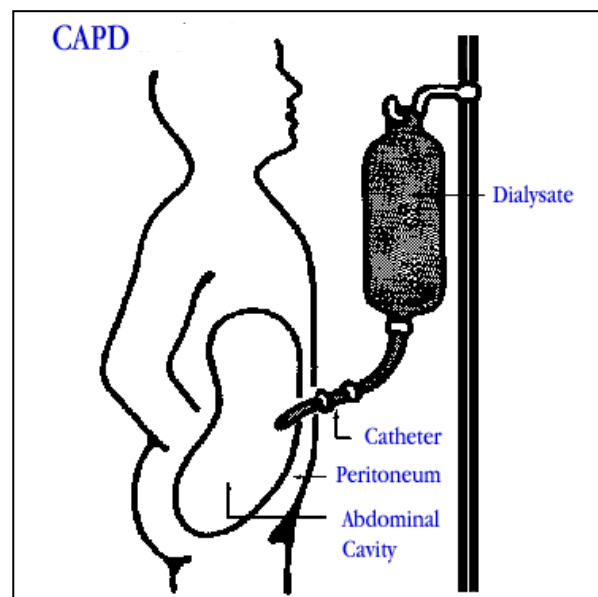
One of the first questions a new patient on hemodialysis asks is, "How long is the treatment?" On the average, each treatment lasts about three to five hours, depending on body size and type of access, and is performed three times a week. Your doctor will advise you on how much dialysis you will need. You can never have too much dialysis but you can have too little.

If you have treatment in a dialysis center, your doctor may order that your dialyzer be used more than once. This is known as reuse. If so, it will be marked with your name and will be used only by you. For many years, artificial kidneys have been successfully "reused". It is considered to be a safe medical practice **when done properly**. Your dialysis center is required by the Medicare program to follow strict rules of safety in its reuse procedures. Ask your doctor to explain the benefits and risks of reuse to you. Be sure to read the consent form thoroughly before making a decision.

## PERITONEAL DIALYSIS

Peritoneal dialysis is another form of dialysis that works well for some people. It uses the body's own "system" instead of an artificial kidney machine. Most people who dialyze at home do peritoneal dialysis.

Here's how it works: A soft, thin, plastic tube called a catheter is surgically placed into your peritoneal cavity. The peritoneal cavity is located in your abdomen. The inner lining of the cavity is called the "peritoneal membrane" and acts like a filter. This is the body's own "system". Dialysis fluid is drained from a plastic bag into the peritoneal cavity through the catheter. After several hours, the fluid is drained back out, carrying waste and extra body fluid with it. The amount of dialysis fluid put in to you will depend on your body size.



One of the good things about this kind of dialysis is that it is done slowly and gradually. Most people do not experience a "washed out" feeling, which many people describe after a hemodialysis treatment. Peritoneal dialysis allows for fewer diet restrictions. Also, once you are trained, you can do the treatment at home. Training takes approximately 2 weeks. The main drawback to peritoneal dialysis is the risk of infection (peritonitis). However, there are medications to clear up the infection if caught in time. It is important to follow your nurse's and doctor's instructions on how to prevent infection.

There are two kinds of peritoneal dialysis. They are:

A) Continuous Ambulatory Peritoneal Dialysis (CAPD)

B) Continual Cycling Peritoneal Dialysis (CCPD)

## **CONTINUOUS AMBULATORY PERITONEAL DIALYSIS (CAPD)**

This is the most common form of peritoneal dialysis. It allows you to go about your daily activities while the dialysis fluid stays in your abdomen. Several times a day you must do an "exchange" of fluid: simply draining out the old fluid and replacing it with new. Your physician will prescribe how often the exchanges should be performed. The exchanges can be performed at home or work.

## **CONTINUOUS CYCLING PERITONEAL DIALYSIS (CCPD)**

This is a form of peritoneal dialysis requiring a machine called a "cycler". You will still need a catheter implanted in your peritoneum, but instead of performing exchanges during the day, the cycler machine will do the exchanges for you. The exchanges are commonly performed at night while you sleep. You must set up the machine before "hooking up" to it and throw away the used supplies in the morning. Many patients combine both CAPD and CCPD treatments. They will do one or two exchanges during the day and use the cycler at night. Your doctor and nurses can help you decide whether CAPD, CCPD, or a combination of the two would work best for you.

## **KIDNEY TRANSPLANT**

Kidney transplantation is a treatment option for some people who have kidney failure. A successful transplant is the only way to replace your normal

kidneys' functions, **but it is not a cure for your kidney disease.** A successful kidney transplant can improve your quality of life and well-being. On average, patients with successful transplants live longer than those who remain on any type of dialysis. It can also provide you with increased independence and help you return to a more normal lifestyle.

There are several types of kidney transplants.

A **LIVING RELATED TRANSPLANT** takes place when a family member, such as a brother, sister, parent, or one of your children is the kidney donor. Because a person only needs one kidney to live and function normally, the family member gives his or her "spare" kidney to you. The family donor must be in good health and meet other requirements. Special tests are performed to determine if any family member can give a kidney that will "match" your body.

A **DECEASED DONOR TRANSPLANT** takes place when healthy kidneys of someone who has died are donated as a "gift of life." A person may indicate his or her wish to become an organ donor by signing his or her driver's license or an organ donor card and telling their family members of their wishes. An individual's next of kin can also give permission for organ donation at the time of death.

Donated kidneys are matched to all kidney patients with compatible blood types on the transplant waiting list. The recipient is then selected according to medical need, best possible match, length of time on the waiting list, and other medical factors.

Another type of kidney transplant may take place, called a **LIVING UNRELATED DONOR TRANSPLANT**. It occurs when someone who is not a blood relative is the living kidney donor. These transplants are becoming more common despite the difficulty in matching the kidney patient and the unrelated kidney donor. Donated kidneys from living donors tend to last longer than kidneys from deceased donors.

While a successful kidney transplant can lead to normal kidney function and an improved lifestyle, there are several problems that may happen after the transplant. The most common problems are infection and rejection. Rejection may occur at any time, but usually within the first 3 months. Rejection is a normal response of your immune system to guard your body against the invasion of all foreign matter such as bacteria, viruses, etc. Your immune system sees your transplanted kidney as an "invader" and it will try to "attack"

it. A rejection episode does not mean you will lose your kidney. Most often rejection is reversible, but occasionally it is not.

You will need to take special medications to keep your transplanted kidney from rejecting. These medications may cause some possible side effects. (See Chapter 2 - Medicines and Kidney Failure, Anti-Rejection Medications.) All drugs have side effects. They are more common when your dose is high and they may disappear as the dosage of your medications is reduced.

You may wonder how you could afford a kidney transplant. Medicare and most private-pay insurance companies pay for the transplant as well as pre-transplant testing. Medicare will also cover the hospital and physician expenses of the donor's surgery and testing. Medicare will also cover the cost of transplant medications for three years following the operation. However, there are no provisions by Medicare to include other donor expenses such as transportation, paid leave of absence from work, etc.

A transplant is not possible for everyone. You must be medically suitable and be willing to take the special transplant medications as long as you have your transplanted kidney. If you are interested in a transplant, ask your doctor about it, and he/she will explain the procedure and possible side effects. Your physician can also refer you to a transplant program for testing. During the testing you will undergo specific tests to determine your overall health and suitability as a transplant candidate.

You will also have an opportunity to learn more information about transplantation from the transplant team, and possibly meet and talk with some transplant patients. The financial counselor and the social worker will assist you in developing a plan to ensure success with your kidney transplant.

The waiting time for a kidney transplant may be short or it may take much longer than you had hoped. It is not always easy to find a compatible kidney for your body. It may be necessary for you to go on dialysis while you are awaiting your kidney transplant. Therefore, it is important for you to know all about your other treatment options.

## **SUMMARY OF KIDNEY FAILURE TREATMENTS**

Listed are some of the advantages and disadvantages of each form of treatment for kidney failure. You will want to discuss these with your physician and your family.

# **HEMODIALYSIS IN-CENTER**

## **BENEFITS**

- Treatment is provided by well-trained staff
- Treatment is usually only three times a week
- When off dialysis, normal activities can resume
- With prior authorization, travel may be supported by dialysis arrangements in other facilities
- Monitoring of blood pressure, pulse, weight and temperature are done each treatment
- Patients will have regular contact with a Social Worker, Dietitian, Nurse and Physician
- Socialization with other patients and staff

## **POSSIBLE CONCERNS**

- Patient must go to a center for treatment
- Patient must be connected to a machine for several hours
- Patient must adhere to schedule provided by dialysis center
- Patient has less control over treatment than at home
- Hemodialysis requires diet and fluid restrictions
- Patient has greater exposure to communicable diseases
- Frequent travel is limited

## **DAILY HEMODIALYSIS**

### **BENEFITS**

- Patient has few dietary restrictions
- Patient has better phosphorous control
- Patient has better blood pressure control
- Improved sexual activity
- Patient experiences less weakness

### **POSSIBLE CONCERNS**

- Requires special training that is not readily available
- Treatment performed daily; greater commitment of time
- Travel is limited
- Not currently covered by Medicare
- Available in few centers

## **HOME HEMODIALYSIS**

### **BENEFITS**

- Patient can be trained to do the treatment on themselves with the assistance of a partner at home
- Patient uses own machine
- Patient can dialyze at convenient hours
- Studies show that home hemodialysis patients live longer than in-center patients
- Medicare coverage begins when the patient begins training

## **POSSIBLE CONCERNS**

- Requires extensive training
- Must have adequate storage for supplies
- Usually requires a partner

## **CONTINUOUS AMBULATORY PERITONEAL DIALYSIS (CAPD)**

### **BENEFITS**

- Allows the patient to be more independent and perform own treatment
- Can be done at flexible hours
- Can be done in many locations and allows greater ease in travel
- Does not require a machine or partner
- Fewer dietary restrictions than hemodialysis
- Training is shorter than for home hemodialysis
- Easier to continue school, work, and other daily activities
- Better control of blood pressure with medicines

### **POSSIBLE CONCERNS**

- Risk of Peritonitis (infection of the peritoneum)
- Must take supplies with you when traveling
- Must be performed several times daily, seven days a week
- The dialysis fluid may increase the size of the abdomen
- Body image may be altered due to the catheter placed in the abdomen
- Must be adequate space in the patient's home for supplies

## **CONTINUOUS CYCLING PERITONEAL DIALYSIS (CCPD)**

### **BENEFITS**

- Can be performed while patient sleeps
- Patient can go about their usual routine during the day
- Patient doesn't need a partner like in home hemodialysis

### **POSSIBLE CONCERNS**

- Altered body image due to catheter in abdomen
- Risk of peritonitis
- Requires setting up machine before treatment and throwing away used supplies at end of treatment
- Must take supplies, including cycler machine, when traveling
- Limited activity during treatment
- Usually requires at least 10 hours a night for treatment

## **TRANSPLANTATION**

### **BENEFITS**

- Only way to replace kidney function
- Frees the patient from dialysis
- Fewer dietary and fluid restrictions
- Improves feeling of well-being and normalcy
- May improve desire for sexual activity
- Increased independence and mobility
- Increased energy level and more active lifestyle
- Living donor kidney lasts longer

## POSSIBLE CONCERNS

- Rejection risk
- Susceptible to infections
- Side effects from medications (See Chapter 2, Anti-rejection drugs)
- Possible changes in appearance (weight gain, swelling of face)
- Cost of medications once Medicare coverage ends
- Increased risk of cancer

The question of the best method of treatment is a difficult one to answer. The advantages and disadvantages to each kind of treatment affect each person differently. Some patients prefer transplantation even with the risk of rejection and return to dialysis. Others prefer dialysis.

Kidney patients should learn all they can about each method of treatment. Talk with medical staff, listen to both home and in-center dialysis patients, speak with transplanted patients, and talk with families. Then you can make the best decision about your own treatment.

At the beginning of your treatment, it is not uncommon that you may experience decreased energy during your treatments. You may also experience some tiredness and poor appetite after a treatment. If this occurs, be sure to speak to your nurses and/or your physician.

## THE TREATMENT TEAM

There are several different professionals who participate in your individual care planning. They make up the multidisciplinary treatment team. The team works together to come up with a plan of care best suited to your particular medical, physical, psychosocial and nutritional needs.

**The NEPHROLOGIST** is the Medical Doctor who specializes in the care of patients with kidney failure. He/she may also have special training in issues related to hypertension (high blood pressure), diabetes and urinary tract diseases. The Nephrologist makes the ultimate decision of your dialysis prescription, which includes the duration of your treatment, the type of dialyzer you need and the mixture of your dialysate fluid.

**The TRANSPLANT SURGEON** is the Medical Doctor who specializes in surgeries related to organ placement. The Surgeon determines if you are suitable to receive a kidney based on your current medical condition and medical history. After the surgery, the surgeon and nephrologist will manage your transplant care, including monitoring for infection or rejection.

**A NURSE** may have several functions in the facility. First, a Nurse may act as a facility manager or administrator, to oversee the day-to-day center performance. Additionally, a Nurse supervises the in-center treatment-related activity. He/she administers medicines, follows through with orders from the Nephrologist and provides necessary documentation. If you perform dialysis at home, a Nurse is usually your primary contact for questions and/or concerns about your care.

**A PATIENT CARE TECHNICIAN (or PCT)** remains in the treatment area during your hemodialysis treatment. He/she is responsible for monitoring your treatment. A PCT cannulates your arm and assists with the initiation and termination of your daily treatment. The PCT and the Nurse work closely together to administer the best dialysis treatment prescribed for you.

**THE SOCIAL WORKER** is responsible for assisting you and your family in areas related to your psychosocial needs. He/she offers supportive counseling and is knowledgeable of adjustment, coping and grieving issues you may be experiencing. The Social Worker is knowledgeable of community resources and can make referrals for you as needed. He/she promotes your overall well-being by assisting you reach your fullest potential vocationally, financially, emotionally and socially.

