



LIVING WITH KIDNEY DISEASE: A PATIENT MANUAL

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Living With Kidney Disease - A Patient Manual has been prepared for kidney patients and their families to increase their understanding of kidney disease and the different ways in which it may be treated.

Members of The Renal Network, Inc. including patients, family members, board members, and staff prepared this manual. For this edition a special thanks goes to the 2001 Patient Leadership Committee's Special Project Sub-committee for their review and updates.

Table of Contents

FUNCTIONS OF THE KIDNEY	1
TYPES OF KIDNEY FAILURE	2
Acute Kidney Failure	2
Chronic Kidney Disease	2
TREATMENT	3
Dialysis	3
Transplantation	3
Medications	3
Diet	4
HEMODIALYSIS	4
Artificial Kidney	4
Artificial Kidney Reuse	5
High Flux/High Efficiency Dialysis	5
Incenter (Outpatient) Hemodialysis	5
Home Hemodialysis	6
Blood Access	6
Fistula	7
Synthetic Grafts	7
Catheters	7
Subcutaneous Port Access	8
Needles For Blood Access	8
Bruit/Pulse	9
Daily Dialysis	9
Nocturnal Home Hemodialysis	9
PERITONEAL DIALYSIS	10
CAPD: Continuous Ambulatory Peritoneal Dialysis	12
CCPD: Continuous Cycling Peritoneal Dialysis	12
	13
LABORATORY VALUES	13
Levels	13
Blood Levels For Dialysis Patients	15

PROBLEMS ASSOCIATED WITH DIALYSIS	16
Headaches	16
Nausea/Vomiting	16
Fluid Overload	16
Low Blood Pressure (Hemodialysis)	17
Muscle Cramping (Hemodialysis)	17
Anemia	18
High Blood Pressure	19
Infection	19
Bone Disease	20
Itching	21
Nervous Movements	22
Blood Leaks (Hemodialysis)	22
KIDNEY TRANSPLANTATION	22
Donor	23
Kidney Pancreas Transplants	24
Selection Criteria	25
Laboratory Testing (Initial)	26
Surgery And Hospital Stay	27
Rejection	27
Medications	28
Diet	29
Advantages And Disadvantages	29
NUTRITION AND KIDNEY DISEASE	30
Protein, Fat And Carbohydrate	30
Phosphorus (P)	31
Sodium (Na) And Water	31
Potassium (K)	32
Summary	33
KIDNEY FAILURE IN CHILDREN	33
Treatment	34
Hemodialysis	35
Peritoneal Dialysis	35
Transplantation	36
Helping Children And Families Cope With Renal Disease	37

LIVING WITH RENAL DISEASE	38
Psychosocial Aspects	39
Living With The Renal Diet	40
Work And Relaxation Activities	42
Exercise	43
Dialysis While Traveling	45
Impact On Families	46
Intimacy	46
Hepatitis B	48
Aids And The Dialysis Patient	48
FINANCES	50
Medicare And Dialysis	50
Social Security Disability	51
Supplemental Social Security Income (SSI)	51
Veteran Affairs	51
Vocational Rehabilitation	52
PATIENT SERVICE AND INFORMATION	54
Illinois	54
Indiana	57
Kentucky	58
Ohio	63
RESOURCES AVAILABLE TO ALL FOUR STATES	66
Renal Organizations	66
Government or Government-funded Agencies	69
Of General Interest	70
THE RENAL NETWORK, INC. (ESRD Network 9/10)	72
APPENDIX I - Patient Rights And Responsibilities	72
APPENDIX II - Facility Rules And Regulations	78
APPENDIX III - Glossary of Terms	80

FUNCTIONS OF THE KIDNEY

Your kidneys play an important part in keeping your body healthy. They are about as big as a fist and weigh about five or six ounces. They have four important jobs:

1. They remove waste products through urine.
2. They control the amount of water that stays in your body.
3. They maintain the chemical balance of the body.
4. They make hormones These hormones help to control blood pressure, make blood cells, and maintain bones.

As blood flows throughout your body, it picks up body waste. This "dirty" blood enters the kidneys through the renal artery. The kidney filters out the extra fluid and waste products, creating urine. The urine passes through the ureters into the bladder. The clean blood flows back to other parts of your body. This process takes place throughout the life of your kidneys.

