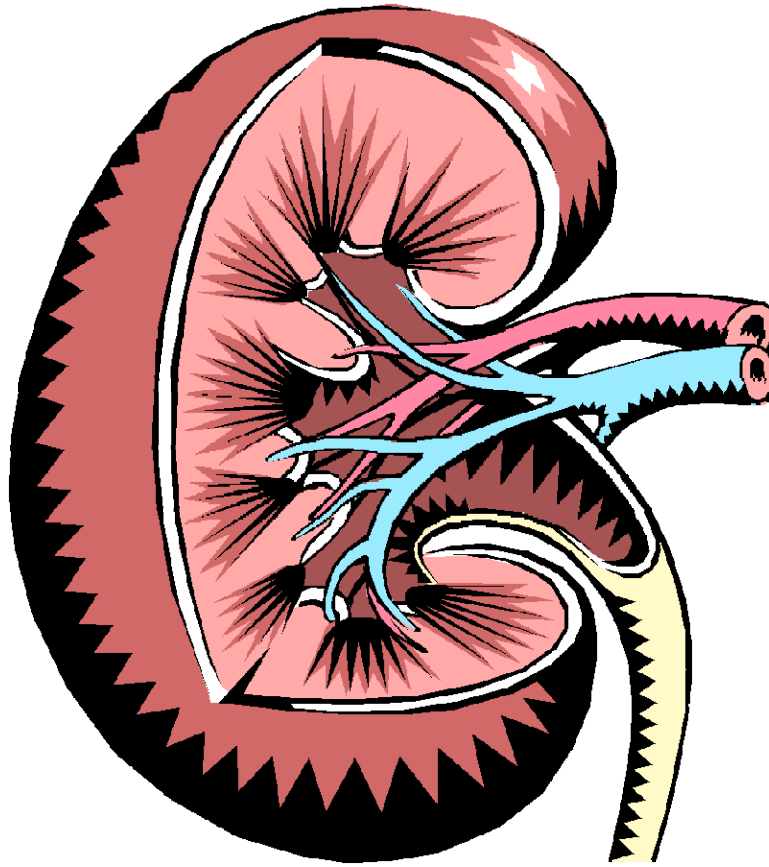


End Stage Renal Disease New Patient Education Manual



Carolinas HealthCare System
Renal Services
Charlotte, North Carolina

INTRODUCTION

This is a basic manual designed to introduce patients and their families to End Stage Renal Disease. This guide book was written by dedicated health care professionals who work within our hospital system using the latest medical education and research available.

Our renal health care professionals strive to improve the lives of people with, or at risk for, End Stage Renal Disease by promoting and advancing quality care. If at anytime we can be of additional assistance, please feel free to contact a member of our team through your bedside nurse or by calling us directly at the following numbers:

Locations

Carolinas Medical Center Kidney Dialysis Unit

1000 Blyth Blvd

10th floor

Charlotte, North Carolina 28173

704-355-2098

Primary Renal Pt Services Floor

10 Tower

704-355-6210

Carolinas Medical Center Mercy Dialysis Unit

2001 Vail Avenue

Charlotte, North Carolina

704-304-5033

Mercy Hospitals Primary Renal Floor

3 North

704-304-5391

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Chapter 1

Understanding What the Kidney Does And What Happens When It Fails

What are the Kidneys?

Your kidneys are two kidney bean shaped organs located one on either side of the mid-back below your ribcage.

What do they do?

Your kidneys are a filter for your body. They clean out the extra waste products that come from the food we eat and the fluids we drink.

This extra waste is in the blood. The kidneys clean waste products and fluid. Normally, this waste is taken out of the body down tubes called the ureters located at the bottom of the kidney. It then goes into the bladder as a holding area until it is passed out of the body.

What happens when my kidneys don't work?

The kidneys are made up of thousands of tiny filters called nephrons. When these filters are damaged, this causes less waste products and fluid to be cleaned from the blood.

When the kidneys fail, waste products build up in your blood stream causing you to feel ill. This is an immediate sign that treatment is needed. We will talk more about treatment options in this handbook.

Many times patients report they continue to feel fine – even though their kidney's have failed –so, by the time you have “symptoms” you may require urgent treatment.

How can they tell when my kidneys don't work?

There are tests and procedures your kidney doctor (a Nephrologists) will do to tell what's affecting your kidney function. Some of those tests are:

1. *Renal Function Panel* – This is a blood test to check for abnormal results on how your body is clearing waste products correctly.
2. *Biopsy*- A procedure that's done by a kidney doctor to check your kidney for any abnormalities.
3. *24- Hour Creatinine clearance* – A 24 hour urine test. Your nurse will instruct you on how to collect the urine.

The information collected from the blood test and the 24 hour creatinine clearance gives the doctor a percentage of your kidney's remaining function.

This is called **the glomerular filtration rate or GFR**. We encourage all people at risk of kidney failure to ask their primary care doctor, “What is my GFR”?

STAGES OF KIDNEY DISEASE

Stage	Description	Glomerular Filtration Rate
At increased risk	Risk factors for kidney disease (e.g., diabetes, high blood pressure, family history, older age, etc.)	(GFR) More than 90
1	Kidney damage (protein in the urine) and normal filtration rate.	More than 90
2	Kidney damage and mild decrease in filtration rate	60 to 89
3	Moderate decrease in filtration rate	30 to 59
4	Severe decrease in filtration rate	15 to 29
5	Kidney failure (dialysis or kidney transplant needed)	Less than 15

What Caused my Kidneys to Fail?

Sometimes we just don't know but there are several reasons your kidney may not work. The two most common causes are:

1. Diabetes (Sugar in the blood)
2. Hypertension(High Blood pressure)

These both affect the blood vessels slowly over time and cause damage to the nephrons or the filters of the kidneys.

Other causes:

3. Infections that affect the nephrons
4. Birth defects – these can cause blockages of the urine flow that cause damage to the kidney.
5. Trauma- Caused by accidents or from a medication or poison ingested or inhaled into the body.

What are the symptoms of the kidneys not working?

1. Urinating more than normal or less than normal
2. Feeling tired
3. Loss of appetite – bad taste in the mouth
4. Nausea, vomiting
5. Swelling in face, hands and feet
6. Increased difficulty in breathing
7. Itchy Skin

I’m hearing the doctors and nurses talk about Chronic and Acute Renal Failure, What’s the difference?

Acute Renal Failure

Some kidney problems are brought on quickly. For example, an accident, sudden loss of blood or low blood pressure. Some drugs or poisons can also make your kidneys stop working. This is *acute renal failure*.

Some patients with acute renal failure will “recover” over time and no ongoing treatment will be needed.

Chronic Renal Failure

Chronic renal failure is how most kidney function decreases. Chronic renal failure usually happens slowly overtime from a known or unknown cause. An example would be untreated high blood pressure or poorly controlled diabetes.

Chronic Renal Failure develops into End Stage Renal Disease (ESRD). This is a medical term for kidney disease that requires dialysis or kidney transplant for a patient to stay alive.

YOUR QUESTIONS AND NOTES – My kidney failure is because of:

Chapter 2

Treatment Options for Kidney Failure

You have been told your kidneys are not functioning properly and you are faced with some tough decisions. There are three treatment options for kidney failure: lifelong dialysis (hemodialysis or peritoneal dialysis) or kidney transplantation.

The question of the best method of treatment is complex for each person. All treatments affect each person differently. Kidney patients should learn all they can about each method of treatment to make a better decision for you.

Together with your physician, your initial treatment option will be selected. The physician will review your medical condition/limitations, lifestyle and your preference. Only by understanding the pros and cons of the different treatments can patients then choose the best treatment suited for their situation.

It is not uncommon for patients to try multiple treatment options throughout their life. **Developing kidney failure means you have some choices to make about your treatment.**

TREATMENT OPTIONS: HEMODIALYSIS

Hemodialysis is the most common therapy, or treatment for patients with kidney failure. Hemodialysis can take place in your home or more commonly in a dialysis center.

Hemodialysis means “to clean the blood.” It is the process where your blood is slowly withdrawn from the body and circulated through a machine. The machine is equipped with an “artificial kidney” or a dialyzer. This machine is designed to remove toxins and excess water, from the body. In a person without kidney disease the kidneys work to assist in removing these toxins by being urinated out of the body.

The body is slowly cleansed over a 3-4 hour period 3 times a week.

Like all treatments, hemodialysis will affect your lifestyle. It has its advantages and disadvantages. Some of these are highlighted for you below:

IN CENTER HEMODIALYSIS	
PROS	CONS
Facilities are widely available	Center chosen for you based on availability
Trained professionals with you at all times	Treatments are scheduled by the center and are relatively fixed.
Socialization- get to know other patients with similar problems	Travel to & from dialysis unit 3 times a week for about 3-4 hour treatment.
	Transportation has to be set up.