**THE DIETITIAN** is responsible for managing your nutritional needs. He/she will update you monthly on what changes (if any) need to be made to your diet. The Dietitian can suggest meal preparation specific to your renal diet as well as tips on how to monitor your potassium, phosphorous, protein and fluid intake.

**A FINANCIAL COUNSELOR** works with patients to assist you in managing your insurance and financial needs. Upon admission, this person may inquire about your financial status to help identify what your greatest needs are. The financial counselor works closely with the social worker to incorporate psychosocial aspects of your financial needs. At some facilities, they may act as the financial counselor.

**YOU!** As a kidney patient, you have the right and responsibility to play an active role in your care planning. Never be afraid to ask questions and utilize the resources available to you. The treatment team is most effective in planning your dialysis treatment and care with your input.

## CHAPTER 2

# MEDICINES AND KIDNEY FAILURE



Whether you are on dialysis or receive a kidney transplant, you will need to take several medications. If you are being treated for medical problems other than your kidney failure, dialysis or transplantation, your present medications may not change. However, it is important to discuss with your kidney doctor any medications you are taking to ensure safety and correct dosage.

Kidney disease can change the way in which your body absorbs and uses drugs; therefore, it is important to take medications as ordered by your doctors. Over-the-counter medications should be approved by your doctor before use to ensure that they will not be harmful.

### General Information About Medications



- 1) Know what each medication is for and the dose you are to take. Take them faithfully. This can prevent many unnecessary problems. If you have difficulty taking a medication, or have side effects, always discuss this with your physician before you discontinue or change the dosage of the medication.
- 2) Laxatives and stool softeners should be taken only as prescribed. Tell your doctor if you are constipated. Be aware that nausea and vomiting, abdominal cramps and even diarrhea can be a symptom of constipation. Kidney failure is a failure of proper waste removal. Therefore, constipation, another type of failure of proper waste removal, can make you even sicker than you might expect. Given that fluid restriction and use of constipating phosphate binders are often part of the dialysis experience, carefully tracking your bowel activity is a part of good health care.
- 3) The fact is that not only is kidney failure associated with 'soft bones', but phosphate deposits throughout the body can cause complications in the form of vascular disease (literally, 'hardening of the arteries'), and more misery through itching associated with these deposits. Also, poor phosphorus control is associated with worsening high blood pressure, which also is associated with more dialysis-related complications such as heart failure, strokes, and vascular disease. Therefore, be sure to **take your phosphate binders exactly as prescribed, and as many**

**as prescribed.**

- 4) Do not take aspirin unless your doctor tells you to. Use Tylenol for pain or fever, as directed.
- 5) Most medications prescribed "once a day" should be taken after dialysis, because some medications can be removed by dialysis. Ask your nephrologist and dialysis care team to guide you on when to take your medications.
- 6) Unless otherwise ordered, take your blood pressure medication on dialysis days after dialysis instead of before, since this will drop your blood pressure while on the machine. Otherwise, the necessary fluid removal during dialysis could be difficult and uncomfortable for you.
- 7) If you need to visit the dentist, it is preferred that it be on a non-dialysis day or a minimum of four (4) hours after your treatment. It is also very important that you notify your dialysis nurse or physician BEFORE your treatment if you have a dentist appointment so that adjustments can be made in your heparin dosage and antibiotics can be prescribed if necessary.
- 8) Any doctor you visit should be informed that you are a dialysis or transplant patient. Communication should occur between your nephrologist (kidney doctor) and any other doctor before surgery or when new medications are prescribed.

This next section lists the most commonly prescribed medications for patients with kidney disease. You should be informed about how they help you and their side effects. If you are on any medication not listed, you can get information about it from your doctor, pharmacist, or dialysis nurse.

## **PHOSPHATE BINDERS**

Examples include antacids, such as Tums, Tums-Ex, or PhosLo. These calcium-containing antacids both lower stomach acid and bind the phosphorus in the food you eat while it is still in the stomach. When blood phosphorus levels are high, calcium is 'pulled out of the bones', both by the phosphorus itself, and by the overactive parathyroid glands, which are stimulated by high blood phosphorus levels. When this happens, the bones become weak enough to spontaneously fracture, and calcium and phosphorus deposit in and damage soft tissues throughout the body. These medicines work best when taken with meals, but they work

whenever any digesting food is in the gut. Phosphorus bound in the intestine is eliminated through bowel movements.

Almost all over-the-counter antacids (such as Maalox, Mylanta, Riopan, etc) contain magnesium and aluminum and should be avoided, as it is hard to 'dialyze off' magnesium, and aluminum. Aluminum also deposits in the bones and makes them even weaker.

Phosphate binders such as Renagel, bind and lower cholesterol. This agent binds phosphorus without raising calcium and also is the only non-constipating phosphate binder. Lanthanum carbonate (Fosrenol) is a non-calcium containing phosphate binder.

### **CALCIUM-CONTAINING PHOSPHATE BINDERS**

Examples include Phoslo (Calcium Acetate) or Tums (Calcium Carbonate), which are effective phosphate binders. Although calcium supplements can strengthen the bones, not every dialysis patient needs extra calcium, which also complexes with phosphorus to deposit in both the bone and soft tissue. That said, lowering phosphorus is very important, and these agents are very potent phosphate binders.

Although there has been much publicity recently about the importance of a normal calcium level, keeping the phosphorus level down to 5 Meq/L or less is much more important—all of the side effects of renal bone disease (also known as renal osteodystrophy) start with a high blood phosphorus, and can be prevented by keeping the phosphorus level down. **For the dialysis patient, phosphorus control is almost as important as blood pressure control or coming to and completing every dialysis treatment.**

### **LAXATIVES AND STOOL SOFTENERS**

Examples include Dulcolax, Colace, Sorbitol, and Metamucil.

A combination of medications, fluid restrictions, and decreased activity may cause constipation. Laxatives and stool softeners can help relieve the problem. It is important that you keep your bowels moving regularly. If you find that your stools are too hard or too soft, you can regulate the amount of stool softener as necessary.

### **VITAMINS**

Examples include Nephrovite, Nephrocap, Nephron FA and Hemocyte Plus. Vitamins are frequently prescribed because of diet restrictions and loss of vitamins during dialysis. Vitamin supplements that have been formulated for

the needs of dialysis patients are used.

## **ION EXCHANGE RESIN (KAYEXALATE)**

This medication is used only as needed to lower a very high potassium level. It may be necessary to limit your dietary intake of potassium by avoiding high potassium foods. If your potassium becomes dangerously high or if you always have high potassium levels, your doctor may prescribe Kayexalate on a regular basis. Kayexalate causes constipation if taken alone. In order to properly move it through the intestine, Kayexalate is usually given with a laxative called Sorbitol. Soft bowel movements and lowered potassium are expected after taking these medications.

## **BLOOD PRESSURE MEDICATIONS**

Examples include Metoprolol (Lopressor), Propranolol (Inderal), Captopril (Capoten), Atenolol (Tenormin), Clonidine (Catapres), Nifedipine (Procardia), Hydralazine (Apresoline), Prazosin (minipres), Minoxidil (Lonitin), Diltiazem (Cardizem), Nadolol (Corgard), and Norvasc. Hypertension can be partially controlled by removing excess fluid through the dialysis treatment & by decreasing your dietary sodium (salt) intake. Once you have reached your optimum weight, you will need blood pressure medication if your blood pressure isn't controlled. **At least some dialysis experts believe blood pressure control is the most important part of the care of dialysis patients, from the standpoint of preventing dangerous side effects such as strokes, heart attacks, heart failure, and peripheral vascular disease.**

Side effects from these medications include a slow heartbeat from certain of the group which do this; other meds can cause blood vessel dilation with dizziness, palpitations, visual disturbances and/or weakness. Sexual side effects can occur from these medicines, but also from kidney failure or other diseases that may cause kidney failure.

Almost always your doctor will NOT want you to take blood pressure medications before dialysis, as this may make for a difficult treatment with low blood pressure & difficulty removing fluid (which will later result in high blood pressure because you're not at your optimum weight).

## **ANTIPRURITICS (Anti-Itching Medications)**

Examples include Benadryl, Hydroxyzine, Temaril, and Atarax. Itching is a frequent symptom of kidney failure, one that is not always relieved by dialysis. In some cases, itching may respond to improved phosphorus control.

## **PAIN MEDICATIONS**

Tylenol is primarily used for the relief of pain and to decrease your body temperature associated with fever. Tylenol can be purchased over-the-counter so you won't need a prescription to take them. Tylenol is less irritating to the stomach than aspirin and should always be used unless aspirin is specifically ordered by your physician. It is important not to take these medications on a continual basis without first checking with your doctor. Any prolonged fever or pain should be reported to your doctor.

Darvocet, Percocet, and Codeine are generally prescribed for more severe pain, and only for short periods because they can be addicting. They have a sedative effect. These drugs can cause nausea, vomiting, dizziness, and light-headedness. In addition, Codeine and Percocet can be constipating.



## **CARDIAC DRUGS**

A number of cardiac medications are ordered on an individual basis—but digoxin (digitalis) and nitroglycerine are of particular importance to the dialysis patient.

**Digoxin** can cause nausea, vomiting, slow heart beat, and visual disturbances when it builds up—since it is removed from the body by the kidney, these complications are common in dialysis patients.

**Nitroglycerine preparations** (standard nitroglycerine taken under the tongue, or the more long-acting agents such as Imdur or Isordil or Isosorbide) all cause blood vessel dilation (just like some of the blood pressure medications) and can lead to very low blood pressure, particularly when taken just after dialysis. If longer acting nitrates are taken before dialysis, they can contribute to blood pressure instability during the treatment.

## **ANTI-ANEMIA HORMONE**

One of the main problems most kidney patients on dialysis face is anemia, which is a low number of red blood cells found in the blood. This number is measured by a lab test called the *hemoglobin*. This test measures the percentage of red blood cells in your blood. In general, your hemoglobin level should be greater than 11 gm/dl. Recent studies have shown that a hemoglobin greater than 11gm/dl helps patients feel better and live longer. Your hemoglobin level will be checked on a regular basis by the dialysis center staff.

Anemia occurs because the kidneys are no longer able to produce a special hormone called erythropoietin. Erythropoietin causes the body to make red blood cells, which helps to provide you with energy and stamina.

Epogen was approved for use by the Food and Drug Administration in June 1989 to treat this condition. Epogen eliminates the need for routine blood transfusions, increases energy levels, and improves the overall quality of life for kidney patients. Epogen helps your body to make more red blood cells. Your doctor will adjust the amount of Epogen you receive according to your hematocrit level.

Because it is an expensive medication, Medicare has agreed to fund Epogen (& more recently Aranesp) for dialysis patients. Check with your doctor for more information about Epogen.

## **IRON PREPARATIONS**

Examples include, Ferrous Sulfate, Niferex, Feosol, Fergon, Infed, Ferrlecit and Venofer. A low level of iron in the body also causes anemia. Iron is used to form red blood cells. Kidney patients often have low iron levels because of diet restrictions and loss of blood during hemodialysis. Your body must have enough iron in order for Epogen to work. Iron medications are often prescribed in order to increase the amount of iron in your body. These medications come in pill form or can be injected directly into your bloodstream during hemodialysis. If you are taking iron pills, be sure to take them between meals because the body will absorb the medication better. Also, remember not to take the iron medication at the same time as antacids or phosphate binders because this will also decrease the absorption of iron.

Iron medication darkens the color of the feces and may cause constipation. Ask your doctor for a stool softener if necessary.

## **TRANSPLANT MEDICATIONS** (kidney transplant recipients)

Examples include Cyclosporine, Azathioprine, Adrenocorticosteroids, and Cyclophosphamide. These medications keep your body from "fighting" or rejecting the transplanted kidney. To keep from losing the kidney, these drugs must be taken exactly as your doctor has told you. Some of them have side effects that you will want to discuss with your doctor or nurse. Some of these side effects are listed below (NOTE - all patients do not experience all side effects):

- Risk of infection: It is harder for your body to fight an infection, for example a cold or the flu
- Problems with the liver and/or the transplanted kidney
- Thin hair, acne, and facial hair growth
- Pain in the joints
- Possibility of developing cardio vascular disease, diabetes, cataracts, high blood pressure, cardiac disease, vascular disease or cancer
- Shaking of the hands
- Weight gain

## **STOMACH MEDICATIONS**

These medications are used to help your body digest food and to decrease stomach acid. Your doctor may prescribe them if you have an ulcer, persistent nausea, vomiting, or increased stomach acid related to diabetes. Cimetidine (Tagamet) and Ranitidine (Zantac) are used primarily to decrease the acidity in your stomach. Adverse side-effects are uncommon, but may include diarrhea, dizziness, drowsiness, rash and headache. "Proton pump inhibitors", such as Nexium or Protonix, also act strongly to decrease stomach acid. Paradoxically, they can also cause abdominal pain or diarrhea.

Metoclopramide (Reglan) help your body to digest food faster. This medication should diminish symptoms of nausea, vomiting, heartburn, and persistent fullness after meals. Metoclopramide should be taken 30 minutes before meals to obtain the best results. The most frequent side effects are restlessness, drowsiness, and fatigue.

## **SEDATIVES AND TRANQUILIZERS**

Examples include Valium, Dalmane, Ambien and Restoril. These medications are used primarily for sleeplessness or nervousness. Your physician may prescribe them for you during stressful periods or to aid you in relaxation. Keep in mind that they can be addictive, and it is best to utilize other techniques when possible. Regular sleeping patterns and exercise will probably be enough to prevent the need for these drugs. It is important to

take them only as directed. The main side effect is drowsiness.

## **PSYCHOTROPIC MEDICATIONS**

Examples include Lexapro and Doxepin. It is not uncommon to experience adjustment and coping issues or feelings of depression and anxiety. It is important to use these drugs as directed as they may cause dependency. Many dialysis patients have other health issues that requiring careful monitoring of these drugs.