Most people are born with two kidneys. If something happens and one kidney doesn't work, the healthy kidney can adequately do the work of two kidneys. If the kidneys are still working, but not as well as possible, they can be treated with medicine and a special diet.

If both kidneys cannot function, waste products and water will build up in the body. This is called uremia. You may have had some of the symptoms of uremia: weakness, fatigue, nausea, vomiting, itching of the skin, muscle cramps, blurred vision, joint aches and pains, and sleep problems. Kidney failure can happen suddenly or over many years.

When both kidneys have stopped working, the patient may be treated with dialysis or kidney transplantation.

TYPES OF KIDNEY FAILURE

Acute Kidney Failure

Acute kidney failure is a sudden and complete loss of kidney function. Many things can cause acute kidney failure, such as accidents, medicines, surgery, low blood pressure from shock, blockages of the bladder or kidney, or serious infections. Without enough blood, the kidneys cannot work. The kidneys may start working again with medical treatment. Patients with acute kidney failure may need dialysis therapy until the kidneys start to work again.

Chronic Kidney Disease

Chronic kidney disease (CKD) or End-stage Renal Disease (ESRD) is a gradual decrease of kidney function in both kidneys over a period of time.

The most common reasons for chronic kidney disease are:

1. Damage to kidneys as a result of diabetes and high blood pressure.
2. Kidney diseases:
 - Polycystic disease – a hereditary disease which causes a slow destruction of the kidneys.
 - Glomerulonephritis – swelling of the filter parts of the kidney (called the glomeruli) that work to remove waste and fluid from the blood.
3. Damage to the kidney from heart disease or drug abuse.
4. Kidney infections.
5. Kidney stones or a blockage present from birth.

With chronic kidney disease, waste builds up in the blood. These wastes must be removed by dialysis treatments. Once the kidneys stop working, they will usually not work again. The patient will need regular dialysis or a kidney transplant. Your doctor will explain to you why your kidneys stopped working.

TREATMENT

Kidney failure is treated with a special diet, medicines, regular dialysis treatments and, possibly, a kidney transplant. Your treatment is based on your special needs. Age, the type of kidney disease, state of health, and your lifestyle are a few of the things that your doctor considers.

Dialysis

Once your kidneys stop working and your doctor decides it is time to start treatment, the two of you will decide which kind of dialysis is best for you. Hemodialysis and peritoneal dialysis are the two kinds of dialysis.

Hemodialysis uses a dialysis machine and an artificial kidney. Peritoneal dialysis uses your abdomen's peritoneal membrane (a thin layer of tissue in your body) as a filter or artificial kidney.

Transplantation

Another way to treat kidney failure is transplantation. Kidneys are transplanted from cadavers (persons who have recently died) or from living donors. You and your doctor will want to consider many factors before deciding whether or not you would like to receive a transplant.

Medications

The medicines you must take will help keep the chemicals in your body in balance between dialysis treatments. These are a few of the common medications that your doctor may prescribe for you:

1. Multi-vitamins: replace vitamins lost during dialysis and add vitamins you may not be getting with the special renal diet.
2. Phosphate binders: control your phosphorous level and help prevent bone disease.
3. Calcium supplements: are used if your body needs calcium and for phosphate binding.

4. Other common medications: iron, high blood pressure medicines, heart stimulants, and stool softeners.
5. Synthetic Erythropoietin: a drug to prevent anemia.

Since your kidneys cannot remove extra amounts of medications, you must take medications as your doctor has told you. Do not take over-the-counter (**OTC**) medications without your doctor's approval.

Diet

All foods you eat contain products that end up as wastes in you blood. Since your kidneys no longer work to remove these wastes, your diet must limit some foods. This will help to limit the build up of these harmful wastes in your blood. You must follow your diet if you want to stay healthy.

HEMODIALYSIS

Hemodialysis uses an artificial kidney (called a dialyzer) to remove wastes and fluids from your blood. Dialysis treatments will typically be needed three times a week for the rest of your life (or until you receive a kidney transplant).

Artificial Kidney

The artificial kidney is man-made. It removes wastes and water from your blood.

The artificial kidney has two compartments. One lets blood flow through it; the other lets solution called dialysate or bath flow through it. A thin material separates the compartments. The blood and dialysate flow in opposite directions. Wastes leave your blood and go into the dialysate.