HOME HEMODIALYSIS	
PROS	CONS
A helper (family or friend) will help you do your own treatments	You are required to have a helper (friend or family) in the home
Can do the treatments at the time you chose (still must be done according to the doctors orders)	You and your required helper need to be trained to use the machine and supplies provided by the home dialysis company.
Gain a sense of independence and control over your treatments	For emergencies you need to call 911 (no professionals around)
A home dialysis company will help you get the equipment you need.	Need space for storing the machine and supplies
Do not have to travel to dialysis unit	

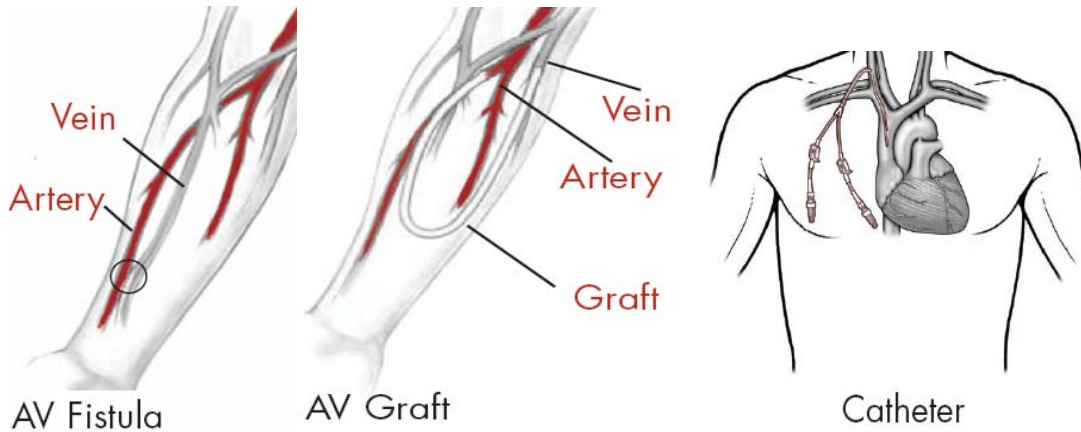
ACCESS

The lifeline of a dialysis patient is their dialysis access. Before starting dialysis doctors need to create an access to your blood. To be more specific, a surgical procedure will be done to connect an artery to a vein to create a site through which you will receive your dialysis treatments.

An evaluation of your veins and how soon you need to start dialyzing may assist the doctors in determining the type of access placed. Sometimes a doctor will use “vein mapping” to determine which type of access is best. Vein mapping uses a painless sound wave (ultrasound) to look at your veins.

Some type of access will be necessary for you to receive your dialysis treatments. There are 3 types of accesses.

1. **Fistula** - One of your veins is reconnected to an artery, allowing greater blood flow through the vein. Because it is your own vein it often last longer and may have fewer problems than the other two types.
2. **Graft** – An artificial tube is inserted just under the skin and is connected at one end to an artery and the other end to a vein. Sometimes this access requires more maintenance and does include an increased risk of clotting.
3. **Catheter** – Sometimes used for temporary access, this is a long, two sided tube inserted through the skin and into a vein.



The table below contains some more basic information on each for you to compare.

Fistula	Graft	Catheter
<p>Created by surgically connecting an artery to a vein. This is the access of preference.</p> <p>Usually takes 6-12 weeks after surgery before it is ready to be used (a catheter may be needed until then.)</p> <p>Is usually placed in the arm</p> <p>Requires needles to access fistula</p> <p>Lower risk for infection</p> <p>Lower risk for clotting</p> <p>Better performance</p> <p>Longer lasting</p> <p>Can be used for many years</p> <p>Daily exercises (squeezing a ball) are required to enhance maturation of the new fistula.</p>	<p>Created surgically by attaching synthetic tubing to an artery at one end & vein at the other.</p> <p>Ready for use in 2 to 3 weeks. Some may be ready 1 day after surgery.</p> <p>Usually placed in the arm, but the leg can also be used.</p> <p>Requires needles to access graft.</p>	<p>A catheter is a narrow flexible tube that is inserted into a large vein in the neck, groin or chest. The chest is the most common. There are two tubes exiting your skin. They will be used to remove blood from your body. Catheters are ready immediately after placement.</p> <p>It is not the recommended access for long-term dialysis due to frequent infection.</p>

ACCESS CARE

Access problems can occur in all patients. It is very important to take proper care of your dialysis access at all times.

Caring for your fistula or graft

- Your access should be kept clean & free of injury. Washing with soap and water daily and again before each dialysis treatment
- Inspect your access sight for signs of infection daily (pain, tenderness, swelling & redness). Be sure to notify your doctor or dialysis unit nurse if you notice any problems.
- Avoid tight clothing, jewelry or pressure on the access area.
- Do not carry heavy items across your access or wear tight jewelry or clothing and tight bandages
- Try not to sleep on this arm, excessive pressure can stop the blood flow
- Do not allow blood pressure to be taken or blood drawn from this arm. Ask the nurse to use a hand vein if possible if you need an IV or blood test
- If bleeding should occur at home, after treatment, apply pressure to the site firmly & call 911 or go to the nearest hospital.
- You may shower with a fistula or graft.
- Dialysis staff will teach you to feel for the “trill”, or, a pulse type feeling so you know your access is working

Catheter Care

- You are not allowed to swim, take showers, or soak in baths. Care must be taken to keep site from getting wet. Keep the catheter site dry and ends secured.
- Site must be checked for infection (redness, swelling, pain, fever or drainage from site).
- Be careful not to pull or tug on the catheter.
- Scissors or sharp objects should never be used near the catheter.
- Catheters can work better depending on your position. Pay attention to what works best for you.
- Do not remove the dressing from the catheter site.
- If bleeding occurs at the site, apply firm pressure over the site until it stops. If bleeding does not stop after 20 minutes, call your doctor. If severe bleeding occurs, call 911.
- Do not disturb clamps located on your catheter. They must remain clamped at all times.
- If a cap comes off and the clamp is open, clamp the catheter immediately to avoid bleeding or air embolism. Lie down on your left side with your head below your heart, call your center or doctor. If chest pain or difficulty breathing occurs call 911.

TREATMENT OPTIONS: PERITONEAL DIALYSIS (PD)

What is PD?

PD uses part of the body to clean your blood. *The peritoneum is a membrane that lines the abdominal cavity inside your belly.* It is like a bag, holding the internal organs.

To do PD, this bag is filled up with a special fluid called “dialysate” (dye-al-i-sate). Wastes and extra fluid in the blood slowly flow into the dialysate.

After a few hours, the dialysate has all the wastes and fluid it can hold so it is drained out. Clean dialysate is then put back in.

Putting the dialysate in, letting it sit for a few hours, and then draining is called an “exchange.”

Where is PD done and by who?

Patients are trained to do PD exchanges themselves at home, at work, or when traveling. PD exchanges are painless.

How does peritoneal dialysis clean the blood?

To clean the blood, dialysis has to take out wastes and extra fluid while keeping in the things the body needs, like blood cells. During dialysis, blood and dialysate are kept apart by a membrane.

Wastes and fluid flow out through tiny holes in the membrane. Blood cells and protein, which the body needs to keep, are too big to fit through the membrane so they stay in the blood.

Dialysate helps to pull the wastes out of the blood. Once dialysate is used, it is thrown away.

How does dialysate get in and out of the peritoneum?

A minor surgery is done to put a soft, flexible plastic tube called a “catheter” into the belly. Your doctor will make a small cut, often below and a little to the side of your belly button, and then guide the catheter through the slit into the peritoneal cavity. This becomes your access to PD.

Dialysate goes into the peritoneum through the catheter. The end of the catheter that is inside your belly has many holes to allow the free flow of dialysate in and out. The catheter stays in the body all the time and hangs out a few inches. It’s covered up when it isn’t being used.

What are the types of PD?

Continuous Ambulatory Peritoneal Dialysis (CAPD)

CAPD is the type of dialysis where people do PD exchanges by hand or manually every few hours. Most people on CAPD do 3-5 exchanges each day. Each one takes about 30 minutes. Exchanges must be done very carefully to prevent painful infections called “peritonitis.”

Because dialysis is taking place all the time with PD, there are fewer food and fluid limits. Since patients do their own PD, it is easier to work and travel.

Continuous Cycling Peritoneal Dialysis (CCPD)

Some people need more blood cleaning than PD can give them or they may not be able to do their exchanges at work due to it being too dusty or dirty. In this case, there is another way to do PD: CCPD. CCPD is the type of dialysis where people use a machine to do their exchanges at night while they are sleeping. Sometimes CCPD is also called Automated PD (APD). People do CCPD at night plus one or more exchanges during the day to feel their best and remove enough fluid. The machine is called a cyclor and fits into suitcases for travel. Sometimes people on CCPD can do regular CAPD when they are traveling.

How effective is PD?

PD is more likely to provide good dialysis for people who are small and people whose kidneys are still working a little bit (called “residual renal/kidney function”). It is still important to measure kidney function and as the kidneys keep failing, more PD may be needed for patients to feel their best.

Infections of the peritoneum, called peritonitis, can make PD less effective by causing scar tissue. Some people who get peritonitis have to stop doing PD and switch to hemodialysis.

How do I prevent problems?