## **HERBS**

Examples include Ginseng, Green Tea, Echinacea, Aloe, Kava Kava and Licorice Root. These products can be purchased over the counter in a drug store. They are classified as dietary supplements. Often the ingredients are not identified. Some herbs can cause serious health conditions such as cancer or be the direct cause of kidney failure. At this time there are no clinical trials to support their safety and effectiveness. Patients with any type of kidney problems should consult their physician before taking these products.

## **CHAPTER 3**



## ***ROUTINE TESTS AND CHECKS***

You'll need to be tested often to be sure your treatment is working as it should. Some of these tests are done with every dialysis, some are done once a month, and some are done when the doctor sees that you need testing.

With each dialysis your blood pressure, weight, pulse, and temperature will be checked to see if there are any changes in your general health. For example, a change in weight might show you've been drinking too many liquids. In that case, the extra fluid must be removed during dialysis.

A blood test may be done frequently to show the amount of red blood cells in your body. This is called your hemoglobin. A low blood count might show that you're losing blood somewhere in your body or that you need to start taking the medication Epogen or Aranesp.

About once a month several blood tests are done to see if you are getting enough dialysis. Transplant patients also have their blood checked to see if the transplanted kidney is working well. These tests also check for problems with your bones or liver and for problems with your diet or medications. A guide to blood chemistries and what they mean is at the end of this chapter. Chest x-rays and electrocardiograms (EKG's or ECG's) will be ordered as necessary to check on changes in your heart or lungs that might need treatment. For infection control purposes, other routine test may be performed monthly or annually, for example, to check for tuberculosis and hepatitis B.

### **ADEQUACY**

Adequacy means the effectiveness of the dialysis treatment. In hemodialysis, this is determined by how much of the waste products are being removed from your blood during your treatment which can be measured by two different calculations: URR or Urea Reduction Ratio, and  $KT/V$  (spoken as "K/T over V"). These values are used by your doctor to see how well your dialysis is working. They are determined by lab tests that are usually performed once a month. When patients do not receive adequate dialysis, they often experience weakness, fatigue, weight loss, poor appetite, nausea, and are more likely to experience medical complications and premature death. On the other hand, studies have shown that hemodialysis patients feel better and live longer when they have a URR of at least 65% and a  $KT/V$  of at least 1.2.

### **URR**

In order to determine the Urea Reduction Ratio, a blood sample is taken before and after the dialysis treatment. The Urea Reduction Ratio measures the fraction of Blood Urea Nitrogen (BUN) that was removed from your blood during the treatment. BUN is one of the waste products found in your blood.

## **KT/V**

This calculation is more complicated. It is determined by:

K=speed at which the dialysis is removing the BUN from the body

T=time spent on dialysis

V=volume or size of the patient

It is important for patients to be aware of the adequacy of the treatment that they are receiving. Patients are encouraged to discuss this with their doctor. Several factors affect the effectiveness of hemodialysis. These include blood flow, time spent on dialysis, and type of dialyzer used. Your doctor may adjust these factors if your dialysis is not as effective as it could be in removing the poisons from your blood.

The adequacy of peritoneal dialysis can also be measured using the formula KT/V. This is determined by taking blood, urine, and dialysate samples and calculating the amount of poisons that are removed from the blood over the course of a week. If you are on peritoneal dialysis, your KT/V should be at least 1.8. Your doctor may adjust factors such as number of exchanges, volume, or dwell time in order to make your dialysis treatments more effective.

## **ANEMIA**

As you read in an earlier chapter, anemia is a low number of red blood cells found in the blood. Anemia occurs because the kidneys are no longer able to produce a special hormone called erythropoietin. Low iron due to blood loss is another cause of anemia. Blood loss can occur in a number of ways, such as menstrual cycles in women or during surgery.

## **HGB**

This number of red blood cells found in the body is measured by a lab test called the *hemoglobin*. In general, your hemoglobin level should be greater than 11 gm/dl. Recent studies have shown that a hemoglobin greater than 11gm/dl helps patients feel better and live longer. Your hemoglobin level will be checked on a regular basis by the dialysis center staff.

## **DIALYSIS FACILITY COMPARE**

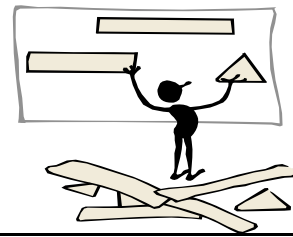
Information about how your facility compares to other facilities in the areas of adequacy and anemia is provided on Dialysis Facility Compare. It is an important resource available on the Internet at [www.medicare.gov](http://www.medicare.gov). This website can help you:

- Search for Medicare certified dialysis facilities in any State,
- Compare the services offered at dialysis facilities,
- Compare the quality of dialysis facilities, and
- Find more information and links on kidney disease and dialysis treatments.

### **How to Use Dialysis Facility Compare**

1. Go to [www.medicare.gov](http://www.medicare.gov) on the Internet and click on Dialysis Facility Compare.
2. Select a State.
3. Narrow your search by selecting a county, city, zip code, or name of a facility.
4. Select the facilities that you would like to get more information about. If you select more than one facility, you will be able to compare the information on all the facilities you choose.
5. Choose from two areas to get more information:
  - a. **Facility Characteristics:**
    - Name, address, and phone number,
    - The date the facility was certified by Medicare,
    - Whether or not the facility offers shifts starting at 5:00 pm or later,
    - The number of treatment stations, and
    - The types of dialysis offered (in-center hemodialysis, home hemodialysis, PD, etc.).
  - b. **Quality Measures:**
    - The percent of patients who received adequate dialysis,
    - The percent of patients whose anemia was adequately managed, and
    - Patient survival information.

## COMMON LAB TESTS



TEST	NORMAL VALUE	FUNCTION
CALCIUM	8.5-10.5 mg/dL	blood clotting, formation of bones and teeth, transmission of nerve impulses and muscle contractions
CREATININE	0.6-1.5 mg/dL; usually high in kidney failure	waste product of muscle and protein breakdown
GLUCOSE	70-110 mg/dL; higher in uncontrolled diabetes	acts as fuel for the body
MAGNESIUM	1.5-2.0 mEq/L; may be normal or high in kidney failure	assists in the breakdown of foods
PHOSPHORUS	3.0-4.5 mg/dL; usually high in kidney failure	used to store energy for body processes, directly affects calcium level in body; may cause itching if too high
POTASSIUM	3.5-5.0 mEq/L; usually high in kidney failure	helps to maintain regular heart rhythm, transmission of nerve impulses and muscle contractions

SODIUM	135-145 mEq/L; may be low, normal, or high in kidney failure	fluid regulation, transmission of nerve impulses and muscle contractions
BLOOD UREA NITROGEN (BUN)	8-25 mg/dL; usually high in kidney failure	waste product of protein breakdown
ALBUMIN	3.5-5.0 g/dL; usually low in kidney failure	form of protein used to indicate nutritional status
CHLORIDE	100-106 mEq/L; may be low, normal, or high in kidney failure	fluid regulation
HEMOGLOBIN	11-12 gm/dL; usually low in kidney failure	percentage of red blood cells in the blood that transport oxygen to body tissues



## **CHAPTER 4**

### **CHANGES IN YOUR DIET**

If you've never before realized what a special person you are – that no other person on earth is exactly like you – you'll realize it now as you begin to learn how kidney patients should eat. The food you eat is critically important as to how well you do on dialysis. While you're on dialysis or while you're recovering from a transplant, your doctor and dietitian will watch with extreme care the chemical balance of your blood and the fluid in your body. Together, they will design a diet plan based on your conditions and symptoms. Following your diet is one of your major responsibilities as a kidney patient. It is something you can do to feel better and to get the greatest benefit from your treatment.

You will become very much aware of the need for balance and moderation in diet. Your usual eating habits will change with your body needs. Protein, sodium, potassium, fluids, calories, vitamins, phosphorus and calcium and other minerals, fats, and carbohydrates are nutrients that come from foods you eat. The type and amount of foods and fluids will change to meet your needs while on dialysis. It will take time to learn everything you need to know about diet. Your dietitian has special knowledge of all the nutritional needs of a person with kidney failure. Together you will try to prevent the build-up of certain materials in your bloodstream – waste materials that were formerly removed by your kidneys. You can live well on dialysis, but it's not a perfect substitute for a healthy kidney's filtering system.

The following section can help you understand why your diet may be changed.

**PROTEIN** is a nutrient that is needed by everyone for growth, repairing tissues, and keeping a healthy body. High quality protein comes from animal foods. Low quality protein comes from plant foods and can be made in the body only if the high quality proteins are present. High quality protein foods are meats, milk, fish, poultry, and eggs. Low quality protein foods are fruits and vegetables. Protein substitutes include pro-cell, protein powder and supplemental drinks such as Ensure.

Since your kidneys are not working, it's important to eat the right amount of both of these kinds of protein every day. If you don't have enough protein and calories in your diet, your body will use up your own body protein such as your muscles. Any extra protein in the diet is broken down by your body into waste materials. Urea is one example of the waste material measured in the blood

as BUN (Blood Urea Nitrogen). Following the right diet and getting enough dialysis will help control the BUN, and other blood chemistries.

**SODIUM** is a mineral which helps control water retention and blood pressure. The body needs a small amount of sodium every day but too much sodium can build up, making you thirsty which causes you to drink too much fluid. The body will hold this fluid causing fast weight gain, high blood pressure, and other problems. Salt and foods that contain a lot of sodium must be carefully restricted. Controlling the amount of sodium in your diet is the key to how much fluid you gain between dialysis treatments.

**POTASSIUM** is a mineral that is necessary for life. High potassium is found in certain fruits and vegetables such as bananas, peaches, tomatoes, potatoes, melons, etc. It is important to the health of all muscles, especially the heart, and it must be present in the body in the right amount. Too much or too little is dangerous for the heart. The food you eat determines the amount of potassium that builds up in your body, so it's important to know which foods to control. For dialysis patients, too much potassium can cause death.

**FLUID** is found in all foods. Most of it is found in liquids and in foods that become liquid at room temperature. When the kidneys cannot get rid of extra fluid as urine, it builds up in the body causing weight gain, high blood pressure, swelling of hands, feet and abdomen, shortness of breath, and other problems. It's very important for you to control the amount of fluid in your diet. The amount of fluid allowed for each person between treatments is different and must be determined by your doctor or dietitian. Some patients may continue to produce some urine when they first start dialysis, which decreases over time.

**PHOSPHORUS** is a mineral that helps keep bones and teeth strong, but if it builds up in the bloodstream it can pull calcium from the bones into soft tissue like skin, lungs, blood vessels, and the heart. These soft tissues become harder and lose their ability to work right. The skin becomes itchy. Bones can become weak and may break. The heart muscle becomes weak and the lungs don't get enough air into the body. Almost all foods have phosphorus in them, especially milk and milk products (cheese, yogurt, nuts, chocolate, dried beans, peas, etc.).

Phosphorus is not removed well during dialysis and must be controlled with diet and medications. Phosphate binders can partially block the entry of phosphorus from the diet into the body. Your prescribed phosphate binder may contain calcium (e.g., Phoslo or Tums) or be calcium free (e.g., Renagel

or Fosrenol). The prescribed medicine should be taken with meals. (See Chapter 2, Medicines and Kidney Failure.)

**CALCIUM** is a mineral that is stored in the bones and teeth. It's usually found in the body along with phosphorus. Both minerals work together to help keep bones and teeth strong. It is difficult to get adequate amounts of calcium in your diet because it is mostly found in milk and milk products (which are limited due to their phosphorus content). So calcium supplements may be necessary to maintain normal blood levels. Os-Cal, Tums, Calcium Carbonate, Caltrate, and Calcium acetate are a few products that are used.

**CALORIES** are more important than ever when the kidneys stop working because they help maintain your weight, give you energy, and satisfy hunger. Calories come from three nutrients: proteins, carbohydrates, (starches and sugar), and fats.

If there are not enough calories coming from carbohydrates and fats, the body will take the calories from the protein you have eaten and use it to provide energy instead of using it to repair and build tissue. After a while even your own muscles may be broken down to supply energy. This can cause you to lose weight and your BUN to rise. All foods supply calories. You get extra calories from foods such as margarine, oils, sugar, jellies, syrup, hard candies, and sweetened beverages.

**OTHER MINERALS AND VITAMINS** – Vitamins and minerals are body regulators that can be dialyzed out of our body or lost during food preparation. It's important, therefore, that they be replaced. When your doctor prescribes a vitamin and mineral supplement for you, be sure that you take it as directed.

Following the prescribed diet is "easier said than done". If you don't control your diet, you will have problems and probably feel sick. Eating foods in moderation will help you live a healthier life. Please consult with your dietitian for dietary changes during this time.

## **CHAPTER 5**

# **REHABILITATION**

### **Emotions**

Just as each person's body is different, everyone responds differently to what happens to him or her. However, there are some common responses to being told that you have an incurable disease such as kidney failure. Many people say that facing a life threatening disease like kidney failure is the hardest thing they have ever had to do. Many say it is like dealing with the death of a loved one. They feel **SHOCK, DENIAL, ANGER, GUILT, FEAR, ANXIETY** and, with time and help, **ACCEPTANCE** of their new life. Many people have questions but they don't know who to direct them to. The best doctors and nurses will answer your questions.

**SHOCK AND DENIAL:** Common reactions include: "Oh no, not me!" "This can't be happening to me." "It's not real." Some people try to act as though their kidneys have not really failed. They eat whatever they want, drink more fluids than they are allowed, and refuse to take their medicines. Sometimes they even miss dialysis treatments to see what will happen. This kind of behavior is called denial, and can be life-threatening.

**ANGER:** Many people feel angry toward themselves, others, and even God for their being sick. They have a hard time understanding why this has happened to them. If this anger is not talked about, it can keep them from doing what they need to do to take care of themselves.

**FEAR and ANXIETY:** Many patients feel uneasy about the machines, the needles, all the medical procedures, and medical "talk". We suggest you ask questions about your illness and treatment, and understand as much as you can. Asking questions will help reduce your fears and anxieties and help you feel more in control of your health. **No question is too silly.** Having some control over your treatment is important since kidney disease causes you to lose control in so many areas of your life. You are the most important person on your health care team, so talk to the other members of your team. Talking about your fears and anxieties, as well as your hopes and dreams will begin to free you up to make good decisions about your treatment, and to assist the team in caring for you. Your emotional state can affect your health, your medical treatment, and progress.