The used dialysate, with the wastes in it, is drained out of the kidney machine. Your clean blood is returned to your body. Blood goes through the artificial kidney at an average rate of ½ pint per minute.

This means all the blood in your body goes through the artificial kidney two to four times every hour.

In the dialysis unit, you will see different kinds of artificial kidneys. Your doctor will decide which one is best for you. He or she will also decide the number of hours each treatment will last by a specific prescription especially written to ensure that your treatments are designed to best meet your needs.

Artificial Kidney Reuse

Using the same artificial kidney (dialyzer) for more than one dialysis treatment is called reuse. The kidney is rinsed free of blood, chemically cleaned and disinfected after each treatment. The residual volume is measured after each cleaning. A new dialyzer replaces the used artificial kidney when the residual volume is judged to be inadequate.

Facilities that reuse artificial kidneys must follow quality assurance standards. This ensures that the artificial kidneys are cleaned properly and given to the appropriate patient at his or her next treatment. Each patient is assigned his or her own artificial kidney for reuse. **Reused artificial kidneys (dialyzers) should never be switched between patients.**

High Flux/High Efficiency Dialysis

High flux/high efficiency dialysis uses a special dialyzer that allows more molecules to be removed than with common dialysis. With a larger dialyzer, a special kidney machine, and individually prescribed treatments, dialysis times may be shortened and patient symptoms decreased. In high flux/high efficiency dialysis, the blood and dialysate pass through the dialyzer at a faster rate. As with all therapy, your doctor will help decide if you are a candidate.

Incenter (Outpatient) Hemodialysis

Incenter hemodialysis is done in a facility by the staff. The dialysis center schedules dialysis treatment days and times according to the

availability of openings in the unit. Every effort is made to schedule your dialysis sessions according to your specific needs. Some units offer an evening shift for patients who work during the day.

Home Hemodialysis

Home hemodialysis is done in the home by a trained patient and partner. Dialysis treatments done at home can allow a more flexible treatment schedule. Some types of treatment can be done at night when the patient is sleeping. If you are interested in home dialysis, the unit staff will discuss with you and your partner all the requirements and responsibilities needed.

You and your partner must be trained for home dialysis. The length of training will vary with each patient, partner, and dialysis unit. Training sessions usually last several hours, two or three times weekly for six to eight weeks. Through educational materials and actual experience, you and your partner will gain knowledge necessary to dialyze safely at home.

Blood Access

Ideally, six months to a year before beginning hemodialysis, a blood access will be surgically created in your arm or leg. Your veins must allow a large flow of blood to be pumped into the artificial kidney and the blood access helps them do this. Care for your blood access is very important. The doctor and nursing staff will give you instructions on access care. Ask questions when you need more information or reassurance.

The types of blood access are:

1. AV fistulas
2. synthetic grafts or conduits
3. tunneled catheters
4. subcutaneous ports
5. non-tunneled catheters

AV fistulas are the preferred blood access but circumstances may arise that necessitate the use of other types of blood access. Your doctor will help you understand what blood access will work for you.

It is important to learn self-care for your blood access as this will help keep your access healthy.

Fistula

An AV fistula requires a surgical procedure that connects an artery and a vein. It may be created in either your forearm or upper arm. This procedure allows the vein to increase in size and the wall to thicken because of the increased blood flow. After a few weeks, the fistula has matured enough to allow the insertion of needles for dialysis. This is considered a permanent blood access.

Synthetic Grafts

Another type of blood access is a synthetic graft or conduit. It requires surgery and is considered a permanent blood access.

Many grafts are placed in a horseshoe shape with one end attached to an artery and the other to a vein. The graft is placed under the skin and may be inserted in the forearm, upper arm, or leg. After a few weeks, needles are inserted through the skin into the graft for dialysis.

Catheters

The catheter is a special plastic-like tube inserted through the skin most frequently into a large vein in the neck area. The skin at the neck area is numbed with a medicine and the doctor inserts the catheter through the skin usually while you are awake. This can be done as an outpatient.

A sterile dressing is placed at the insertion site. The doctor or nurse will give you instructions on catheter care. It is important to keep the dressing dry and avoid tugging at the site. This may help prevent an infection.

To start dialysis, the catheter caps are removed and the bloodlines from the artificial kidney machine are connected to the catheter. One side takes blood from your body to the machine, while the other side returns the cleaned blood back to you.