Your health care team will show you how to keep your catheter free of bacteria in order to avoid peritonitis. Here are some general rules:

- Store supplies in cool, clean, dry place
- Find a clean, dry, well-lit place to perform your exchanges
- Wash your hands every time you need to handle your catheter
- Clean the exit site with antiseptic every day
- Wear a mask when performing exchanges

Why is it important for me to follow the prescription of my doctor?

One of the big problems with PD is that patients sometimes don't perform all of the exchanges they are supposed to. They either skip exchanges or sometimes skip entire treatment days when using CCPD. Skipping PD treatments has been shown to increase the risk of hospitalization and death.

How can my diet help?

Eating the right foods can help improve your dialysis and your health. You may choose PD over hemodialysis because the diet is less restrictive. With PD, you're removing wastes from your body slowly but constantly, while in hemodialysis, wastes may build up for 2 to 3 days between treatments. You still need to be careful about the foods you eat, however, because PD is much less efficient than working kidneys. A dietitian will help you plan meals. Follow the dietitian's advice closely to get the most from your dialysis treatments.

What are the Pros and Cons of PD?

Pros	Cons
Fewer food and fluid limits so it's easier to choose something that's okay to eat	None
You do the treatments yourself so you are in charge (with a clinic to call if there are problems).	Every single exchange must be done carefully, or your risk for peritonitis increases.
No needles are used for PD	The catheter is always part of your body.
PD treatments are generally painless	Initially abdominal pain can occur after the catheter is place, while the body is healing. Draining "dry" can be uncomfortable.
None	Carrying a liter or two of fluid around in your belly can mean looking a little pregnant all the time. PD dialysate has sugar in it, and can cause weight gain and changes in diabetes control.
You can do PD at home; work, on vacation, or in the car.	Storing PD supplies takes a lot of space, the boxes are heavy, and deliveries may not come at convenient times. Traveling means making prior arrangements.

Pros	Cons
There is no wiped-out feeling like there can be with hemodialysis. You feel the same all the time.	There are no days off. You have to do PD every day.
You decide the schedule and can fit dialysis in around your day. This can make it easier to work full-time	CAPD can feel relentless. With several exchanges each day, it's hard to ever be away from dialysis.
PD supply companies can ship supplies to your travel site, so it's easy to travel.	Even on a trip, exchanges still need to be done several times a day.
You can take part in most of your usual activities.	PD may work better for smaller people. Some people may need more blood cleaning than PD can give them. Scars may make PD unworkable.

TREATMENT OPTIONS: KIDNEY TRANSPLANTATION

Considering a Kidney Transplant???

A kidney transplant is not a cure; it is a treatment. A kidney transplant is when a kidney is removed from one person (called a donor) and surgically placed into another person (called a recipient). Many people prefer a transplant because of the benefits it provides.

A successful kidney transplant may prevent you from ever needing dialysis. If you have started dialysis, a successful transplant should allow you to stop the dialysis treatments. Your energy level should improve as your new kidney will promote the production of red blood cells.

You will have fewer restrictions with your diet and with your fluid intake. You will hopefully be able to return to a more normal lifestyle with increased activity and independence.

How do I find out if I am a candidate?

Your physician or dialysis unit can refer you to a transplant center for evaluation. This evaluation process includes meeting with several members of the transplant team. You will meet with a transplant nurse, social worker, dietician, financial specialist, a transplant nephrologist (kidney doctor) and a surgeon. These meetings will provide you with a great deal of education regarding the transplant process.

The evaluation will also consist of lab work, x-rays and other tests.

Some questions you should ask:

- What are my choices other than transplantation?
- What are the benefits and risks of transplantation?
- What would the evaluation process for me include?
- How long has this hospital been doing my type of transplant?
- What are the success rates and survival rates of transplants at this center and how do they compare with other centers?
- If you are diabetic, are you also eligible for a kidney/pancreas transplant?

The Evaluation

Once the evaluation process is complete, the transplant team will review the information and decide if they feel that transplantation is a reasonable and safe option for you.

If approved, there are two possible types of kidney transplant procedures that your transplant team will discuss with you. The first is a kidney donated from a live donor. This may be someone who is a family member or someone close to you like a friend or co-worker. A living donor is the best option for you. Success rates are slightly better and the surgery is scheduled at a convenient time. But not everyone who needs a kidney has a live donor available.

If that is the case, you would go on the waiting list for a kidney from a deceased donor. A deceased donor is someone who has died and donated their organs for transplantation. Unfortunately, there are not enough deceased donors to meet the huge demand and there is a waiting time for these transplants. Your transplant team will explain to you how kidneys are distributed and the average waiting time for a kidney.



Transplant Surgery

Kidney transplant surgery is approximately a 3-4 hour operation. Your own kidneys (native kidney) are not usually removed. Your new kidney is placed in your lower abdomen. There are some circumstances that may require removal of native kidneys. If you fall into one of these situations, your transplant team will discuss this with you.

After surgery, you will usually be in an intensive care area overnight and most likely be in the hospital for approximately 5-7 days. Although, this is a major operation, most patients begin to feel better almost immediately. Your transplant team will spend a lot of time teaching you how to take care of the new kidney and about your medicines before you go home.

Things to consider

Kidney transplantation is an elective surgery. You do not have to have the surgery. The advantages of transplantation include: freedom from dialysis, less dietary restrictions, generally better survival rates than dialysis and overall more energy. It is easier to continue working with a transplant as compared to being on dialysis.

The disadvantages include multiple medicines, the follow-up and increased risks of infections and a slight increased risk of cancer. As with any transplant there is always a risk the body would reject the new kidney at any point.

The transplant teams will discuss the risks and benefits in greater detail with you. The success rates for kidney transplantation are very good. At Carolinas Medical Center approximately 93% of the kidneys are still working at one year.

Unfortunately, not everyone is a candidate for transplantation. Because there are not enough kidneys available for transplantation, candidates are selected that have the best possible chance of success.

The selection process requires that you have a good support system in place. Following transplantation you will have to take medicines for as long as you have the kidney, which hopefully will be the rest of your life. These medicines are very expensive and may have some negative side effects. You will also need to make very frequent visits to your transplant physician (as many as 2-3 times a week at first). As time goes on, these visits will become less frequent and if possible, some may be with your local kidney doctor.

This is just a brief overview of kidney transplantation. If you would like more information, please talk to your kidney doctor or you can call the Transplant Center at Carolinas Medical Center at (704) 355-6649 or (800) 562-5752.

TREATMENT OPTIONS: NO THERAPY

Like anything else you also have the option not to pursue any of the above treatments for your kidney disease. The reality is that your body needs your kidneys to function to continue to live, so to select no therapy for your kidney disease you must understand that this would lead to your death.

You would want to discuss this option over time with your physician and your family.



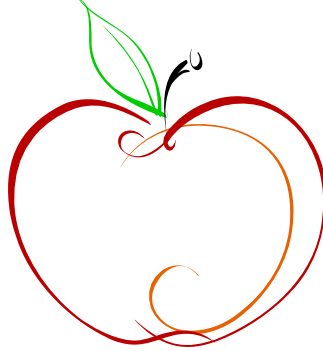
YOUR QUESTIONS AND NOTES:

Chapter 3

CHANGES IN YOUR DIET

The food you eat is very important as to how well you will do on dialysis. While you are on dialysis or recovering from a transplant, your kidney doctor and dietitian will watch the chemical balance of your blood and the fluid in your body. Together, they will design a plan for your diet based on your conditions and symptoms.

Your diet management is one of your most important responsibilities as a kidney patient. The need for balance and moderation is necessary. This is your opportunity to take control over how well you do between treatments. It will take some time to learn all of what you need to know about the renal diet – your renal dietitian will be there to help you.



Your Diet Prescription:

_____ Grams Protein
_____ Grams Sodium
_____ Ounces Fluid per day
_____ Grams Potassium
_____ Grams Phosphorus

Dietitian: _____

Phone #: _____

Sodium

Sodium is a mineral that helps regulate the body's water balance. Although sodium is commonly referred to as salt they are not the same things. Table salt is sodium chloride: 40% sodium and 60% chloride. One teaspoon of table salt contains 2,300 milligrams (mg) of sodium. Small amounts of sodium are naturally present in a wide variety of foods. About 75% of the sodium in our food is added by manufacturers and another 15% is added at the stove or table.