**GUILT:** "What did I do?" is a common question many ask. "If I had only.... I would not be sick." Some patients become overwhelmed with **GUILT** and

**BLAME.** Understanding your medical situation helps to alleviate guilt and blame.

**DEPRESSION:** Some people have feelings of sadness, grief and loss of hope. Fortunately, there are ways to overcome these feelings. **TALKING** about your thoughts, feelings, and problems with your doctor, social worker, a trusted family member, friend, pastor, or other members of the health care team is usually very helpful and comforting. Having other activities to occupy your time is also a good way to take care of your feelings of depression. **Education about kidney failure and its treatment, as well as exercise and physical fitness are also ways to cope with your feelings of depression.**

**ACCEPTANCE:** There can be a time in your life when you will come to accept what has happened to you, and you can make the necessary changes and shifts in your life to make room for your treatment. If you should have to return to the hospital in months and years to come, don't be surprised if all the old feelings come up again. Remember how important it is to share your feelings with the people who are there to help you.

**THE PATIENT WHO NEEDS HELP** coping with the emotional stresses of kidney failure can find help. Since all these feelings are **NORMAL**, it is normal to need help coping with them. As noted, your doctor, social worker and other members of the health care team, as well as family, friends, pastors and other patients and their families are good people to talk with about what you are going through. Some people may also choose to go to local mental health clinics, counseling agencies or support groups.

Discuss these other resources with your social worker. Remember to **TALK**, since talking is your key to coping with your feelings. Dialysis and transplantation can give you a "second chance at life." Make the most of it! Kidney patients and their families can live productive and satisfying lives, despite the fact their lives have been turned upside down. With support from family, friends and the medical team, life can once again be enjoyed.

## **LIFESTYLE CHANGES**

Making treatment for kidney failure part of your life will require a number of changes in your lifestyle...

- You and the people you live with will need to rearrange some household and family activities, depending on your treatment schedule and how you adjust to it. Some people need time to rest after dialysis; others go right back to their usual activities. Some patients who do home dialysis may only have to make very minor changes in their work, school, or family schedules. Try to continue activities that are important to you, and talk with others in your household about these changes. Keeping communication open among family members is very important.
- Sexual relationships are another area in which kidney patients may find a need to make adjustments. Discuss your sexual concerns with your partner first. Talk with your doctor, social worker or nurse on your health care team about different options for men and women regarding this topic. Very often the stress and anxiety related to kidney failure and treatment can affect your interest in and ability to enjoy sex. Talking with other kidney patients may also be helpful.
- It is important to eat and drink what your dietitian suggests. However, it is possible to adjust a kidney diet to allow special events (such as a parties or eating out) if you adjust your total intake between dialysis treatments.
- It is likewise important to follow your dietitian's and doctor's recommendations regarding your diet, particularly salt restrictions. Your dialysis, medications and diet will work together to keep you feeling your best. Because home dialysis patients have more control over the timing of their meals and dialysis times, they may have more diet options. Your dietitian will assist you in balancing the dietary requirements with your daily lifestyle.
- Perhaps one of the greatest adjustments you will have to make as a dialysis patient will be giving up some of the control you once exercised

over your life. Some patients need help to bring about a balance between the dependence upon the machine, staff and family, and the independence they need to continue to have in order to feel in control of their lives. Home dialysis patients generally have more control over their treatment and lives that can maintain their independence.

- Dialysis may mean postponing some life goals and dreams, but it does not necessarily have to mean giving up on them altogether. As a matter of fact, kidney failure could result in your setting new and exciting goals for your life (such as going back to school) that you had not considered before. You don't have to stop working. Your treatment team will assist you in identifying your rehabilitation goals.

Remember that not only the patient but also family members are affected when one person has an illness like kidney disease. They often go through the very same stages as the patient. However, a large study showed that most families are brought closer together in this situation. Family members can give much-needed encouragement and can help you stick with your treatment schedule, your diet, and your medications. In turn, there can be important rewards for family members, as these two quotes show:

From the parent of a child with kidney disease:

“As parents with a child on dialysis, we deal with the impact of strong emotions: anger, anguish, fear, frustration, guilt. BUT even stronger are: HOPE that the discoveries being made at this very minute will benefit us tomorrow...JOY, for we are actually able to do something; we are involved, a vital link in the chain of care, creating a second chance at life for our child...AND GRATITUDE.”

From the wife of a dialysis patient:

“Supporters experience many of the same feelings as the persons on dialysis. Suddenly there are many adjustments that must be made. This could all lead to a less-than-pleasant life for everyone unless the supporter makes a firm decision from the start to accept this as a new challenge.”

“You will find new ways to prepare food. Dialysis hours can be filled with new interests that you may previously not have had time to share together. With a little planning you can find new places to travel where dialysis treatment is available. It's all a matter of the right attitude!”

“Do not emphasize what can no longer be done, but what still can be done.”

At the beginning, a supporter must resist the impulse to be overprotective. This isn't the easy, but it is absolutely necessary for the happy future of you both. This new life can be filled with opportunities to prove your individual strengths, which can offer a sense of security that others may never know.”



## VACATION AND TRAVEL

Many patients are concerned that they will no longer be able to travel if on dialysis. In the United States many dialysis centers accept vacationing patients. It is very important to **plan a trip well in advance** so that you can be assured that the center does accept visitors and that you will be able to be dialyzed during your vacation. Your social worker and head nurse will work closely with you and the center that you will be visiting. They will require in advance your treatment plan, which includes your medical history, length and frequency of treatment, current medications, and laboratory values and any known allergies or treatment problems. Here are some helpful questions:

1. What schedule will I be on?
2. Will my insurance pay for my treatments?
3. What blood tests and lab tests are required?
4. Will the facility staff assist me in making transportation arrangements to and from dialysis?

In recent years, many dialysis centers in popular vacation spots such as Florida and Hawaii, have encouraged patients to visit. Other states, as well, regularly advertise transient dialysis spots. Special excursions, and cruises as well as camping trips, are offered in some areas of the U.S.

Your Medicare and other health coverage can be used to pay for your dialysis while on vacation. However, Medicare does not pay for dialysis outside the U.S. Of course, if you are a Peritoneal Dialysis patient, and independent of a machine, you have the freedom to travel at any time. You might consider getting a listing of the dialysis centers along your route of travel so as to feel secure should you need any assistance while on your vacation. If you are a CAPD patient, your dialysis supplier can arrange to have your supplies sent in advance to where you are going. The social worker or head nurse at your center will be able to provide more

information, as well as assist you in making your arrangements.

## **JOBS AND EDUCATION**

### **CAN KIDNEY PATIENTS RETURN TO WORK?**

Many kidney patients can and do return, or continue, to work. By work, we mean a paid job, volunteer work, homemaking, or student activities.

Work is important for many reasons besides earning dollars. Work gives purpose and structure to our lives and helps us to feel good about who we are. It also provides contact with other people and a source of friendships.

The telephone numbers for the Georgia, North Carolina and South Carolina Vocational Rehabilitation Regional Offices are listed under the individual state you may be looking for. Other resources for jobs/education may include (you may need to check your telephone book for some of these listed which may be specific to your area only):

- Goodwill Industries

- Continuing Education Programs through local colleges and universities

- Literacy Programs in your area

- Department of Adult Education in county schools

- The American Kidney Fund – patient educational scholarship program

- The National Kidney Foundation – contact your state office for educational opportunities offered.

## **VOCATIONAL READJUSTMENT AND VOCATIONAL REHABILITATION**

If possible, it is desirable for you to continue the job you held before starting treatment. Talk with your employer about changes needed because of your health status, energy level, and need for treatment. The Americans with Disabilities Act requires employers to make reasonable accommodations for your job.

However, if a job change is needed, the most important things to consider are your education and training, job experiences, current interests, and endurance and physical capabilities. The Conditions for Coverage require dialysis facilities to make arrangements to accommodate employed patients who wish to be dialysis during their non-working hours.

The best place for you to start the vocational rehabilitation process is in your dialysis or transplant center. Your social worker can direct you to appropriate sources of help. Your physician can determine if you have physical problems which could be helped by a specialist in rehabilitation medicine.

Your social worker can refer you to state vocational rehabilitation or rehabilitation services departments. These agencies have counselors trained to work with kidney failure patients. Rehabilitation counselors help patients return to school or to employment. After making an extensive evaluation of your history and potential, the counselor works with community resources to locate specific job opportunities suited to your needs. Rehabilitation counselors can also help you arrange to attend college or to complete your GED if you did not finish high school. Your social worker should be aware of educational services for people.

***Many opportunities for continuing education are available to senior citizens. Ask your social worker for information about programs in your community.***

## EXERCISE



**Before beginning any exercise program, talk with your doctor about what you can safely do.** Physical activity, or exercise, is good for most people and has special benefits for kidney patients. Exercise can help you feel better both physically and mentally.

Some of the special benefits of exercise for kidney patients include improved bowel function, increased energy, better sleep patterns, and decreased need for blood pressure medicines. Because patients who exercise feel that they are doing something to improve their health, they are proud of themselves and feel better.

Walking and swimming are two very good forms of exercise for kidney patients because they do not put stress on joints. There are other exercise programs as well. If you are stable with your treatment - whether hemodialysis, peritoneal dialysis, or transplantation - and have no serious health problems, ask your doctor about exercise.



## **CHAPTER 6**

### ***PATIENT RIGHTS AND RESPONSIBILITIES***

You are entitled to expect high quality care under the Medicare/ESRD program. This section describes your rights and responsibilities that you can expect in your dialysis or transplant center.

#### **RIGHTS**

You have a right:

- To receive high quality medical care.
- To expect that all medical treatments and conditions of treatment are in your best interest.
- To know all about your disease and its treatment: the diagnosis, equipment and tests to be used, your progress, your future prospects, the risks involved, and the types of treatment available in clear language that you can understand.
- To participate in the planning of your treatment.
- To be discharged or transferred only for medical or other proper reasons.
- To speak often with the people responsible for your care and progress.
- To be treated with respect and dignity and with regard for your need for privacy.
- To be informed about the diet and medicines prescribed for you.
- To refuse to participate in medical experiments.
- To question or file a grievance about your treatment or bills without fear of reprisal.
- To choose another dialysis center or physician.
- To seek a second medical opinion.
- To expect all communications and records of your care to be treated as confidential.
- To have assistance which deals with specific problems or special needs that include (but not limited to) blindness, hearing loss, language barrier,

limited mental capacity, and financial restrictions.

- To receive information necessary for you to give “informed consent” prior to any new procedure or treatment.
- To refuse to allow a staff member undergoing training to provide treatment unless a fully-trained staff member is present.
- To refuse treatment to the extent permitted by law and to be informed of the medical consequences of your action.
- To be dialyzed at the hours most convenient and desirable to you, as the facility schedule permits.
- To receive information about facilities available to visiting patients and to receive assistance in arranging for dialysis when you plan to travel away from home.
- To know all costs of your care.
- To expect emergency medical care to be available at all times.
- To be protected from discrimination.
- To get information about Medicare that you can understand to help you make health care decisions.
- Have your answers about the Medicare Program answered.
- Get culturally competent services.
- Ability to appeal a decision relating to your claims and benefits.

## **RESPONSIBILITIES**

You have a responsibility:

- To cooperate with members of the medical team caring for you.
- To treat the members of the health care team with respect.
- To take responsibility for your illness by following doctor's orders and your diet and to notify the medical staff if you intend not to.
- To understand what will happen if you do not follow your treatment plan.
- To contact the staff about any medical, psychological, social, dietary, or financial problem with which you want assistance.
- To secure services of a nephrologist to provide you medical management if you transfer to another facility.
- To learn as much as possible about your illness.
- To participate in the planning of your treatment.
- To respect the rights of fellow patients.
- To furnish your facility with complete and current copies of advance directives if you have chosen to use them.
- To decide whether or not the information you get from your caregivers is enough for you to feel comfortable in agreeing to undergo new procedures.
- To make every effort to keep and be on time for all scheduled appointments and dialysis treatments.
- To plan your travel in advance when dialyzing away from your usual

facility.

- To know your treatment costs and provide accurate and complete information about your Medicare eligibility and other financial matters.
- To recognize what constitutes an emergency.
- To know and follow your facility's posted rules and regulations.
- # To know the grievance procedure in your facility.
- # To know your health privacy rights.

## **COMPLAINT & GRIEVANCE PROCEDURE**

You are beginning a long term relationship with the doctors and staff who will work with you as partners in your health care. Such day to day contact may result in misunderstandings. These can be handled by open discussions between the persons involved. If you have a problem, you are encouraged to solve it informally by contacting the center social worker, medical director or administrator first. Your center has a local grievance procedure to follow if needed.

Sometimes, problems can develop which require outside help. The Southeastern Kidney Council (Network 6) has a complaint and grievance procedure for this purpose which every dialysis clinic and transplant center in Georgia, South Carolina, and North Carolina is required to make available to you. One important requirement of the grievance procedure is that each dialysis clinic or transplant center have a patient representative whose role is to assist patients in solving problems, preparing grievances, and understanding the grievance procedure. Staff at your treatment center can tell you how to contact your patient representative.

To file a complaint or grievance, call the Southeastern Kidney Council at (800) **524-7139** or **(919) 855-0882** or send a letter describing the problem. In your letter, please include your name, address and telephone number so we can follow-up on your grievance. You will have the choice of remaining anonymous or giving consent to use your name when contacting the facility to resolve your complaint. Your facility has a copy of the Network 6 grievance procedure, which will identify what steps you should take to resolve your grievance. If you have any questions about the grievance process, please call the Network.