The catheter is usually considered a temporary blood access. However, some types of catheters are considered to be permanent. They may be referred to as Permcaths. These catheters are inserted the same way except they are tunneled underneath the skin to form a barrier against germs.

Both types of catheters are more prone to infection than fistulas and grafts.

Subcutaneous Port Access

The subcutaneous port access is a valve inserted under the skin in the chest area. It requires the insertion of two needles that open the valve to access the blood for dialysis. The same sites are used every treatment. When the needles are removed, the valve closes automatically, preventing bleeding through the skin. These are also known as “buttonholes.” These ports are usually temporary while the patient is waiting for a permanent access.

Needles For Blood Access

For each dialysis treatment, sterile needles are inserted through the skin into the fistula or graft. This is called cannulation. One needle pulls the blood from your access, while the other needle returns the cleaned blood to you. The needles are large and may look scary. The needles need to be large in order to get good blood flows for the dialysis treatment because the better the blood flow, the better you will be dialyzed.

The amount of discomfort or pain felt from the needle insertion, or “stick,” will vary from person to person. The dialysis staff is trained to insert the needles. Your unit may offer various methods to minimize the amount of discomfort you feel. Tell your concerns to the staff. They may be able to make the needle insertions more comfortable for you. ***You may even learn to do this yourself!*** Ask your physician or nurse for more information if you are interested in learning how to stick yourself.

Bruit/Pulse

The fistula and graft accesses should have a rushing sound and/or a super pulse. The rushing sound is called a bruit (pronounced “brew-ee”). The super pulse which you can feel is called a “thrill.” This bruit, when listened to with a stethoscope, is an indication to you that your access is working. You can also hear and feel your thrill. The nurse will teach you how to listen and feel for the bruit and thrill. The absence of the bruit and/or pulse may mean the blood flow has stopped. Notify your doctor or unit immediately if this happens.

Daily Dialysis

Most hemodialysis patients undergo dialysis three times per week for a period of three to four hours. Recently, daily nocturnal dialysis (lasting from eight to ten hours) has been offered at some centers. Both long-nocturnal and short-daytime dialysis are currently in use. Research suggests that daily dialysis may improve the quality of your dialysis treatment as well as quality of life. Since patients on daily dialysis are better dialyzed, they should feel better than patients on dialysis three times per week. Daily dialysis is only offered at a few facilities at the present time. If you are interested, ask your dialysis staff if and where it is offered in your area.

Nocturnal Home Hemodialysis

Nocturnal home hemodialysis is hemodialysis therapy performed at home, at night while you sleep. Patients dialyze between seven to eight hours every other night. Nocturnal home patients dialyze at slower blood flow rates and for longer periods of time so they do not experience the physical ups and downs that regular hemodialysis or conventional home hemodialysis patients do, such as low blood pressure and cramping.

The additional time on dialysis allows the patient to have improved fluid and waste removal, and may be able to decrease or discontinue some medications. Most importantly it allows the patient to feel better.

Remote Computer Monitoring allows patients without partners to be on nocturnal home hemodialysis. A person (observer) is able to monitor and observe all of the alarms and readings a patient is seeing on his/her machine at home. The observer is stationed at a remote site (clinic). This measure provides the patient with a long distance partner and additional safety and security while they sleep.

Incenter Nocturnal Dialysis is available for patients needing and wanting the benefits of nocturnal home hemodialysis but unwilling or unable to dialyze at home. Incenter nocturnal hemodialysis patients dialyze in the clinic in a bed for eight hours, three nights a week.

PERITONEAL DIALYSIS

Peritoneal dialysis is the oldest method of removing waste from the body.

The peritoneal membrane surrounds the intestine and other organs in the abdominal cavity. It is used as a filter or artificial kidney in peritoneal dialysis.

With peritoneal dialysis, the patient drains a specially prepared sterile solution (dialysate) into the body's peritoneal cavity through a catheter which has been surgically implanted in the patient. The dialysate bathes the peritoneal membrane. Waste products and excess water flow out of the blood, through the peritoneal membrane, and into the dialysate. The patient then drains the dialysate and waste products from the abdomen into an empty solution bag. This process is called an exchange.

The choice between hemodialysis and peritoneal dialysis is a decision which must be made by you and your physician. Not all dialysis patients will benefit from peritoneal treatment. Your doctor can explain you are a candidate for peritoneal treatment. If you are, you must decide if peritoneal treatment is for you.