Sodium must be limited in the diet to help control thirst and blood pressure. Too much sodium in your diet can cause your body to hold onto water. This extra fluid then causes your ankles to swell (edema) and can put strain on your heart and lungs. Alternatives to salts that are recommended are listed for you below:



Acceptable Seasonings

Lawrys Seasoned pepper
Mrs. Dash Extra Spicy
Mrs. Dash Onion-Herb
Mrs. Dash Table Blend
Mrs. Dash Lemon Pepper
Mrs. Dash Garlic and Herb
Mrs. Dash Original Blend
McCormick Lemon Pepper Salt Free
McCormick Garlic-Herb Salt Free
McCormick All Purpose Salt Free
McCormick Onion and Herb Salt Free
Durkee Smart Seasonings All Purpose Blend Salt Free
Durkee Smart Seasonings Pepper and Herb
Durkee Smart Seasonings Garlic and Italian Herbs
Durkee Smart Seasonings Garlic and Parsley

Limiting fluids

Because your kidneys no longer work, your body will hold onto extra water. This can cause your blood pressure to be high or cause you to have a difficult time breathing. Patients on dialysis must follow a strict fluid restriction every day. **It is important to always remember that all foods that are liquid at room temperature count towards your daily fluid intake:**

- ♦Water for taking medication & drinking
- ♦Ice cream, sherbets, and sorbets
- ♦Milk, cream and liquid creamer
- ♦Ice cubes and ice chips
- ♦Coffee and Tea
- ♦Soups
- ♦Gelatin
- ♦Soda
- ♦Popsicles

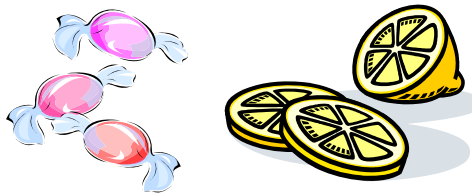


Calculating your fluid intake:

Use the chart below to help convert between units of measure. Always remember to measure your fluid intake.

4.2 Cups	34 Ounces	1 Liter	1000 ml
4 Cups	32 Ounces	1 Quart	1000 ml
2 Cups	16 Ounces	1 Pint	500 ml
1 Cup	8 Ounces	½ Pint	250 ml
½ Cup	4 Ounces	8 Tablespoons	120 ml
1/3 Cup	3 Ounces	5 Tablespoons + 1 teaspoon	80 ml
¼ Cup	2 Ounces	4 Tablespoons	60 ml
1/8 Cup	1 Ounce	2 Tablespoons	30 ml

Tip: You may decrease your thirst by sucking on a lemon wedge or hard candy.



LIFE STYLE:

Every patient has a different lifestyle. Some lifestyle choices may affect your diet and fluid intake. Other life style choices may affect your quality of life. Special activities you should talk to your doctor about may include alcohol consumption, smoking cigarettes, having sexual activity.

Anything you drink including alcohol must be counted in the fluid limit.

Questions to ask my doctor about my lifestyle: _____

Potassium

Potassium is a mineral that helps the heart to beat normally and helps muscles and nerves to work properly. Potassium is found in most foods. Meats, dairy foods, fruits and vegetables all contain potassium. Some low sodium products, especially salt substitutes, contain extremely large amounts of potassium and should be avoided by all dialysis patients.

You will need to lower the potassium in your diet to prevent the potassium that is in your blood from getting too high between your hemodialysis. High levels of potassium in your blood will affect the rhythm of your heart beat and can be very dangerous.

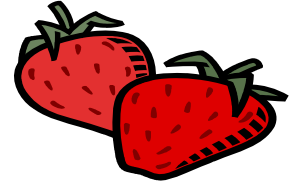
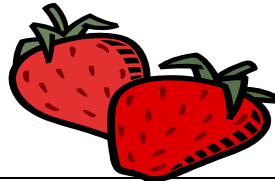
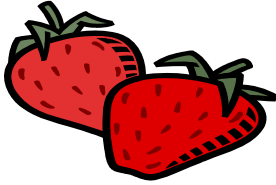
Your blood potassium level will be checked during your monthly lab work and monitored by your health care team.

Potassium

Fruits and Vegetables Lowest in Potassium

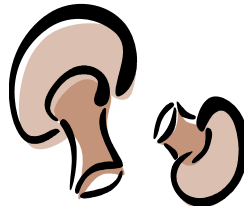
To decrease the amount of potassium in your diet, eat these low potassium fruits and vegetables most often. Fruits and vegetables not listed here as either high or low, contain a medium amount of potassium. Eat these medium potassium fruits and vegetables in moderate amounts.

Fruits



apples	fresh peach
applesauce	frozen grape juice
blackberries	fruit cocktail
blueberries	pineapple
canned mandarin oranges	plums
canned peaches	raspberries
canned pears	strawberries
fresh grapefruit	tangerine

Vegetables

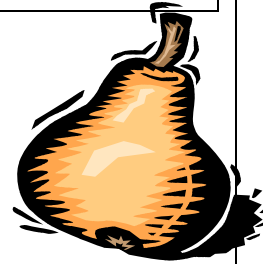
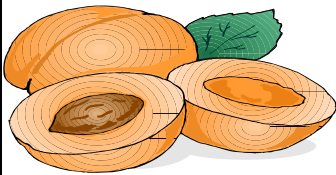


alfalfa sprouts	frozen/canned peas
bean sprouts	green beans
cabbage	green peppers
canned mushrooms	lettuce
canned/frozen corn	mustard greens
collards	onions
cooked carrots	radishes
cucumbers	turnip greens
fresh mushrooms	water chestnuts
frozen broccoli	yellow beans
frozen cauliflower	yellow squash

Foods That are High in Potassium

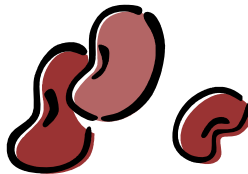
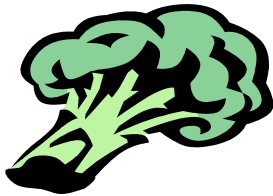
Too much potassium in your blood is very dangerous because it can upset the rhythm of your heartbeat without any warning. Keep your blood potassium level safe by avoiding the foods listed below that are high in potassium.

Fruit



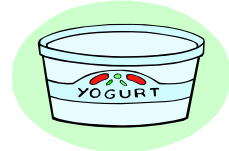
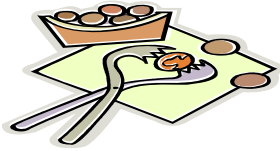
apricots	honeydew melon	papaya
bananas	kiwi fruit	prunes
cantaloupe	oranges	prune juice
dates	orange juice	rhubarb
figs	nectarines	tangelos
fresh pears		

Vegetables



acorn squash	cooked mushrooms	pumpkin
avocado	french fries	soybeans
baked beans	fresh broccoli	spinach
baked potato	kidney beans	stewed tomatoes
beet greens	lentils	sweet potatoes
beets	lima beans	tomato juice
black-eyed peas	navy beans	tomato paste
boiled chard	parsnips	tomato sauce
Brussels sprouts	pinto beans	un-soaked potatoes
butternut squash	potato chips	V-8 juice

Other Foods



banana cream pie	eggnog	pumpkin pie
bran cereals	molasses	salt substitutes
brewed coffee	nuts	spaghetti sauce
brown sugar	peanut butter	yogurt
chocolate milk	pork & beans	wheat germ

Phosphorus

Phosphorus is a mineral that has an important role in all cell functions and that is combined with calcium to make bones. In dialysis patients the balance between phosphorus and calcium is very important. High blood phosphorus levels upset the body's delicate phosphorus and calcium balance and can ultimately result in itching, bone pain and brittle bones that break easily.

Usually dialysis alone can not remove enough phosphorus to keep your blood phosphorus in the normal range. For this reason you need to limit the amount of phosphorus in your diet and take a medicine called a "phosphorus binder" that is prescribed by your doctor. This medicine is taken with meals and will "bind" the phosphorus in the food you just ate so that it cannot be absorbed into your blood. High phosphorus foods like dairy products, nuts, whole grain and bran breads and cereals, dried beans, and cola drinks need to be limited in your diet. Your blood phosphorus and calcium level will be part of your monthly lab work and monitored by your health care team.

Foods High in Phosphorus

While your blood phosphorus is high, **do not eat these high phosphorus foods.**

Nuts & Seeds	Whole Grains	Dried Beans
almonds	brown rice	black-eyed peas
cashews	whole wheat breads	kidney beans
peanuts	bran muffins	lentils
pecans	oat bran	lima beans
pumpkin seeds	bran cereals	navy beans
sunflower seeds	oatmeal	pinto beans

◆ **Other Items to Avoid:**

American processed cheese	Cream pies
Canned salmon with bones	Fresh green peas
Caramel, chocolate & cocoa	Instant pudding
Cheesecake	Pecan pie
Coconut custard pie	Pimento processed cheese spread
Cola type soft drinks	Processed cheeses

◆ **Dairy products are high in phosphorus.**

◆ **While your phosphorus is high, limit your choices from the dairy list to 1/2 cup or 1 ounce per day.**

canned or cooked pudding	ice milk or ice cream
cottage cheese	milk
creamed soups	natural cheese