You can also file a complaint or grievance by contacting your state regulatory agency directly. Each office is responsible for overseeing the regulatory and/or licensure requirements of the facilities. You can file your complaint by calling:

- Georgia (404) 657-5550
- North Carolina (800) 624-3004
- South Carolina (803) 545-4300

## **REUSE OF THE ARTIFICIAL KIDNEY**

You read about the artificial kidney, or dialyzer, in a previous chapter. Some facilities participate in reuse, in which the dialyzer is reused for additional treatments. Reuse is the process by which a dialyzer is sterilized to remove impurities before each use. A dialyzer may be reused

between 20 and 30 times. It is your right to be informed of your facility's participation in reuse. In Georgia, the 1988 Legislature passed legislation restricting the reuse of artificial kidneys (Official Code of Georgia Annotated, Title 31, Chapter 16-7). This law says:

- 1) The owners or operators of dialysis clinics cannot make doctors or patients reuse dialyzers.
- 2) The decision whether or not to reuse an artificial kidney must be made between the doctor and the patient.
- 3) The owners or operators of dialysis clinics cannot stop a doctor from working in their units just because he or she will not reuse dialyzers if this decision is based on the patient's informed consent.
- 4) If the owners or operators of a dialysis center do not follow the law, they cannot expect payment for treatments given during the time the law was not being followed.

As of this writing, there are no state laws in South Carolina or North Carolina.

## **Advance Directives**

Thinking about death is not something any of us like to do, however it is certain for all of us. At any moment, in any of our lives, we could be faced with life or death decisions. With the advance of medical technology, sometimes the attempt to prolong life can mean inflicting more pain and suffering. An advance directive is "a legal paper that tells doctors and health care providers how you would want medical decisions made if you were no longer able to communicate or make these decisions for yourself."

There are two types of advance directives:

1. The Living Will
2. A Durable Power of Attorney

**The Living Will:** This will allow you to inform your health care provider in writing what medical care you would or would not like if you are unable to make the decision.

**A Health Care Power of Attorney:** This will allow you to specify an individual such as your spouse or parent to act on your behalf if you are unable. You should ask this person first, since many are uncomfortable with making these types of decisions. It is also important that you convey your wishes to this person and they are comfortable with the choices you have made.

Your state may allow you to have both of these advance directives or only one. Make sure that your physician is aware of your wishes and which advance directives you have.

An advance directive may include all or any of the treatments listed below:

**Cardiopulmonary Resuscitation (CPR):** this will revive a dying person with some or all of: heart massage, drugs, electric shocks and artificial breathing.

**Tube Feedings:** giving nutrition to sustain life through a tube in a vein or into the stomach.

**Blood Transfusions:** the injection of blood from one person to another.

**Kidney Dialysis:** the process by which toxins are removed from the blood by means of a dialyzer.

**Artificial Breathing (Respiration):** a respirator or machine would be used to breathe for you if you are unable.

To obtain more information on advance directives, it is best to check with a lawyer or state bar associations concerning state differences. You do not require a lawyer to prepare the actual advance directive. Forms may be obtained from state bar associations, senior citizen centers and some health care providers.

## **CHAPTER 7**

# **DISASTER PREPAREDNESS**



There may come a time when a disaster or emergency will affect your ability to obtain your dialysis. It is important to be prepared for all kinds of emergencies, including natural disasters. Natural disasters can cause a disruption in your dialysis routine. Hurricanes are the most likely disaster to be troublesome for the southeast. The Atlantic Hurricane Season begins on June 1 and ends on November 30 of each year. After the hurricane season has ended, the winter approaches threatening to bring ice and snow storms. You may not be able to totally avoid a natural disaster, but you can be prepared for one! Your facility is required to review in-center emergency procedures with you annually, but what can you do at home? Developing a personal plan is the best preparation for disasters. Here are some tips:

### **Planning and Preparedness:**

- Make sure your dialysis clinic has your current address, phone number, and emergency contacts.
- Prepare an emergency box with food, water, medications, and supplies.
- Have your doctor, dialysis clinic, and hospital phone numbers written in a handy place.
- Wear a bracelet or pendant identifying yourself as a dialysis patient.
- Contact your local power company to request priority consideration in the event of a power outage.
- Develop an Emergency Diet Plan with your dietitian.

### **In Case You are Stuck at Home:**

- Stay at home unless you are hurt.
- Wait for instructions from your dialysis clinic.
- Start an Emergency Diet Plan ( for more information on the emergency diet plan, see your social worker for a copy of the CMS publication *Preparing for Emergencies: A Guide for People on Dialysis*)
- Protect your dialysis access.

- If you live alone, ask a neighbor, friend, or family member to check on you regularly.
- Tune in to official radio or television emergency broadcast channels.

If you have specific questions about disaster preparedness in your state, you may contact the Emergency Management Division at:

- Georgia Emergency Management Agency at (404) 635-7000  
[www.gema.state.ga.us](http://www.gema.state.ga.us)
- North Carolina Division of Emergency Management at (919) 733-3300  
[www.dem.dcc.state.nc.us](http://www.dem.dcc.state.nc.us)
- South Carolina Emergency Management Division at (803) 737-8500  
[www.scemd.org](http://www.scemd.org)

## **CHAPTER 8**

### **WHERE TO TURN FOR HELP**



Listed below are some resources and services in your local area. Some resources are the same in all three states, (for example, Medicare and Vocational Rehabilitation). Other resources and services are different depending on your particular state. You may never need any of these services outside of Medicare; however many patients do. If you have financial and other problems that you cannot solve on your own, help is available. The list below is not complete, but it should get you started toward solving whatever problem you have. The social worker in your dialysis or transplant center can help you make contact with many of these resources.



#### **PAYING FOR YOUR TREATMENT**

The chief source for paying for your treatment is Medicare and/or Medicaid. Most people with kidney failure, regardless of age, are eligible. It is part of your Social Security plan. If you have both Medicare and Medicaid, your bills will be paid. If you have Medicare and a secondary coverage, the bills may be paid for at 80% by Medicare and the remainder by your secondary insurance. For further information, please contact Medicare or discuss this with your social worker.

#### **Two types of Medicare coverage are provided:**

Part A pays your hospital bills while you're actually staying in a hospital or in a skilled nursing facility. It also pays for home-bound health care. For example, it covers the cost of a visiting nurse or the cost of physical, occupational, or speech therapy at home.

Part B pays your doctor bills and your dialysis treatments. It also pays for hospital care given to you as an out-patient (an out-patient does not stay overnight in the hospital). For example, it pays for out-patient dialysis, physical or speech therapy, and for some medical supplies.

Medicare payments under Plan B will begin the first day of the third month after dialysis begins - unless you begin training for home dialysis. In that case, the coverage begins at once. If you're admitted to a hospital to prepare for a kidney transplant, payments will begin up to two months before the operation and will continue for 36 months after the operation (unless the kidney rejects (which means it does not adjust to your body), or

for the life of the kidney if you qualify for Medicare due to age or another disability, Even then, Medicare payments will continue to help pay for the dialysis which will be needed.

If you have private insurance through your employer or on your own, it will be considered your "primary insurance" for the first thirty (30) months of your treatment. This means your bills will be submitted first to your private insurance for payment. Any unpaid amounts will then be submitted to Medicare. Charges not covered by your private insurance may be covered by Medicare.

What if you're afraid you can't fill that 20 percent gap that Medicare does not cover? A social worker will help you find out about help from other sources such as: Medicaid, Veterans Hospital, Indian Health Services, State Kidney Disease Funds, Private Health Insurance such as Blue Cross/Blue Shield, or Federal Employees' Health Plans. For example, if you're a veteran, your best bet might be to get treatment from a veteran's hospital.

If you now have life and/or health insurance, be sure to keep up the payment. It's hard to get - and very expensive to pay for - after your disease has been diagnosed.

What if you're disabled - perhaps even enough to have to stop work - as a result of kidney failure? You may be eligible for monthly disability payments while you're on dialysis or while you're waiting for a transplant.

Talk to the social worker about the details of how you can get help. Every approved dialysis center has a person who's trained to help you get the benefits you need.

Through the Social Security Administration, you can obtain a "Medicare Handbook". This will prove to be a good referral source for you and your family.

**SOCIAL SECURITY DISABILITY (SSDI):** If you are disabled, your eligibility is based on earnings paid into Social Security. Medicare goes with Social Security after a waiting period for disability or at age 65.

**SUPPLEMENTAL SECURITY INCOME (SSI):** Eligibility is based on income and resources. People who have SSI will also have Medicaid. Most dialysis patients who are not able to work can qualify for either SSDI or SSI. Go to the nearest Social Security Office to apply for both.

## MEDICARE PART D

The Medicare Prescription program (Medicare D) became effective on January 1, 2006. This program was enacted into law in Title 1 of the Medicare Prescription Drug, Improvement and Modernization Act of 2003 (MMA). **Medicare D is a voluntary program, which is available to assist with the costs of brand-named, and generic prescription medications.** Requirements to participate are simple; you must be a Medicare recipient. There is a premium for this plan, but some may be eligible for a program to assist in paying a portion or the entire premium, depending on the person's income. This program is your state pharmacy assistance program (SPAP) and is applied through the Social Security office. If you have a state kidney program or get help through pharmaceutical companies for medications, please contact them to see how they will help people with Medicare D.

The enrollment period for Medicare D is from November 15 to December 31 of each year. The plan will start on January 1 of the following year. You can also change plans if you desire during this period of time. If you become eligible for Medicare after January 2006 and want to enroll for Medicare D you can do so. Please check the details for this with your local Social Security Office if you are in this situation.

Medicare D is offered through Medicare Advantage Prescription Drug Plans (MA-PDs), Private Prescription Drug Plans (PDPs), Program of All Inclusive Care for the Elderly (PACE), and 1876 Cost plans. Many different companies are selling these programs and have different premium amounts as well as coverage terms.

If you have Medicaid and Medicare, the Medicare program will automatically enroll you in a plan and your medication coverage will not change. You will have to carry the insurance medication card with you to get your medications. If you have a COBRA plan which covers medications, check to see which plan is best for you. Please, talk with your insurance representative or employer personnel department before making any changes. If you have Veteran's benefits, please contact your VA Representative to see which option is best for your medication coverage. If you have a complaint, contact the plan you choose. If your plan does not take care of your complaint, call 1-800-MEDICARE (1-800-633-4227; TTY: 1-877-486-2048). To compare plans and apply or check to see if your medication is on the plan formulary, you may check with the plan you choose, or contact Medicare at 1-800-MEDICARE (1-800-633-4227) or [www.medicare.gov](http://www.medicare.gov) (TTY: 1-877-486-2048). To apply for Medicare D state pharmacy assistance program (SPAP), call 1-800-772-1213 or

[www.socialsecurity.gov](http://www.socialsecurity.gov) (TTY: 1-800-325-0778). After you receive the insurance card for the plan you have chosen, do not forget to carry it with you when you get your medications. Also, please keep all of the information you receive and a copy of the applications you complete for future reference.

## DIRECTORY OF STATE INSURANCE DEPARTMENTS

The insurance offices listed in the left column are responsible for enforcing the laws and providing the public with information about insurance. The middle column lists the telephone number to call for consumer services. The right column, list the agencies on aging. They are responsible for coordinating services for older adults.

INSURANCE DEPARTMENT	CONSUMER SERVICES	AGENCY ON AGING
Georgia Department of Insurance Two Martin Luther King Jr., Dr., Suite 704 Atlanta, GA 30334 (404) 656-2070	(800) 656-2298 SHIP (800) 669-8387	Georgia Council on Aging 2 Peachtree St, NW Suite 32-270 Atlanta, GA 30303 (404) 657-5343
North Carolina Department of Insurance 1204 Mail Service Center Raleigh, NC 27699-1204 (919) 733-2032	(800) 546-5664 SHIP (800) 443-9354	Division of Aging and Adult Services 2101 Mail Service Center Raleigh, NC 27699-2101 (919) 733-3983
South Carolina Department of Insurance PO Box 100105 Columbia, SC 29202-3105 (803) 737-6160	(800) 768-3467 SHIP (800) 868-9095	Office on Aging 1301 Gervais St Suite 200 Columbia, SC 29201 (803) 734-9900

## **RESOURCES BY STATE**

The resources listed may assist in various ways for different needs (emergency, housing, non –emergency housing, clothes, food, medications, transportation, education) as well as needs not mentioned in this book. Resources specific to states have been identified under each state. There may be more resources that can be identified for the purposes of this book.

### **GEORGIA:**

#### **KIDNEY ORGANIZATIONS**

National Kidney Foundation of Georgia: 2951 Flowers Road South, Suite 211, Atlanta, GA, 30341; (770) 452-1539 or (800) 633-2339.

Georgia Association of Kidney Patients. [www.gakp.org](http://www.gakp.org).

#### **FINANCIAL/INSURANCE**

Medicare Fiscal Intermediary-Blue Cross Blue Shield of Georgia (800) 633-4227 – Part A bills and services, hospital care, nursing skilled care and fraud.

Social Security Administration (800) 772-1213 – address changes, lost Medicare card, Social Security benefits.

Operation Blessing: (800) 730-2537 or (866) 895-5865 - Sponsored by the 700 Club in Virginia Beach, Virginia and local church congregations. There are 2 centers that serve areas of North Carolina and Georgia. Assistance can be obtained for rent, food, and utilities on a one time per year grant per family. Grants are usually small, and OB should be regarded as a "last resort." Service centers listed below serve specific zip codes.

Georgia Department of Community Health (800) 322-4260 – Offer low income programs to help pay medical bills.

## **GOVERNMENT**

Georgia Office of Consumer Affairs-Intake Line (404) 651-8600 or the State Government Information and Referral Service United Way "HELP" line: P.O. Box 1158, Statesboro, GA, 30459; (912) 489-8475.

Georgia State Government Directory Assistance (404) 656-2000

Georgia Government (404) 818-6600 – Atlanta Metro or (866) 351-0001 – Toll free Statewide [www.Georgia.gov](http://www.Georgia.gov)

Georgia Department of Labor Rehabilitation Services (404) 486-6331 or toll free (866) 489-0001.