Some patients feel there are advantages to peritoneal dialysis over hemodialysis.

In peritoneal dialysis, the peritoneal cavity is full of dialysate fluid, which is changed throughout the day when the patient makes exchanges. This causes the dialysis, or cleansing process, to continue throughout the day, every day. Waste products are constantly being pulled from the system into the dialysis fluid. Poisons don't build up in the blood between dialysis treatments. Because it is a continuous treatment the peritoneal dialysis patient may have fewer dietary and fluid restrictions than the hemodialysis patient. However, just like the hemodialysis patient, it is important that the peritoneal dialysis patient limit salt and salty foods because these cause the body to retain water. Your physician or renal dietitian can explain the peritoneal dialysis diet to you.

Since the patient performs the treatments, it is not necessary to visit the dialysis center three times a week. This allows greater freedom in scheduling day-to-day activities or working. Many peritoneal dialysis patients feel they are freer to travel. They simply take their supplies with them, or make arrangements to have their supplies shipped to wherever they stay. They do, however, need to arrange for transient dialysis in case of emergencies.

There are disadvantages to peritoneal dialysis, as well. Some individuals get tired of making an average of four exchanges per day. Some may skip exchanges, or do them only when it's convenient for them. This can cause serious complications. It is important for the peritoneal dialysis patient to perform the number of exchanges each day as prescribed by the doctor. Fewer exchanges mean the body is not being cleansed adequately.

Some patients refer to the presence of the permanent catheter in their abdomen a disadvantage. They think it does not look good and negatively impacts their body image. Weight gain can also occur since some of the stronger dialysate prescriptions contain more calories.

The major drawback to peritoneal dialysis is infection of the peritoneal cavity, called peritonitis. This infection can cause severe physical discomfort and hospitalization may be required. You can help prevent peritonitis by careful attention to detail during the dialysis process.

Infections may also develop at the catheter exit site. Daily cleaning and dressing of the exit site can help keep this area free from infection.

Several techniques of peritoneal dialysis have been developed. Your doctor will help you decide which method of peritoneal dialysis would best suit your health and lifestyle. The doctor will prescribe the number of times per day you are to do the exchanges.

Two different types of peritoneal dialysis are available: CAPD and CCPD.

CAPD: Continuous Ambulatory Peritoneal Dialysis

Continuous Ambulatory Peritoneal Dialysis (CAPD) uses liquid called dialysate, which is contained in prepared sterile bags. The patient attaches tubing in the shape of a Y with two bags attached to his/her catheter. One of the bags is empty; the other contains dialysate. The empty bag is used to drain off used dialysate fluid and waste products. Then the bag containing the fluid is drained into the patient's peritoneum and left in for three to six hours while the dialysis process takes place. Once the clean fluid has drained into the patient, he/she clamps or caps off the catheter. The bags and Y-tubing are removed and discarded. The patient repeats this process three to five times a day, every day.

This exchange process is completed three to five times per day, every day. At night, the CAPD patient allows the dialysate to remain in the peritoneal cavity for up to eight hours before exchanging bags.

Several companies now have disconnect or "bagless" CAPD systems. This disconnect system has several advantages. The patient no longer wears the tubing and bag used for the exchange. Disconnect systems may decrease peritonitis infection rates.

CCPD: Continuous Cycling Peritoneal Dialysis

With Continuous Cycling Peritoneal Dialysis (CCPD), exchanges are performed while the patient sleeps. A machine, called a cycler, does four functions: it warms, fills, drains, and weighs the solution at timed

intervals throughout the night. This process allows some patients to be free of exchanges throughout the daytime hours.

Most cycler patients, however, perform a minimum of one mid-day exchange in order to achieve adequate dialysis. At least 30% of required clearance levels can be achieved with a mid-day exchange.

LABORATORY VALUES

Levels

Blood samples will be taken from you each month to check the amount of wastes in your blood. You should know most of the waste products by name, what part they play in your kidney disease and its treatment, and what your normal levels should be.

Creatinine (CR) – Creatinine is a waste product of muscle breakdown. Healthy kidneys remove creatinine from the blood. With kidney failure, creatinine builds in the blood until it is removed by dialysis. A high level of creatinine may cause itching and damage to nerve endings. High creatinine levels may cause numbness and tingling of toes.