Remember to take your phosphorus binders with your meals!
Tums, Oscal, Phoslo

Food Group	Serving	Foods Allowed	Foods to Avoid
Milk and Milk Products	½ cup to 1 ounce each day	Milk, ice cream, pudding, plain or fruit yogurt, cheddar, Swiss, Colby mozzarella and Monterey jack cheeses,	Buttermilk, chocolate milk, fast food milkshakes, Velveeta® type cheese, processed cheeses like Cheese-Wiz®, and pimento cheese spreads
	3 Tablespoons	Cream cheese	
	4 Tablespoon	Sour Cream	
Meat, Poultry, Fish, Eggs	Eat _____ ounces each day 1 egg = 1 ounce of meat	Fresh pork, beef, lamb,, game, chicken, turkey, fish, seafood, eggs	Canned, cured, smoked, pickled or process meats such as hot dogs, sausage, ham, luncheon meats; frozen pot pies and TV dinners; canned stews and chili
Breads, crackers, cereals, pasta and rice	Eat _____ servings per day 1 serving or 1 slice, 4 crackers or ½ cup	White bread and rolls, English Muffin, bagels, muffins, cornbread made with regular cornmeal, biscuits and pancakes made with all-purpose flour, frozen waffles with less than 300mg sodium per serving, tortillas Plain crackers, Melba toast ®, graham crackers Corn and rice cereals, grits, oatmeal Noodles, pasta, white rice	Whole grain breads and crackers, biscuits and pancake mixes, self-rising cornmeal and flour, crackers with more than 150mg sodium per serving. Instant flavored grits, raisin bran cereal, most bran cereals, cereals with nuts or dried fruits, granola, cereals with more than 20% of the daily value of phosphorus Brown rice, whole wheat pasta
Vegetables	Eat _____ servings per day Serving is ½ cup *Potatoes can be eaten if they are peeled, cut up in small pieces, and soaked in a large pan of water for at least 4 hours. Drain this water and add fresh water. Cook and prepare as desired.	alfalfa sprouts, asparagus, bean sprouts, broccoli, cabbage, cooked carrots, celery, collards, corn, cucumbers, cauliflower, green beans, green peas, green peppers, lettuce, frozen mixed vegetables, mushrooms (fresh, raw, or canned), mustard greens, onions, *soaked white and sweet potatoes, radishes, summer squash, turnip greens, water chestnuts, wax beans	baked potatoes, baked beans, beets, beet greens, black-eyed peas, brussels sprouts, chard, kidney beans, lentils, lima beans, cooked fresh mushrooms, parsnips, pinto beans, *unsoaked potatoes , pumpkin, sauerkraut, soybeans, spaghetti sauce, spinach, stewed tomatoes, sweet potatoes, tomato juice, tomato paste, tomato sauce, V-8 juice, winter squash.

Food Group	Serving	Foods Allowed	Foods to Avoid
Fruits	Eat ____ servings per day 1 serving is ½ cup or 1 small fruit	Apples, applesauce, apple juice, blackberries, blueberries, cherries, canned fruit cocktail, cranberries, cranberry juice, frozen grape juice, 15 grapes, grapefruit juice, 1/2 fresh grapefruit, canned mandarin oranges, small fresh peach, canned peaches, canned pears, pineapple, pineapple juice, plums, raspberries, strawberries, tangerine, watermelon.	Apricots, banana, cantaloupe, dates, figs, mixed dried fruits, fresh pears, honeydew melon, kiwifruit, nectarines, oranges, orange juice, papaya, prunes, prune juice, raisins, rhubarb, tangelos.
Fats	Eat ____ servings per day 1 serving is 1 teaspoon	Butter, margarine, mayonnaise, home made meat gravy, lower sodium salad dressings, and vegetable oils.	Bacon, bacon fat, instant gravy mixes, salt pork, salad dressings with more than 300mg sodium per serving.
Beverages	Limit to ____ cups daily	Coffee, ginger-ale, Kool-Aid, lemon-lime soda, , lemonade, tea, water, non-cola drinks like Sprite®, 7-Up®, Mountain dew	Cola type drinks like Coke® and Pepsi ®, Gatorade ® type drinks orange juice, prune juice, tomato juice, V-8 juice
Candy and sweets Avoid if diabetic		Gum drops, candy corn, fruit roll-ups, hard candy, honey, jams, jellies, jelly beans, marshmallows, mints, sugar.	Brown sugar, candy with nuts, chocolate, molasses, sorghum
Desserts		Cool-Whip®, plain and filled cookies without chocolate or nuts, yellow cake, pound cake, doughnuts, pastries, fruit pie, Rice Krispie Treats®.	Banana cake, banana pudding, pecan pie, pumpkin pie, sweet potato pie, desserts made with chocolate, nuts, or coconut.
Snacks		Unsalted corn chips, unsalted pretzels, unsalted popcorn, unsalted tortilla chips; limit Lance/NAB® sandwich crackers to 3 packages a week.	nuts, potato chips, salted snacks, pumpkin seeds, sunflower seeds
Seasonings and condiments		non-dairy creamer, black pepper, flavor extracts, herbs, spices, salt-free spice blends like Mrs. Dash®, Texas Pete®, vinegar, flavored vegetable oils, small amounts of cocktail sauce, ketchup, mustard, tartar sauce, Worcestershire Sauce	Accent, bouillon cubes, gravy mixes, olives, pickles, salsa, salt substitutes, seasoning mix packages, soy sauce

CHAPTER FOUR

SOCIAL AND EMOTIONAL ADJUSTMENTS OF THE KIDNEY PATIENT & THE ROLE OF THE RENAL SOCIAL WORKER

It is very common to experience a flood of emotions when dealing with an incurable disease such as kidney failure. Everyone experiences different emotions at different times and adjust at varying rates. It is important to remember that you have a support system at your dialysis unit available to you. Expect to feel emotions such as denial, guilt, fear, anxiety and acceptance at different times. All of these feelings are very normal, as is the need to have someone who assists you in coping.

Remember that a chronic illness also affects family members and those that love you. They can be your biggest supporter and provide you the encouragement you need for all that you will be balancing with your emotions, treatment schedule, diet and medications.

We understand that there are many questions running through your mind about how this process works and how it may affect your life. Changes in your lifestyle will be required of you as a kidney patient – this varies somewhat by the treatment option you select.

Lifestyle Changes

Loss of Control

One of the biggest obstacles you will have to face is loss of some control in your daily life decisions. Your kidney disease and required treatments have clear restrictions on schedule, time and, of course, diet.

Daily Schedule

As a kidney patient and their family sits down to review the treatment options you will likely need to adjust some of your daily work and family activities to adjust to your treatment schedule. Some treatment options require major to minor alterations in work schedules or family activities.

Working with your family and dialysis unit staff to preserve your independence for those activities that are the most important requires open communication, patience and flexibility

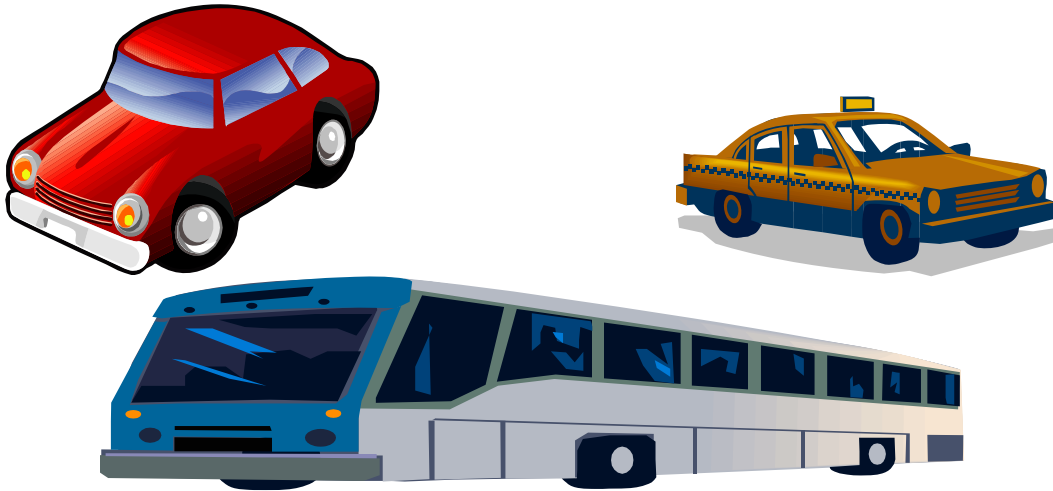
Work

You don't have to stop working – this depends on you and your individual goals/opportunities. You will need to talk with your employer about changes needed because of your health status, energy level and treatment schedule. The Americans with Disabilities Act requires employers to make all reasonable accommodations for your job.

If you decided it is time for a career change or to return to school instead, your social worker can refer you to various agencies such as a vocational rehabilitation to assist you. This agency assists patients to return to school or change employment.

Meal Time

As you have already learned your diet and fluid restrictions are critical to your health. Work closely with the renal dietitian and your physician to find a prescription that works best for your life. If you have a special event coming up, talk to your dietitian. He or she may help you make the necessary adjustments for this occasion.



Travel

Having kidney failure does not mean you can't travel, it does require that you plan trips well in advance (at least 30 days) and ensure your dialysis staff has arranged for you to receive treatment as a visitor in your destination city. There are dialysis centers all over the United States and now even cruise lines that are dedicated to serving kidney patients and their families.

In advance of your trip, your treatment plan, medical history, lab values and medications will arrive at your visiting center – just like at your home location. Medicare will cover your dialysis all over the United States. If you are a Peritoneal Dialysis patient, you have the freedom to travel any time but still need to plan for your supplies and equipment.