US Department of Housing and Urban Development (HUD), 40 Marietta St, Five Points Plaza, Atlanta, Georgia. (404) 331-4111.

Department of Veterans Service, Floyd Veterans Memorial Building, Atlanta, Georgia 30334-4800. (404) 929-5345.

## **SOCIAL SERVICES**

Department of Family and Children Services (DFCS) (404) 657-7660- Programs offered to assist with AFDC, transportation, food stamps or other needs. The local DFCS office is listed in your phone book under the county you live in.

## **GENERAL/OTHER**

Division of Aging Services, Department of Human Resources, 2 Peachtree Street, N.E. 36<sup>th</sup> Floor, Atlanta, Georgia 30303-3176. (404) 657-5258

## **NORTH CAROLINA:**

## **KIDNEY ORGANIZATIONS**

National Kidney Foundation of NC: 5950 Fairview Road, Suite 550,

Charlotte, NC 28210; (704) 552-1351 or (800) 356-5362 - Funds for patient services are available to each dialysis facility if that facility has participated in the annual Car Raffle Fund Raiser. Money is made available for any reason/cause that is agreed upon by you and your social worker. The NKF of NC also provides money for younger dialysis and transplant patients to attend specialized summer camps.

State Kidney Program: The State Kidney Program (919) 855-3701 under management of the Division of Health Services of the Department of Human Services, provides financial assistance to financially eligible renal patients for dialysis costs, transportation, costs associated with preparation for transplantation, and for transplant follow-up. The SKP also provides assistance to patients for costs associated with training for a home dialysis, and for emergency installations in their homes necessary for home dialysis to take place. Thirdly, the SKP provides assistance up to \$300 a year per patient for prescription and non-prescription drugs, for financially eligible patients.

## **FINANCIAL/INSURANCE**

Medicare Fiscal Intermediary-Palmetto GBA (800) 633-4227 – Part A bills and services, hospital care, nursing skilled care and fraud.

Social Security Administration: (800) 772-1213 – address changes, lost Medicare card, Social Security benefits.

North Carolina Department of Health and Human Services: (919) 855-4100 OR TTY (877) 733-4851- low income programs (such as Medicaid) to help pay medical bills.

Operation Blessing: PO Box 2364, Fayetteville, NC 28302. (910) 483-0523 or (800) 730-2537 - Sponsored by the 700 Club in Virginia Beach, Virginia and local church congregations. There are 2 centers that serve areas of North Carolina and Georgia. Assistance can be obtained for rent, food, and utilities on a one time per year grant per family. Grants are usually small, and OB should be regarded as a "last resort." Service centers listed below serve specific zip codes.

## **GOVERNMENT**

NC Division of Vocational Rehabilitation Services, 2801 Mail Service Center, Raleigh, NC 27699-2801. (919) 855-3500.

Governor's Emergency Hotline (888) 835-9966 24 hr/7 day toll free, English and Spanish Deaf and Hard of Hearing should call (877) 877-1765.

US Department of Housing and Urban Development, Asheville Building, 1500 Pinecroft Rd, Suite 401, Greensboro, NC 27407-3838. (336) 547-4138.

NC Department of Environment, Health and Natural Resources Division of Health Program, 1915 Mail Service Center Raleigh, NC 27699. (919) 715-7503.

Veterans Administration (VA): For eligible patients, there may be financial resources available through the VA. 251 North Main Street, Winston Salem, NC 27155-1000. (800) 827-1000.

## **SOCIAL SERVICES**

The Department of Social Services - may be able to provide temporary emergency help to eligible kidney patients through AFDC payments, transportation assistance, food stamps, fuel assistance, or other special local programs. DSS is listed in your phone book under the name of the county where you live. State office (919) 733-3055.

## **GENERAL/OTHER**

NC Department of Health and Human Services CARE-LINE: (800) 662-7030 – information and referral services (TTY 877-452-2514)

CDC/AIDS Hotline: American Social Health Association, P.O. Box 13827, RTP, NC, 27709; (800) 342-2437

American Social Health Association, PO Box 13827, RTP, NC 27709. (919) 361-8400.

NC Care line Information and Referral Service (800) 662-7030 – English and Spanish Raleigh area: (919) 855-4400 Deaf and Hard of Hearing: TTY (877) 452-2514

Division of Aging and Adult Services, 2101 Mail Services Center, Raleigh, NC 27699-2101. (919) 733-3983.

## **SOUTH CAROLINA:**

### **KIDNEY ORGANIZATIONS**

National Kidney Foundation of SC: 500 Taylor Street, Suite 101, Columbia, SC 29201; (803) 799-3805 or (888) 848-5277 - provides emergency financial assistance to pay for special needs to patients such as medications, transportation, dentist, eye glasses and various other needs. For information and application, contact the social worker at your dialysis or transplant center.

### **FINANCIAL/INSURANCE**

Medicare Fiscal Intermediary-Palmetto GBA (800) 633-4227 – Part A bills and services, hospital care, nursing skilled care and fraud.

Social Security Administration (800) 772-1213 – address changes, lost Medicare card, Social Security benefits.

South Carolina Department of Health and Human Services (888) 549-0820 - low income programs (such as Medicaid) to help pay medical bills.

### **GOVERNMENT**

US Department of Housing and Urban Development Columbia Field Office, 1835 Assembly Street 13<sup>th</sup> floor, Columbia, SC 29201-2480 (803) 765-5592.

Department of Health and Human Services, Office of Senior and Long Term Care Service, P.O. Box 8206, Columbia, SC 29202-8206 (803) 898-2501.

### **SOCIAL SERVICES**

Department of Social Services: Some dialysis patients may qualify for emergency help, Aid to Families with Dependent Children, (AFDC), transportation, food stamps, or other special local programs. The Department of Social Services is listed in your phone book under the name of the county where you live. State office (803) 898 -2501.

## **GENERAL/OTHER**

Veterans Administration (VA): SC Veteran's Administration Regional Office, 1801 Assembly Street, Columbia, SC 29201-2495 (800) 827-1000. For eligible patients, there may be financial resources available through the VA.

South Carolina Vocational Rehabilitation Department, 1410 Boston Ave, West Columbia, SC 29201. (800) 827-1000.

Palmetto AIDS Life Support Services of SC (PALSS) (800) 922-7319. Statewide services organization comprised of volunteers that include health professionals, members of the public and community leaders. Objectives are include, providing physical and emotional support to people with AIDS, ARC and HIV infection as well as families, friends and loved ones, acting as an advocacy and resource agency, and providing information and education to the public about AIDS.

Donate Life in South Carolina, 22 Centre East, 4200 E. North Street, Greenville, SC 29615. 1-87-PASSITON.

Cancer Society of Greenville County, 113 Mills Ave, Greenville, SC 29605. (864) 232-8439

## **ALL STATES**

### **Kidney Organizations**

Southeastern Kidney Council, Inc.  
1000 St. Albans Drive, Suite 270  
Raleigh, NC 27609  
Telephone: (919) 855-0882  
Toll free (for patients only): (800) 524-7139  
Fax: (919) 855-0753  
Email: [info@nw6.esrd.net](mailto:info@nw6.esrd.net)  
Website: [www.esrdnetwork6.org](http://www.esrdnetwork6.org)

Network 6 contracts with the federal government to assure quality care in all dialysis and transplant centers in Georgia, North Carolina and South Carolina. In order to carry out this responsibility, the Network concentrates on the following activities:

1. Working with dialysis and transplant facilities to promote quality of care.
2. Helping patients and facilities in resolving patient grievances and complaints.
3. Providing education to improve quality of life and patient care.
4. Collecting information about the incidence of End Stage Renal Disease in the region.

American Kidney Fund (AKF): Southeast Office: 7 Dunwoody Park, Atlanta, GA, 30338; (404) 395-6211. National Office: 6110 Executive Boulevard, Suite 1010, Rockville, MD, 20852; (301) 881-3052 or (800) 638-8299. The AKF provides funds directly to patients to help cover some of the costs not covered by Medicare or any other resource or agency. Such costs could be transportation, special dietary needs, medications, transplant donor costs, home supplies, Medicare and other insurance premiums, and "hidden expenses" related to the patient's conditions. The individual direct financial assistance grants are provided on a one time basis with no restriction on the number of times a patient may apply for funding. The grant may take several weeks to arrive from the national office in Bethesda, Maryland. The AKF provides money for financial emergencies to patients in centers who are participating in the AKF In-Center Emergency Fund. This Emergency Fund is available to all centers within the country, by application.

The National Kidney Foundation, Inc. (NKF) (800) 622-9010. 30 East 33rd Street, New York, NY 10016. A nonprofit voluntary health organization, which seeks to prevent kidney and urinary tract diseases, improve the health and well being of individuals and families affected by these diseases, and increase the availability of all organs for transplantation. Goals include supporting research and research training, continuing education and health care professionals, expanding patient services and community resources, educating the public, shaping health policy, and fund raising. Medic-alert jewelry, medication assistance, education assistance and summer kidney camps are examples of the many services offered. Each state NKF may provide different patient service programs.

(Please see listings for state offices under each state category)

American Association of Kidney Patients (AAKP) 100 S. Ashley Drive Suite 280, Tampa, Florida 33602 (800) 749-2257

Internet: [www.aakp.org](http://www.aakp.org). AAKP is a nonprofit association, which exists to serve the needs, interests and welfare of all kidney patients and their families. Its mission is to improve the lives of fellow kidney patients and their families by helping them to deal with the physical, emotional and social impact of kidney disease. To accomplish these goals, AAKP engages in a variety of educational and supportive programs. All AAKP members receive a subscription to RENALIFE, a quarterly magazine for kidney patients. It contains articles on health, experiences of other kidney patients, reports on current medical developments, and activities in the government that affect patients' lives.

Renal Support Network (RSN), 1311 N. Maryland Avenue, Glendale, CA 91207. (818) 543-0896. Internet: [www.rsnhope.org](http://www.rsnhope.org). The Renal Support Network (RSN) is a nonprofit, patient-focused, patient-run organization established in 1993 to provide non-medical services to those affected by chronic kidney disease (CKD). RSN strives to help patients develop their personal coping skills, special talents, and employability by educating and empowering them (and their family members) to take control of the course and management of the disease. A vital role of RSN is to provide lawmakers and policymakers with the patients' perspective on the needs and capabilities of people with CKD.

### **Transplant/Organ Donation**

The Gift of Life Foundation, 4511 Himes Ave. Suite 262, Tampa, Florida 33614. (813) 855-7600

Coalition on Donation, 700 North 4<sup>th</sup> St, Richmond, VA 23219. (804) 782-4920.

Children's Organ Transplant Association (COTA), 2501 COTA Drive, Bloomington, IN 47403. (800)366-2682

National Foundation for Transplants, 1102 Brookfield Rd, Suite 200 Memphis, Tenn. 38119. (901) 684-1697 or (800) 389-3863.

United Network for Organ Sharing (UNOS) P.O. Box 2484,  
Richmond, VA 23218. (888) 894-6361

## **Information/Referrals**

United Way 2-1-1 Connects people with community services and volunteer opportunities. This agency supports many programs all over the world, which is done through many human resource agencies.

## **General/Other**

Centers for Disease Control (800) CDC-INFO or (800) 232-4636  
(888) 232-6348 TTY.

National Mental Health Association 2000 N. Beauregard Street, 6<sup>th</sup>  
Floor, Alexandria, VA 22311 (703) 684-7722 Toll free: (800) 969-  
6642 TTY: (800) 433-5959

Addresses all aspects of mental health and mental illness. If you are  
in a CRISIS – call: (800) SUICIDE or (800) 784-2433

American Diabetes Association, 1701 North Beauregard Street  
Alexandria, VA 22311 (800) DIABETES or (800) 342-2383  
Research, information and advocacy

Center for Substance Abuse Treatment (800) 622-HELP or (800)  
622-4357 TDD (800) 487-4889 will assist to link people with  
community-based substance abuse services.

American Red Cross National Headquarters, 2025 E. Street NW  
Washington, DC 20006 (202) 303-4498 Donation Hotlines: 1-800-  
REDCROSS or (800) 733-2767

US Department of Veteran's Affairs VA Benefits: (800) 827-1000  
Education: (888) 442-4551 Healthcare: (877) 222-8387 Income  
Verification: (800) 929-8387 TDD: 1-800-829-4833 Internet:  
[www.va.gov](http://www.va.gov)

Goodwill Industries - Please refer to your telephone book for your  
local listing.

Salvation Army - Please refer to your telephone book for your local listing.

## **Medical Alert Systems**

Medical Identification necklaces, bracelets or cards are available at many local drug stores. Check with your drug store or Medic-Alert Foundation International, 2323 Colorado Ave., Turlock, CA 95382. 1-888-633-4298 Fax: 1-209-669-2450.

Patient Identification cards are available from AAKP (address listed earlier in this book).

### **Examples of Personal Medical Alert Systems**

This is a list of a few of hundreds of suppliers. This list is not inclusive of all suppliers:

Lifeline Systems: 1-800-451-0525

American Medical Alarms, Inc.: 1-800-542-0438

Life Alert: 1-800-360-0329

Life Alert USA

## **Financial/Reimbursement**

Centers for Medicare and Medicaid Services (CMS), 7500 Security Blvd, Baltimore, Maryland 21244. 1-800-MEDICARE.

Social Security Administration (SSA) (800) 772-1213 – Each city has a certain office location for people to visit for assistance. Please call 1-800-722-1213, or look in your telephone book, for the location nearest you. The SSA will assist with any concerns or questions, etc. regarding Social Security, Medicare, SSDI, SSI or retirement.

US Department of Health and Human Services Centers for Medicare and Medicaid Services, 7500 Security Boulevard, Baltimore, Maryland 21244-1850 Internet: [www.medicare.gov](http://www.medicare.gov) Telephone: (800) MEDICARE or (800) 633-4227 TTY: (877) 486-2048.

LEGAL AID SOCIETY: provides limited free civil legal services to those who are unable to afford such services. Refer to your telephone directory. It may be listed by county or city.

## Transportation Options

If you have problems getting a ride to dialysis, or for your transplant follow-up, the following are examples of agencies that might help you depending on where you live or your financial situations. The social worker in your dialysis or transplant center is your link to these resources.

- A. The Department of Social Services (DSS) or Department of Family and Children Services (DFCS) will provide transportation to patients who are medicaid eligible. They may do so through a variety of methods, including a van system, volunteer drivers, chore workers, vouchers for gasoline, and by contracting with local transit systems or cabs.
- B. The Council on Aging, Comprehensive Health Centers, and the Red Cross, as well as United Way Agencies provide transportation for dialysis and other medically necessary appointments. Several counties may be served by the same van system.
- C. The American Kidney Fund: The AKF can provides funds directly to patients to help with some of the costs not presently covered by Medicare or any other agencies. These include transportation to and from the dialysis centers. The AKF is a "last resort" resource.
- D. American Red Cross – refer to your phone book for the local chapter nearest you.
- E. Senior Citizens organizations, Council or Centers  
Neighborhood service centers and community action agencies, Civil Defense, EMS, or Rescue Squads (during hurricanes and other natural emergencies).

## **MEDICAL/DENTAL SERVICES**

Local County Health Departments: (Listed by county). If your county health department cannot provide the medical service you need, they will send you to the correct agency.

Ambulance Services: Available from most hospitals and some privately owned ambulance companies. Most want payment when you use them, but Medicare will reimburse in most cases. Refer to your telephone directory.

Medical Alert Systems: Depending on your overall medical condition, you may need a system to put you in immediate contact with a hospital emergency room. Some companies include Lifeline systems (800) 451-0525, American Medical Alarms, Inc. (800) 542-0438, and Life Alert (800) 360-0329.

Medical Identification necklaces, bracelets or cards are available at many local drug stores. Check with your drug store or Medic-Alert Foundation International, 2323 Colorado Ave, Turlock, CA 95382. (888) 633-4298.

Patient Identification card available from AAKP – (contact information listed under kidney organizations section).

Affordable Dentures (800) 336-8873 - Low cost dentures.

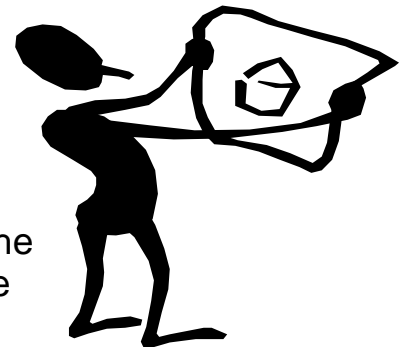
Please contact your state Dental Association for assistance programs. Remember, Medicare will pay toward a dental evaluation and treatment to help get patients ready for transplant.

If you have any other medical problems such as diabetes, heart disease, lupus, arthritis, or sickle cell disease, there are national and state organizations for each one of these diseases. Ask your social worker, because often these organizations also have specific resources. A few of these organizations are listed below:

American Council of the Blind	(800) 424-8666
Cancer Information Service	(800) 422-6237

National Easter Seal Society	(800) 221-6827
Sickle Cell Disease (National Assoc.)	(800) 421-8453
American Diabetes Association	(703) 549-1500
American Heart Association	(800) 242-8721
American Lung Association	(212) 315-8700
Assoc. for Care of Children's Health	(202) 244-1801
Council for Exceptional Children	(703) 620-3660
Juvenile Diabetes Foundation	(212) 889-7575

## CHAPTER 9 REVIEW QUESTIONS



The following are just a few questions to help you review the material in this handbook. These questions will emphasize important points, and help to refresh your memory.

**Q. *Do I believe I can live a happy, full, productive life even though I have kidney failure?***

A. You should. As with many other problems in life, it is not so much the things that happen to us that determine the outcome of our lives, but how we see these things. People who are hopeful about their future and have a sense of control over their lives and treatment adjust to kidney failure much better than those who feel like helpless victims. Your attitude toward life with kidney disease will make the difference.

**Q. *What does ESRD stand for?***

A. ESRD stands for end-stage renal disease. This is simply the name given to any condition where kidney function decreases to a point where you must be treated with dialysis or a transplant.

**Q. *What are causes of kidney disease?***

- A.
- Hypertension (high blood pressure)
  - Diabetes (too much sugar in the blood)
  - Chronic glomerulonephritis (inflammation of the kidneys)
  - Pyelonephritis (infection of the kidneys)
  - Polycystic kidneys (inherited disease causing pockets of fluid inside the kidneys)
  - Kidney stones
  - AIDS
  - Analgesic abuse (headache powders, ibuprophen, and other anti-inflammatory drugs)
  - IV Drug abuse
  - Moonshine abuse (Lead Nephropathy)
  - Arteriosclerosis (hardening of the arteries)
  - Accident, injury or trauma (where the kidneys are damaged and

- do not recover)
- Sickle Cell Disease
- Systematic Lupus Erythematosus (SLE)

**Q. *Do I understand all the new words being used?***

A. Your health care team (doctors, nurses, social workers, dietitians, technicians) may use words which are new to you. Ask them to tell you what these words mean. Remember, they had to learn them once.

**Q. *What are some of the chemicals in the blood which your kidneys regulate?***

- A.
- Urea
  - Potassium
  - Phosphorus
  - Calcium
  - Magnesium
  - Sodium
  - Creatinine
  - PTH

**Q. *Does my doctor take the time to talk with me, answer questions I have and tell me what I should be doing?***

A. It is important to know as much as possible about your disease and treatment. Your doctor should take the time necessary to answer questions about your treatment and explain the reasons for your treatment. All members of the team should be concerned about your care, but it's a two-way street. You must be concerned about the advice given and do your best to help in your own care. Follow your diet, take your medicines and exercise regularly. All this will help you gain a positive outlook, and be much healthier as well.

**Q. *Can patients dialyze themselves in a dialysis center?***

A. Yes, with staff assistance. Self care encourages independence. Some centers in the county offer self-care while others allow patients to help staff.

**Q. *Do I understand my diet, how much fluid I can drink, my medicines, how often I receive dialysis treatment and the overall plan for my medical care?***

A. Every person on dialysis has an individual plan for treatment. Your plan will depend on the cause of your kidney disease, any other disease problem you may have - your size, age and other factors. Your plan

may change at times. If it does, ask why. It may be hard at first, but the better you understand your diet, medicines and treatment plan, the better you will be able to take care of yourself.

**Q. *What is uremia?***

A. Uremia is a condition where waste products build up in the body to levels high enough to make a person sick. Urea is a toxic waste product which is produced when the body breaks down protein. Kidneys normally filter urea out of one's bloodstream. But, in a person without healthy kidneys, this is done by dialysis.

**Q. *Will a transplant cure any other problems I may have, for example, diabetes or high blood pressure?***

A. A kidney transplant only replaces the need for dialysis treatments. If you had medical problems before your kidney disease occurred or have developed problems since, a transplant will not cure these. However, many people have generally improved health after a transplant.

**Q. *Is a kidney transplant a cure for kidney failure?***

A. Kidney transplantation is a form of treatment. For many patients, it is a good treatment option. However, it has problems of rejection and side effects of medications.

**Q. *Am I being treated for anything else?***

A. Some people have problems before their kidneys fail or develop problems after they go on dialysis. Examples are diabetes, high blood pressure, heart disease, anemia or bone problems. Ask your doctor if he or she is treating you for anything else.

**Q. *Why is it so important to understand the different forms of treatment?***

A. Only by understanding the pros and cons of the different treatments can patients then choose the treatment best suited for their own situations.

**Q. *What drug is taken with meals to help prevent bone disease?***

A. Phosphate binders are taken with meals to help prevent bone disease. It is important to take binders regularly. Usually, these are simply calcium supplements or certain kinds of antacids. But, it is important that you take the kind your doctor tells you to. Just any calcium won't do, and many antacids are harmful to kidney patients.

**Q. *Name one drug your doctor might prescribe for you if your heart is***

***a little weak.***

A. Digitalis (or Digoxin) may be prescribed by your doctor to help your heart beat stronger and more regularly. Never stop taking Digitalis without your doctor's permission.

**Q. *What drugs are taken to help keep the body from "fighting" or rejecting a transplanted kidney?***

A. Usually a combination of two or more immunosuppressive medications. Drugs are being developed and experimented with ongoing. If you are interested, talk with your doctor about these. Different transplant centers use different combinations of these drugs. Some transplant centers may be better for your particular needs than others.

**Q. *Can a dialysis patient ask questions?***

A. It is a patient's right and responsibility to ask questions. Righting your questions down prior to any appointment will help you to remember what you want to address.

**Q. *Why are blood tests performed every month or so for kidney patients?***

A. These tests check for problems with your bones and liver, as well as problems with your diet, medications and dialysis. If you have had a transplant, these tests will check to see if your transplanted kidney is working well.

**Q. *Do I know who will pay for my treatment, doctor and hospital bills, and how much it will cost?***

A. Medicare's medical insurance will pay 80 percent of physician services and dialysis treatments (in-center or home). Medicare's hospital insurance pays for inpatient hospital care. Each insurance has certain requirements which your social worker will explain to you. Medicare and your private insurance may work together to pay for your dialysis treatment.

**Q. *What are sources of financial help is available to me?***

A. Medicaid is a sources that may be available to you. It is a federal-state supported program to pay for health care for needy and low income residents. Medicaid benefits vary from state to state. Your social worker can tell you of additional sources of financial aid and can help you identify those sources.

**Q. *Have my rights and responsibilities been explained to me? Was I told that I could be treated elsewhere if I wished?***

- A. A patient's bill of rights is required by the federal government. Each dialysis center has its own plan to deal with complaints and grievances as does the Southeastern Kidney Council and the State Survey Agency. These plans are called complaint and grievance procedures. When you started dialysis treatment, the bill of rights should have been discussed with you and signed by you. If you do not know about the complaint and grievance procedures, ask your doctor, nurse, social worker or patient representative. Know your rights. This is very important. Every dialysis and transplant patient has the right to choose or change physician, type of treatment and facility.

**Q. *Am I involved in making key decisions about my treatment?***

- A. You are part of a team made up of you, your doctor, nurses, social worker, dietitian and others. It is important that you be involved in making decisions about your care. If you do not understand what other team members suggest, ask questions until you do. Only you can make the choice to be involved in decisions about your care. When you do this, you will be acting with the team.

**Q. *Feelings of sadness and loss of hope are normal. What is one of the best ways to overcome these feelings of despair?***

- A. Whether it's a job or a hobby, it is very important to let your healthcare team know what your needs are. Remember, everyone needs this for a well rounded and happy life. You are no different simply because your kidneys have failed. Do not make your illness the center of your life. That is for living.

**Q. *When I visit a facility as a transient (visiting) patient, what common lab work and paperwork will be required?***

- A. If you wish to travel, notify your social worker at least 30 days prior to the travel date so that the appropriate medical records can be sent to the facility you'll be visiting. This includes Hepatitis records, copies of your insurance card and 2728 form, chest x-ray, EKG, standing dialysis orders, daily flowsheets, and medication list. The documentation required varies.

## **CHAPTER 10**

### **COMMONLY USED WORDS**

2728 – The federal medical evidence form that tracks your entitlement to Medicare based on ESRD.

*ACCESS* - A surgically formed connection of an artery and vein or an implanted artificial vessel in the arm or leg to enable easy, multiple access to the blood stream for blood to be processed through an artificial kidney for cleansing and returned to the body. (e.g. - graft, subclavian catheter, fistula, shunt).

*ACUTE RENAL FAILURE* - A sudden, usually reversible loss of kidney function.

*ACUTE TUBULAR NECROSIS (ATN)* - Reversible kidney damage resulting in delayed kidney function.

*ADVANCED DIRECTIVES* - Documents what a patient's wishes are regarding treatment in case that patient is unable to make his/her choices known later.

*AIDS* - Acquired Immune Deficiency Syndrome; a disease in which a person can not fight off normal infection.

*ALBUMIN* - One of a class of proteins in the blood. The level of albumin may reflect the amount of protein intake in diet.

*ANEMIA* - A condition occurring when the blood is deficient in red blood cells and/or hemoglobin which decreases the oxygen-carrying capacity of the blood.

*ANTIBIOTIC* - A medication used to kill germs that may be causing an infection in the body.

*ANTIBODY* - A substance in the body that fights off disease and foreign substances.

*ANTICOAGULANT* - A substance that is given to prevent clotting of the blood (example: Heparin).

*ANTIGEN* - A substance in the body that stimulates the production of

antibodies.

*ANTIHYPERTENSIVE* - A medication that relieves and controls high blood pressure. Examples: Aldomet, Clonidine, Lopressor, Norvasc, Procardia, Vasotec.

*ARTERIAL LINE* - The tube carrying blood from the body into the artificial kidney.

*ARTERIOGRAM, RENAL* - An X-ray test involving injection of dye into the main artery supplying the kidney, to determine if the blood vessels to the kidney are normal.

*ARTIFICIAL KIDNEY* - (Dialyzer) A device which removes waste products from the blood and supplies other needed substances to the blood of persons with renal failure through a physiochemical process called dialysis.

*ASCITES* - Fluid which is retained in the abdominal cavity.

*ASEPTIC TECHNIQUE* - Sterile procedure used to prevent bacteria from entering the body, thus limiting risk of infection.

*BACTERIA* – “Germs” too small to see with the naked eye that can produce diseases or infections.

*BATCH SYSTEM* - A method of supplying dialysate that involves the preparation of a large amount of dialysate by mixing concentrated chemicals with large amounts of purified water.

*BATH* - Dialysate fluid or bath is composed of fluids and chemicals similar to body fluids minus the waste products. Waste products will flow from the blood into the dialysate and then be flushed away.

*BIOCOMPATIBLE* - Similar to the human body and thus less likely to cause a first use reaction.

*BIOPSY* - The process of removing tissue from living patients for diagnostic examination.

*BLADDER* - The part of the urinary tract that receives urine from the kidneys and stores it until urination.