The Role of the Social Worker

Different medical professionals will be involved in your care, one being the social worker. We have already mentioned the social worker but we want to talk more about his/her role in your treatment team. Being on dialysis for the first time can be quite an adjustment from what your life was like before. Social workers will offer support, resources, and help educate both you and your family.

From the time of diagnosis a social worker is available to assist you. Some things your social worker may do include: finding an outpatient dialysis unit; applying for insurance; and relevant community resources such as transportation.

When trying to find an outpatient dialysis unit for the patient we want to find a facility that is closest to your home if possible. The dialysis staff, your kidney doctor, and social worker will send over your paperwork and work together in a process to find the right facility for you.

At each outpatient dialysis unit there should be a social worker who you can use as a resource. He or she will be there to help you with any issues you may have in relation to these topics in this handout as well.

Assisting you with funding/insurance questions *“How am I going to pay for dialysis?”*



MEDICARE

The primary source of paying for your treatment is Medicare and/or Medicaid regardless of your age. These are federal and state insurance programs.

Your social worker will work with you in applying for Medicare. Under your social security benefit any persons diagnosed with End Stage Kidney Disease are able to apply for early Medicare. A person must have enough working quarters to receive early Medicare. Most people with kidney failure will qualify. You must be a U.S citizen or a lawfully admitted noncitizen that has lived in the U.S. for at least five years.

The social worker, with your help, will contact Social Security at 1-800-772-1213 to apply for this insurance. The social worker will also ask if you would like to set up an appointment to apply for Disability. We will talk more about disability in this chapter.

Much of this process can be done over the telephone or in person at the local Social Security office which is located at 5800 Executive Drive Charlotte NC 28212.

This process takes anywhere from a few weeks to months to set up.

MEDCARE PARTS A, B and D

Medicare has two primary parts and a new prescription plan. *Medicare Part A* pays for hospital services while you are actually in the hospital or a skilled nursing facility. It will also cover the cost of home bound services such as visiting nurses, physical, occupational and speech therapy in your home.

Medicare Part B covers your doctor's bills and 80% of your dialysis treatments outside of the hospital. In addition to this it will cover hospital services that do not require you to stay overnight. Part B requires you to pay a monthly premium. Your social worker will help you with various kidney resources if your premium is too high.

Medicare now has a prescription plan for those in need – *Medicare Part D or Medicare Advantage Plans*. You can also apply for this Medicare prescription drug plan. This is voluntary and you also pay a premium for this coverage. As a renal patient with multiple medications, a good prescription plan is very important. Your social worker can guide you to selecting a renal friendly plan. Be careful to have someone help you with this. There are many plans that become very overwhelming. As a renal patient your medication needs are very specific. Some of the Medicare plans will better cover you than others. Let your social worker guide you through this process with a list of your current medications verified by your kidney doctor.

You can also call Medicare directly at 1-800 –MEDICARE (1-800-633-4227) and one of their staff members will help you select the best plan for you based on your medication list.

To apply for Medicare D state pharmacy assistance program, call 1-800-772-1213 or go to their web site www.socialsecurity.gov.

WHEN DOES MEDICARE START??

Medicare Part B will begin the first day of the third month after you start dialysis in your outpatient center. If you are on a home treatment such as home hemo or peritoneal dialysis it will begin at once.

If you are put into the hospital to prepare for a kidney transplant, payments will begin up to two months before the operation and continue only for 36 months after the transplant. If the kidney is rejected by your body and the transplant fails, Medicare will continue to help pay for dialysis which would again be needed.

For more in formation about Medicare you can talk to your social worker, call toll free at 1-800-633-4227, or go to www.medicare.gov.

MEDICAID

If a person is not eligible for Medicare and /or needs a secondary insurance to cover the 20% of the cost of treatment Medicare does not pay, the social worker will encourage the patient to apply for Medicaid.

Medicaid is a state run program which provides medical and hospital coverage for people with limited income and no resources. Many kidney patients benefit from this insurance. You can qualify for both Medicare and Medicaid if you meet the requirements. You have to be considered disabled or blind in order to receive Medicaid coverage. Medicaid is also based on financial guidelines set by each state. You can apply for Medicaid at your local social service agency.

Applications can be done in the hospital at Carolinas Healthcare System (as long as you live in Mecklenburg County) or you can go to your local Department of Social Services to apply for Medicaid.

Mecklenburg County's Department of Social Services is located at 301 Billingsley Road Charlotte NC 28211. For both Medicare and Medicaid there is a list of documents that they require you to have in order to process your application. A general list of documents that you should gather is listed below:

- Your social security number
- Your birth or baptismal certificate
- Names, Addresses and phone numbers of the doctors, caseworkers, hospitals and clinics that took care of you and dates of your visits;
- Name and dosage of all the medicines you take;
- Medical records from your doctors, therapists, hospitals, clinics and caseworkers
- Laboratory and test results;
- A summary of where you worked and the kind of work you did
- A copy of your most recent W-2 Form or, if you are self-employed, your federal tax return for the past year.

Private Insurance and Dialysis

At the time of diagnosis if you have private insurance (i.e. Blue Cross, Humana, and Cigna) it will be considered the primary course of payment for the first 30 months of your treatment. It works like this, your bills for treatment will be submitted first to your private insurance for payment and then to a secondary coverage like Medicare. Sometimes, charges not covered by private insurance are covered by Medicare. Your social worker will help sort this out with you.

OTHER FINANCIAL ASSISTANCE

The Other 20%

Many kidney patients are concerned about their ability to cover the 20% of their treatment not covered by Medicare. If you do not qualify for Medicaid, your social worker will help you look for other kidney related resources to cover this portion of the payment – State Kidney Disease Funds and Veterans Insurances are two examples of such programs. Upon enrollment at the dialysis unit, the social worker will begin working on this with you.

Most dialysis patients who are not able to work can qualify for either Social Security Disability (SSDI) or Supplemental Security Income (SSI).

Social Security Disability (SSDI)

Disability is something that most people do not think they will have to use. However, if you have a medical condition that can last more than a year you can apply. This application can be done at your local social security office, by internet at www.socialsecurity.gov , or by calling 1-800-772-1213.

One should apply for disability benefits as soon as possible after the time of diagnosis. The process can take anywhere from three to five months and beyond.

Supplemental Security Income (SSI)

If you qualified for Medicaid you may also qualify for SSI. This is also designed for those who have very limited resources and income. Applications for this program are done at your nearest Social Security Office.

RESOURCES THAT KIDNEY PATIENTS OFTEN USE

Resources

Social workers do not have all the answers or solutions to your concerns but they will work with you to help in every way possible. There may be many concerns and issues that you may be facing that are not addressed in this manual, but chances are there are community resources to help.

If there are financial issues, there are agencies that can assist you with short term or emergency funding. Sometimes you might be too weak to drive yourself to dialysis, there are sources for transportation. Dialysis patients often take many medications and this can be a financial hardship even with insurance. There are agencies that can help with medications. Maybe you are struggling with depression/substance abuse. A social worker can assist in helping you find a treatment program. Maybe it is hard for you to care for yourself at home. Social workers can help you find the service(s) to best meet your needs.

Sometimes a person can no longer care for themselves at home and alternate living arrangements need to be made. This could be for a short or long period of time. The social worker can help determine what level of care is needed such as an assisted living or skilled nursing facility. This is not an easy decision, but the plan is to do what is in your best interest. Another source for you that social workers use is the local National Kidney Foundation. They too offer supportive and financial assistance.

Transportation Options

Some patients have difficulty with the regular transportation needs to and from their dialysis center or their doctor(s) appointments. Assistance is available in most communities based on where you live, your financial status and your physical ability. Your social worker may work with you and the following resources to help with your transportation needs:

- For those persons that receive Medicaid you can use the taxi cab service through the Dept. of Social Services, it is often free. However you must apply for this service by calling 704-336-4547. You must call 24 hours in advance to schedule your appointment.
- If you only have Medicare you can also use this service however you will have to pay \$2.50 each way for the taxi. Other options are the bus system and for those that are wheelchair bound you can use the Special Transportation System or the CATS bus. This again is an application process. You can call 704-336-2637 to apply for this program.
- The American Red Cross offers limited assistance for those who do not qualify for either of the above. Their service is based on volunteers and often books out well in advance. See your social worker for assistance.
- Union County Transportation also helps those in need in the Union county area.



Other times you will see your Social Worker

Psychosocial Assessments

When you begin your dialysis in the community or have to be hospitalized after starting dialysis, the social worker will meet with you for a Psychosocial Assessment. This document provides information about you that will help us find better ways to assist you. It tells us where you dialyze; who your support person(s) are and how they can be contacted; it provides insurance information; it tells us about how you are functioning at home, whether you are independent or if you need help with such activities as bathing, dressing medications, walking, etc.; it will tell us about the medical equipment you use and any services you are receiving in the home, i.e., physical therapy, home health aid, nursing.

It is hopeful that this information will help us determine if your current services are enough or if there are additional needs. Not all ESRD patients will require services. The Social Worker will help educate you on the different services that are available to you. It is important to remember that the social worker is here to help you and your family.

Family Meeting

Family support and involvement is very important for you. A person with ESRD often has other medical concerns. These may raise questions for the patient and their family. A family meeting can be arranged to discuss these issues in depth. The social worker will also include your kidney doctor and other supportive services at your request.

Advance Care Planning in Chronic Illness

Adjusting to a chronic illness is difficult but it is important to always plan ahead – tell us what you want for yourself when circumstances may become difficult. All patients with chronic illness should also think of *advance care planning*. Advance care planning is a way to let your family and physician know what you want if a time comes when you can no longer speak for yourself.

Many people find these conversations overwhelming. Your social worker can help connect you to resources to complete advance directives for yourself and your family members.

This manual will give you a brief description of what advance care planning is, but be sure to ask your social worker if you have any questions or need assistance – he or she can arrange for someone to walk you through the documents.

Advance Directives are: A general term used to describe the papers that tell your doctor and family your wishes if you can not speak for yourself. As long as you can make decisions, it is both your right and your responsibility to make your own choices. Your advance directive goes into effect **only when you are no longer able to** speak for yourself. These are the legal documents that you create; they guide us in how to best provide the care you desire.

The greatest benefit of your advance directive is its power to communicate your wishes.

Advance directive have two parts:

1. Health Care Power of Attorney (HCPOA) you pick a person that would tell the doctors what you would want if and when you can not speak for yourself. This HCPOA cannot make financial decisions for you.
2. A living will is a written description of the kind of medical treatment you want when you are facing serious illness.

Helpful Questions to ask yourself:

- Who knows what is important to you?
- Who would be able to speak for you?
- Under what circumstance would dying naturally be preferable to being kept alive on a ventilator machine?
- Would you want to be fed by a tube if you could no longer eat?
- Do religious beliefs influence your treatment decisions?

The person you pick to be your HCPOA:

- It is important that you name a person who knows what you would want and whom you trust to carry out your wishes.
- You may name a family member, but it is not necessary to do so. You may choose your spouse, an adult child, a friend or another loved one.
- You will want to be sure you talk with your HCPOA about your wishes and confirm that he or she will act on your behalf.

What to do once you have filled out the forms:

- Advance directives need to be witnessed and notarized.
- Do not sign the forms unless you are in front of a notary.
- Copy your advance directive
- Give your doctor a copy of your advance directive
- Give one to your HCPOA
- Keep a copy for yourself with your important papers
- Carry a copy with you on trips and for hospital admissions.
- You may change your advance directives at any time.
- The directives are valid in other states
- You can still have CPR (cardiopulmonary resuscitation) if your heart stops. A very specific document called a Do Not Resuscitate order (DNR order) must be authorized by your doctor for you not to have CPR. Be sure to discuss this with your doctor.

NOTES: _____

After you get to your unit – be sure to fill in your Social Workers information for your records.

Outpatient Renal Social Worker Information:

Name: _____

Phone number: _____

Dates and Hours they are at my clinic: _____

CHAPTER 5 MEDICATIONS AND COMPLIANCE



Dialysis: Medications

All kidney patients will need to take several medications in addition to whatever medications you may have been taking before being told you had End Stage Renal Disease.

Kidney disease may change how your body reacts to medications, so it is important that you take all of your medications as ordered by the doctor.

As an example, medications that you take once a day should often be taken after dialysis, as some medications can be removed by the dialysis treatment. Your kidney doctor will guide you on when to take your medications.

Just like your diet, your compliance with your medication is key to the success of your treatment. Be sure to ask your kidney doctor about any Over-the-Counter medications as well.

GENERAL MEDICATION TIPS

Kidney Disease often includes a complicated medication schedule. These are some helpful tips about your medication schedule.

- **Know the names of your medications.** Keep a list of your medications with you. Take this list to all of your doctor's appointments and to the hospital with you. It is important to know the medications you are taking at all times.
- When you fill a prescription, bring your list of medications to the pharmacy with you. If the name or appearance of a particular medication is different than what you expected, check with the pharmacist to make sure you have the right drug.
- **Keep your medications in their original bottles.** This prevents confusion.

- **Ask your doctor when to take your medications.** Phosphorus binders usually are taken with meals and calcium and iron supplements between meals. If you're receiving hemodialysis, timing of certain medications may be especially important. Taking blood pressure medication before treatment may make your blood pressure too low.
- **Anticipate the need for refills.** Plan ahead to avoid running out of medication.
- **Tell your doctor if you stop taking any of your medications.** All of the medications your doctor prescribes address specific health problems, such as high blood pressure or infection. If you stop taking a medication without telling your doctor, he or she might think a problem is getting worse. This could result in a new prescription for a stronger medication than you really need.
- **Report any side effects to your doctor.** Common side effects of dialysis medications are nausea, vomiting, diarrhea, itching, rash, dizziness and loss of appetite. If you're uncomfortable, tell your doctor. Your doctor may be able to adjust the dosage of a particular medication or switch you to a different medication may help you feel better.
- **Check with your doctor before taking any over-the-counter (OTC) medications, vitamins or supplements.** Some OTC products can be dangerous for people with poor kidney function. Your doctor may prescribe specific vitamin and mineral supplements designed for people with kidney failure.

Common Medications for dialysis patients

Anti-itching medications

Common medications: Benadryl, Atarax, and Vistaril.

Why you need them: To control or reduce the itching that may occur due to dry skin or a high phosphorus level.

Precautions: If you take antihistamines during hemodialysis, arrange for someone else to drive you home. Antihistamines can cause sleepiness.

Blood thinners

Common medications: Heparin and Coumadin.

Why you need them: To prevent blood clots in the hemodialysis machine, access point and tubing or to keep the peritoneal catheter free of fibrin.

Precautions: If you're injured, tell the emergency team that you're taking blood thinners.

Blood pressure medications

Common medications: Tenormin, Capoten, Cozaar, Lotensin, and clonidine.

Why you need them: To control your blood pressure.

Precautions: If you're receiving hemodialysis, ask your doctor when to take your blood pressure medication. You may need to wait until after your treatment.

Calcium supplements

Common medications: PhosLo, calcium carbonate (Tums, Os-Cal 250, others).

Why you need them: To control the level of calcium in your blood and promote strong bones.

Precautions: To work properly, take calcium supplements between meals. Don't take calcium and iron supplements together.

Erythropoietin

Common medications: Epogen, Procrit, and Aranesp.

Why you need it: To stimulate your bone marrow to produce new red blood cells, which helps prevent anemia.

Iron supplements

Common medications: Feosol, Slow Fe, others.

Why you need them: To increase the amount of iron in your bloodstream, which helps assure the production of red blood cells.

Precautions: Take iron supplements between meals. Don't take iron and calcium supplements together.

Multivitamins

Common medications: Water-soluble multiple vitamins with folic acid (Dialyvite, Nephro-Vite).

Why you need them: To restore vitamins removed by dialysis.

Precautions: Take only the specific vitamin supplements your doctor prescribes.

Phosphate Binders

Common medications: PhosLo, Renagel, Tums, Tums-Ex

Why you need them: To prevent the buildup of phosphorus in your blood. Too much phosphorus draws calcium from your bones and may lead to dangerous calcium deposits in your blood vessels, lungs, eyes and heart.

Precautions: **Take phosphate binders with meals** so that the medication can bind with the phosphorus in your food.

Sedatives

Common medications: Ambien, Xanax.

Why you need them: To manage restlessness, anxiety or difficulty sleeping.

Precautions: To avoid dependency, take sedatives exactly as prescribed.

Stool softeners and laxatives

Common medications: Colace, MiraLax, and Dulcolax.

Why you need them: To manage constipation.

Precautions: Avoid laxatives or enemas containing magnesium or phosphorus. These substances will be absorbed into your bloodstream.

Vitamin D supplements

Common medications: Zemplar, Calcijex, Rocaltrol, Hectorol.

Why you need them: To improve your body's ability to absorb calcium and manage levels of parathyroid hormone.

YOUR QUESTIONS AND NOTES:

CHAPTER SIX PATIENT RESOURCES

You should expect excellent care as a kidney patient. Under the Medicare ESRD/ Benefit –hospitals and centers that provide you services are held to high standards. As a kidney patient you have both rights and responsibilities and a mechanism to make a complaint if you feel that those have not been honored.

In this section we will provide you with some of this basic information as well as other helpful local and national resources for kidney patients.

Rights and Responsibilities

You should always expect high quality medical care that is in your best interest. You are very much a participant in your treatment and should feel that your options are considered by your treatment team. As a participant in your care it becomes your responsibility to speak with the people who care for you often, to know all about your disease and its treatment and to be informed about the diet and medications prescribed for you. You have the right to be provided informed consent prior to any new procedure or treatment - you should always be made to feel comfortable.

You have a responsibility to manage your illness by following the doctor's orders and notify medical staff of any conflicts you may have. You need to ensure that you contact the staff with any area in which you need assistance. It is imperative that you attend all of your medical treatment and arrive on time to allow for your total treatment. Make every effort to know the rules and regulations of your center and how to file a grievance if you ever should need to.