*BLOOD LEAK* - The dialyzer fibers or membrane breaks or tears allowing

blood to leak into the dialysate.

*BLOOD PRESSURE* - Pressure of the blood flowing through the blood vessels.

*BLOOD PUMP* - A pump which is used to bring blood from the patient and push it through the artificial kidney and back to the body.

*BOVINE GRAFT* - A graft made from the artery of a cow. After being specially treated, it is surgically implanted into the arm or leg and is used as an access route to the blood stream.

*BUN* - Blood Urea Nitrogen. Measured routinely in lab tests to help determine dialysis and dietary adequacy. This test is also important in determining how well the kidneys are functioning as well as adequacy of dialysis and nutritional status.

*BRUIT* - The sound of blood pulsating through a fistula or graft that indicates that the access is working.

*DECEASED DONOR* - An individual who has recently passed away of causes that do not affect kidney function. Either the person himself, or his family has generously offered organs and tissues for transplantation.

*CALCIUM* - An important chemical element of the body, needed for strong bones and healthy function of heart and brain.

*CHRONIC KIDNEY DISEASE (CKD)* - Permanent, progressive, irreversible damage to the kidneys.

*CLOTTING TIME* - The time it takes for your blood to form a clot.

*CONGESTIVE HEART FAILURE* - A condition in which the body retains excessive fluid, causing the heart to pump less blood from the lungs into the general circulation than it should. This can result in excessive blood in the lungs and the eventual filling of some of the airways of the lungs with fluid. Treatment consists of removal of body fluid during dialysis, restriction of fluid intake and other measures.

*CONTAMINANT* - Bacteria that is allowed to come into contact with a sterile surface, thus creating the possibility of infection.

*CREATININE* - An end produce of muscle metabolism measured as an indicator of how well the kidneys are functioning.

*CROSS MATCHING* - The testing of a transplant or blood donor and recipient's blood cells and serum to determine if compatibility exists.

*DEHYDRATION* - Occurs when the body does not have enough water. Usually occurs after repeated diarrhea or vomiting.

*DIABETES* – *A metabolic disorder marked by frequent urination and excessive thirst.*

*DIALYSIS* - The process of cleansing and removal of fluid to achieve chemical balance in the blood of patients whose kidneys have failed. Dialysis may refer to hemodialysis or peritoneal dialysis.

*DIALYSIS FLUID* - See Bath.

*DIAPHRAGM* - A layer of muscle separating the abdominal and chest cavities. It is the major muscle for breathing.

*DIASTOLIC* - The bottom blood pressure number which measures the force of the heart muscle at rest, when it expands and fills with blood.

*DISEQUILIBRIUM* - Term used to describe a condition which may result from rapid dialysis therapy. Some symptoms may be headache, cramps, nausea, or vomiting.

*DRY WEIGHT* - A body weight that exists when a limited amount of or no excess fluid is present (weight at which blood pressure and swelling are best controlled).

*DWELL* - In peritoneal dialysis, refers to the time the fluid remains in the abdomen before being drained.

*EDEMA* - Body swelling due to excessive retention of fluid. Most noticed in the dependent body areas such as feet, legs, hands or lower back.

*ENDOTRACHEAL TUBES* - An airway tube inserted through the mouth leading to your windpipe to help you breathe during surgery.

*END-STAGE RENAL DISEASE (ESRD)* - Any irreversible kidney disease

which requires dialysis therapy or kidney transplant in order to sustain the person's life. The term "end-stage" means that the renal disease is permanent and irreversible, and not that the person's condition is terminal.

*EXCHANGE* - The term describes the procedure of changing used dialysate to fresh dialysate solution within the peritoneal cavity during peritoneal dialysis.

*FERRITIN* - Lab test that measures the stored iron in a person's body.

*FIRST USE SYNDROME* - Symptoms that may occur after starting hemodialysis with a new dialyzer. Symptoms may include: chest pain, back pain, nervousness, and itching.

*FISTULA* - A connection surgically made between an artery and a vein beneath the skin that ultimately allows a person to be connected to an artificial kidney machine. See Access.

*FOLIC ACID* - A vitamin necessary for red blood cell production.

*GLOMERULONEPHRITIS* - Also called Bright's Disease or Nephritis. It is an inflammation of the glomeruli (part of the functioning unit in the kidney called the nephron). It usually affects both kidneys and generally first occurs in early childhood. Recovery from the acute form may take one year. Those with the chronic form suffer low, progressive damage which may ultimately lead to dialysis therapy and/or transplantation.

*GLUCOSE* - A type of sugar found in the body.

*HEMATOCRIT* - A measurement of red blood cell volume in the blood.

*HEMATOMA* - A bruise which is caused from blood leaking outside the vessel but under the skin. The bruise can be hard, painful, and swelling may occur.

*HEMOGLOBIN* – The portion of the red blood cells that transports oxygen from the lungs to the tissues.

*HEPARIN* - A substance given to prolong blood clotting time, allowing blood to flow through the artificial kidney without clotting.

*HEPATITIS* - Inflammation of the liver. May be caused by one or more viruses.

*HEPATITIS C* – Infection of the liver.

*HEPATITIS "B" ANTIGEN TEST* - A test, which determines the presence of an antigen associated with a type of hepatitis. Patients who are Hepatitis B antigen positive are infectious to other patients through their blood products.

*HIBERNATION* - A temporary delay in kidney function that sometimes happens right after transplantation with cadaveric transplants. The kidney "goes to sleep" but wakes up again, just as bears do in winter.

*HYPERKALEMIA* - A high level of potassium in the blood; can cause irregular heart beat and ultimately cardiac arrest.

*HYPERTENSION* - High blood pressure.

*HYPERTONIC DIALYSATE* - A strong dialysis bath solution (such as 4.25% dextrose) used in peritoneal dialysis therapy which will withdraw from the body a large amount of fluid.

*HYPOGLYCEMIA* - Low blood sugar.

*HYPOTENSION* - Low blood pressure.

*IRON DEFICIENCY* - Lack of enough available iron to make red blood cells.

*IMMUNOSUPPRESSIVE DRUGS* - Medications given to transplant patients to help prevent rejection of a transplanted kidney. Example: Cyclosporin, Cellcept, Prednisone, Antilymphocyte Globulin.

*INTRAVENOUS* - Within a vein.

*KAYEXALATE* - Brand name for a medication used to prevent potassium buildup in the blood. However, it will increase the sodium content of the body.

*KIDNEY* - One of the two kidney-bean shaped organs located on either side of the spine, just above the waist. They rid the body of waste materials and maintain fluid balance through the production of urine.

*KIDNEY TRANSPLANTATION* - A technique in which a healthy kidney from a qualified donor is surgically implanted in a person with ESRD.

*MEMBRANE* - In hemodialysis, membrane refers to the cellophane-like

substance in the artificial kidney through which wastes from the blood filter into the dialysate fluid. In peritoneal dialysis the membrane is the porous lining covering the peritoneal cavity.

*NEPHRECTOMY* - Surgical removal of a kidney.

*NEPHROLOGIST* - Doctor specializing in diagnosis and treatment of kidney problems, hypertension and other metabolic abnormalities of the body.

*NEPHRONS* - The functional units of the kidney that filter waste substances out of the blood.

*NEPHROSIS* - A condition in which there is a large and abnormal leakage of protein into the urine.

*NEUROPATHY* - Dysfunction of the nerves frequently associated with uremia which is often manifested by numbness, tingling or burning usually in the feet.

*OSTEODYSTROPHY* - Bone disease.

*OSMOSIS* - The passage of fluid through a membrane separating solutions of varying concentrations. The fluid passes through the membrane from the region of lower concentration of dissolved substance to the region of higher concentration of a dissolved substance. The two solutions tend to reach equal concentrations.

*PARATHYROID GLANDS* - Glands producing parathyroid hormone which regulates calcium metabolism.

*PARATHYROIDECTOMY* - The procedure of surgically removing the parathyroid glands.

*PERFUSION MACHINE* - A machine that keeps a donor kidney in the best possible condition outside the body until such time as it can be transplanted into a recipient.

*PERITONEUM* - The lining of the peritoneal cavity that forms a sac like area that holds dialysate for peritoneal dialysis.

*PERITONEAL CAVITY* - Space located under the abdominal layer of muscles and surrounding the bowels, where peritoneal dialysis occurs.

*PERITONITIS* - A painful infection of the peritoneal cavity lining (peritoneum).

*PERITONEAL DIALYSIS* - A process in which dialysate is introduced into and drained from the peritoneal cavity. The peritoneal membrane in the abdomen functions in the same way that the membrane in the artificial kidney functions.

*PHOSPHATE BINDERS* - Medication used to prevent phosphate absorption in persons with kidney disease (i.e., Alternagel, Amphogel, Basaljel, PhosLo, Calcium Carbonate, Os-Cal, etc.). This may help to prevent bone disease.

*POLYCYSTIC KIDNEY DISEASE* - An hereditary disease in which cysts are formed in the kidneys. The cysts get larger with time and gradually squeeze out normal tissue until the kidneys slowly lose ability to function.

*POSITIVE PRESSURE* - Method of removing extra water and salt from the blood by creating pressure inside the blood compartment of the artificial kidney, allowing the process of ultrafiltration to take place.

*POTASSIUM* - An essential chemical element in the body that regulates heart and muscle movement. High or low levels in the blood may cause the heart to stop.

*PTH* – Refers to the hormone secreted by the parathyroid glands.

*PYELONEPHRITIS* - An infectious inflammation of the tissue of the kidneys, which at the onset may not interfere with kidney function, but if left untreated, may lead to kidney failure.

*REHABILITATION* – Restoration to optimal functional status.

*RENAL* - Having to do with, or referring to, the kidneys.

*RENIN* - Hormone produced by the kidney which, when excessive, can cause high blood pressure.

*SALINE* - A salt solution containing sodium and chloride.

*SEMIPERMEABLE MEMBRANE* - A material through which only certain particles may pass, and to which other particles are impermeable.

*SEPSIS* - An infection in the blood caused by bacteria.

*SODIUM* - One of the major chemical elements of the body. Found and taken

into the body most commonly as table salt. When excess amounts cannot be excreted from the body by the kidneys, edema and hypertension may result. The intake of this element must be controlled by diet in patients with most types of renal failure.

*SODIUM MODELING* - A treatment variation of hemodialysis. Sodium modeling may make the dialysis treatment more comfortable by reducing some symptoms such as cramping. It can also reduce drops in you blood pressure.

*STENOSIS* - The narrowing (getting smaller) of a blood vessel which can cause clotting of the vessel.

*STEROID DRUGS* - Natural or synthetic chemical compounds closely related to certain hormones manufactured by the adrenal gland (located on the top of each kidney). These powerful compounds are immunosuppressives. The term “steroid” used in kidney disease actually refers to adrenal adrenal and anabolic steroids, resembling testosterone and are used to build up muscle in certain disease stages.

*STERILE* - Being completely free from all germs.

*STOMACH* - The way to a man's heart - or so they say.

*SYSTOLIC* - The top blood pressure number which measures the force of contraction of the heart muscle as blood is pumped out of the heart chambers.

*THRILL* - The buzzing sensation that can be felt by touching a fistula or graft. This indicates that the access is working.

*TISSUE TYPING* - Refers to the cellular matching of individuals who are to undergo transplantation with their potential donors. The success of the transplant is usually proportioned to the closeness of the tissue match.

*TRANSIENT/VISITING PATIENT* – A dialysis patient who obtains treatment at a facility other than their home facility for a period of 30 days or less.

*TOXINS* - Waste products that accumulate in the blood of ESRD patients that are usually harmful to the body's metabolic systems.

*ULTRA FILTRATION* - Removal of extra fluid from the body by the application of positive or negative pressure to the artificial kidney during dialysis therapy.

*UREMIC SYNDROME OR UREMIA* - Symptoms and signs that result from elevated toxic levels of BUN and Creatinine. Some of the symptoms and signs are nausea, fatigue, loss of appetite, weakness, change in mental status, skin turns a yellow color, itching, and headaches.

*URETER* - One of the two tubes that carry urine from the kidney to the bladder.

*URINARY TRACT* - The body system made up of the kidneys, ureters, bladder, and urethra. It involves the production, transport, storing, and elimination of urine.

*VENOUS LINE* - The tube carrying the blood back into the body from the artificial kidney machine.

## **CHAPTER 11**

### **SUGGESTED READING AND REFERENCES**

If you wish to know more about kidney failure and treatments, reading materials are available on the topics listed below by contacting the Southeastern Kidney Council at (800) 524-7139 or by visiting the resources section of the Southeastern Kidney Council's website at [www.esrdnetwork6.org](http://www.esrdnetwork6.org). This is not a complete listing. If you need more information, talk to your doctor or other staff members. Additional information about Medicare programs and publications are available at (800) Medicare or [www.medicare.gov](http://www.medicare.gov). You may also refer to chapter 8 for contact information to various kidney organizations who may also have reading materials available.

ADVANCE DIRECTIVES

ANEMIA

BONE DISEASE

BOOKS

CHALLENGING PATIENTS

CONTINUOUS QUALITY IMPROVEMENT (CQI)

COOKBOOKS

COPING WITH ESRD

CULTURE SPECIFIC

DIABETES

DISASTER PREPAREDNESS

ENDSTAGE RENAL DISEASE

EXERCISE

FINANCE

HEMODIALYSIS

HEPATITIS

HIGH BLOOD PRESSURE

HIV/AIDS

IMMUNIZATION

INTERNET RESOURCES

K/DOQI RESOURCES

KIDNEY DISEASE

LEGISLATION

MEDICATION ASSISTANCE

NUTRITION

ORGAN DONATION AND TRANSPLANTATION

PATIENT SAFETY

PEDIATRIC KIDNEY DISEASE

PERITONEAL DIALYSIS  
REHABILITATION  
SEXUALITY  
SOCIAL WORK  
SPANISH RESOURCES  
TRAVEL  
TREATMENT OPTIONS  
VASCULAR ACCESS