Complaint and Grievance Procedure

Sometimes in chronic care despite everyone's best efforts there can be misunderstandings. This can be any concern you have such as communication, care or treatment. In the kidney community we like to encourage open communication between the persons involved as a first attempt to resolve the conflict. Feel free to involve the center social worker or center director to assist you in this if you feel comfortable. You should never worry that your concern will have negative impact on your care, we are here to help.

Sometimes conflicts can require outside help. As a kidney patient you should be well informed of your right to resolve any complaints you may have and expect a follow up on your grievance. You have the choice to do so anonymously or by giving consent to use your name.

Within the first days of admission at Carolinas HealthCare System- you will be given a copy of a grievance policy. We encourage you to use it if you feel your concerns have gone unanswered.

To file a complaint or grievance you can use the below resources

A complaint regarding hospital care:

1. Carolinas HealthCare System
Customer Care Line
1000 Blythe Boulevard
Charlotte, North Carolina 28232
Website: www.carolinashealthcare.org
Phone: 704-355-8363
Toll Free: 1-866-492-0012

You can also contact our Kidney Nurse Managers Directly:

CMC Main Kidney Dialysis Unit - Trina Deaton 704-355-2412
CMC Main Kidney Nursing floor 10T – Marissa Laster 704-355-6110

CMC Mercy Kidney Dialysis Unit – Teresa Lundy 704-304-5034
CMC Mercy Kidney Nursing floor 3North – Sherri Wolfe 704-304-5391

2. The Joint Commission
One Renaissance Blvd.
Oakbrook Terrace, IL 60181
Website: www.jointcommission.org
Toll Free: 1-800-994-6610
General phone: (630) 792-5000

A complaint regarding your dialysis center that they have been unable to resolve:

1. The Southeastern Kidney Council (ESRD NETWORK 6)
1000 St. Albans Drive, Suite 270
Raleigh, North Carolina 27609
Website: www.esrdnetwork6.org
Toll free: 1-800-524-7139
2. NC Department of health and Human Services
(Your state regulatory agency)
Division of Facility Services
2712 Mail Service Center
Raleigh, NC 27699
Website: www.facility-services.state.nc.us
1-800-624-3004

OTHER IMPORTANT RESOURCES

Local Nephrologists Offices



Southeast Renal Associates

231 W. Morehead Street Suite A
Charlotte, North Carolina 28208
704-333-4217

Metrolina Nephrology Associates

2711 Randolph Road Building 400
Charlotte, North Carolina 28207
704-348-2992

State and National Kidney Information/Organizations

The National Kidney Foundation of North Carolina

5950 Fairview Road #550 Charlotte, NC 28210
Local 704-552-1351
Toll Free: 1-800-356-5362

www.kidneync.org

This is the local chapter of the National Kidney Foundation (NKF). NKF is a voluntary health organization seeking 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. The goals of the NKF include educating the public and healthcare professionals, supporting research, expanding patient services, and shaping health policy. The NKF is also in charge of the Kidney Disease Outcomes Quality Initiative (K/DOQI), which is an improvement program that develops practice guidelines.

Southeastern Kidney Council, Inc.

1000 St. Albans Drive, Suite 270 Raleigh, NC 27609

Toll free patient phone line: 1-800-524-7139

www.esrdnewtork6.org

Currently, there are eighteen ESRD networks that support the federal government in assuring appropriate care for individuals that receive care through dialysis centers or transplant centers certified by Medicare. We are in network 6 (NC, SC, and GA).

The American Kidney Fund

National office: 6110 Executive Boulevard, Suite 1010, Rockville, MD 20852

Toll Free: 1-800-638-8299

www.kidneyfund.org

The American Kidney Fund (AKF) is our nation's #1 source of direct financial assistance to kidney patients, and is a leader in providing education to those with and at risk for kidney disease. The AKF's goal is to provide assistance to needy patients with ESRD and to educate the public about the prevention and treatment of ESRD.

The American Association of Kidney Patients (AAKP)

100 S. Ashley Drive Suite 280, Tampa, Florida 33602

Toll free: 1-800-749-2257

www.aakp.org

AAKP is a nonprofit association, whose mission is to improve the lives of fellow kidney patients and their families through education and support. All AAKP members receive a subscription to RENALIFE, a quarterly magazine for kidney patients.

The HOPE line

1-800-579-1970 TOLL FREE

A telephone based support system designed to help kidney patients and their families. Patients and their family members can speak to knowledgeable, compassionate peers. Access to resources and empowerment for patients is offered. The hope line is run by the Renal Support network. Renal support network: www.rsnhope.org

www.USRDS.org

The US Renal Data System (USRDS) collects, analyzes, and distributes information about the use of dialysis and transplantation to treat kidney failure in the US. The USRDS publishes an Annual Data Report, which characterizes the total population of people being treated for kidney failure. The report also helps identify problems and opportunities for more focused studies of renal research issues.

www.cms.hhs.gov

The Centers for Medicare and Medicaid Services (CMS) have established regulations called the Conditions for Coverage that must be met by all facilities participating in Medicare.

The Medicare End Stage Renal Disease Program is a national health insurance program for people with end stage renal disease. It promotes research to reduce other medical problems associated with kidney failure and to improve the effectiveness of dialysis and transplantation.

www.niddk.nih.gov

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) perform basic and clinical research on many of the most serious diseases affecting the public's health.

See your social worker for even more resources!!!!

CHAPTER SEVEN

WHAT TO EXPECT AT THE OUTPATIENT DIALYSIS UNIT

General Tips

Each outpatient unit or clinic varies from center to center but there are some basic things we can tell you. The dialysis centers are almost like your doctors office. They have offices, treatment areas and a lobby waiting area.

It is always a good idea to visit your clinic in advance of your first treatment to do paperwork and get a comfort level with the location. At this time you can get a tour of the unit and meet the staff who will be providing care for you. Family members and friends are welcome to join you as support, but they will more than likely need to wait in the lobby area as the treatment area is restricted for those receiving treatment. At this visit you will bring all of your documents such as insurance cards and advance directives.

Remember you will be at the clinic for 3-5 hours so be sure to bring the things you will need. You may want to bring a renal friendly snack to eat in the patient waiting area before you go on treatment, as well as things to read or listen to to pass the time. Televisions are provided in the units for you.

Each clinic attempts to keep their temperature at a comfortable level, but because this is different for everyone you may want to dress in comfortable layers, or bring a sweater or light blanket if you tend to get cold. It is important to remember that the staff will need to get to your dialysis access when you are planning your clothing.

The Treatment Team



There are multiple professionals who will be working with you as partners in your care. They are each a member of your treatment team. Together with your input they come up with a plan of care that works to meet your medical, physical, psychosocial and dietary needs. These are some of the team members you should expect to work with on a regular basis:

The Nephrologist – This is your kidney doctor. They have received special training in caring for people with kidney failure. The Nephrologist leads the team in developing your treatment prescription.

The Transplant Surgeon – is a doctor who specializes in the surgery for organ replacement. This surgeon will be a primary decision maker in determining if you are eligible to receive a kidney transplant based on your medical condition.

A Nurse- A key player in the dialysis facility. They may be the manager or supervise your care. The nurse administers medications, follows the doctor’s orders and provides for your medical documentation. For home dialysis treatments they are your primary support person.

A Patient Care Technician – The technician is very visible in the dialysis unit. They monitor your treatment; cannulate your access and assist with placing you on and off of the dialysis machine. Together, with the nurse, these team members provide treatment for you.

The Social Worker – We have spoken about the role of the Social Worker in Chapter four of this handbook in detail, but this person is responsible for assisting you and your family in your psychosocial needs. The social worker is also your contact for financial and community resources that can assist you in making referrals and promoting your wellbeing.

The Dietitian - is the person who works with you in managing your nutritional needs. They will provide initial and continual education and meal suggestions for you that are renal friendly- they can also assist you in obtaining meal supplements like Ensure.

Never forget that **YOU** are the single most important link to the treatment team. Be sure to ask questions and provide input on your care to all of your team members.

YOUR DIALYSIS ASSIGNMENT

CLINIC: _____

ADDRESS: _____

PHONE: _____

SCHEDULE: _____

Final Words

It has been our pleasure to provide care for you while at Carolinas HealthCare System. We hope you have found this handbook helpful. It is a good deal of information to take in. We recommend you use it as a reference as you begin this journey. Please feel free to contact us if you have questions or suggestions on the information we have provided to you or something we may want to include in the future – as always YOU are the most important member of our team.

Many people are at risk for kidney disease. It is estimated that one in nine Americans is in some stage of kidney failure – It is especially important that all kidney patients educate their families on their increased risk for kidney failure.

Be sure to tell each of your family members the importance of asking for their GFR during their annual physical. Have your loved ones make their primary care doctor aware that kidney disease is in the family – early screening and a healthy lifestyle can help prevent kidney failure for those you love. What greater gift for you to pass on as a kidney patient that the knowledge you now have. Please let us know if we can be of help, as always we are here to provide excellent care.

Thank you.