Blood Urea Nitrogen (BUN) – The BUN is a waste product of protein breakdown. The more protein you eat, the more urea is produced. Your BUN will go up if you eat large amounts of protein. Eating smaller quantities of higher quality protein will provide the adequate nutrition you need while cutting down on protein waste build-up. Other factors can also raise BUN such as infection.

Potassium (K) – Potassium regulates muscle action. The heart is a muscle which is sensitive to potassium. Too much or too little potassium can cause the heart to stop. Your dietitian will give you a list of high potassium foods. You should read this list with the dietitian to be sure you understand it. Salt substitutes are to be avoided because they are made from potassium.

Chloride (Cl) – Chloride is necessary for nerves and muscle to work together.

Sodium (Na) – Sodium is necessary for maintaining the body's cells and water. The higher the level of sodium in the blood, the more water is retained by the body. Too much sodium will make you thirsty, have more swelling (called edema), and cause shortness of breath. Extra sodium and water in your body may cause your blood pressure to rise.

Calcium (Ca) – Calcium is stored in your bones and is needed to keep them strong. If your calcium level is too low, your body will "steal" calcium from your bones, causing them to be weak. High calcium levels may be a sign of a problem but are not generally associated with dialysis.

Phosphorus (P) – Phosphorus is made by protein breakdown and is also found in many foods. It is a chemical that works with calcium to keep bones strong. Often a high phosphorus level will cause a low calcium level and vice versa. Dialysis alone may not be enough to lower the phosphorus level in the blood. A medicine called a phosphorus binder may be taken with meals to control the phosphorus level. Constantly high phosphorus levels lead to bone disease, itching, and other skin problems.

Alkaline Phosphatase (Alk. Phos.) – This is an enzyme that comes from the liver and bones. High levels may indicate liver or bone disease.

Albumin & Total Protein – These levels are measured because they relate to nutritional or protein status.

Glucose – Glucose, or blood sugar, is necessary for energy and maintaining normal body tissue.

Hematocrit (HCT or Crit) – the hematocrit is the amount of red blood cells compared to water (plasma) in the blood. Chronic renal failure causes the hematocrit to go down because the red blood cells do not live as long, and the kidneys no longer make the hormone that helps to make red blood cells. If your hematocrit becomes too low, a blood transfusion may be necessary. Most patients receive synthetic erythropoietin to help with this problem.

Hemoglobin (HGB) - is a protein, carried by red blood cells, which transports oxygen through the body.

Blood Levels For Dialysis Patients

The blood levels listed below are provided for your reference and are to be used as guidelines. Blood levels may vary based upon individual differences or depending on the unit's lab procedures. Talk to your doctor, nurse, and dietitian about your blood levels.

Blood Urea Nitrogen (BUN)	60-110 mg/dl
Creatinine	8.0-20.0 mg/dl
Potassium (K)	3.5-5.0 mEq/L
Calcium (Ca)	8.5-10.5 mg/dl
Blood Sugar (fasting)	60-100 mg/dl
Blood Sugar	less than 140 mg/dl
Alkaline Phosphatase	25-100 units/L
Phosphorus (P)	2.3-4.7 mg/dl
Sodium (Na)	135-145 mEq/L
Albumin	3.8-5.5 gm/dl
Total Protein	6.0-8.0 gm/dl
Hematocrit (HCT or crit)	33%-36%
Hemoglobin (Hgb)	11 - 12

PROBLEMS ASSOCIATED WITH DIALYSIS

While you are on dialysis, you or other patients near you may experience problems. Some of the more common problems are discussed here. They include the following:

Headaches

Headaches are a common symptom during dialysis although the cause is largely unknown. Acetaminophen (Tylenol) may be given during dialysis as treatment. Decreasing the sodium level on your machine during dialysis may also be helpful.

Nausea/Vomiting

Nausea and/or vomiting may occur during routine dialysis treatments. Most cases are probably due to hypotension (low blood pressure). Prevention and treatment of hypotension is important. If nausea and/or vomiting persist, treatment may include giving medication for nausea and vomiting.

Fluid Overload

Because you probably do not urinate as much as you once did, fluid may build up in your system between dialysis treatments. Dialysis removes the excess fluid from your blood.

Acceptable weight gains between treatments vary from patient to patient. However, you play an important part in controlling your weight gain. You cannot drink as much as you once did. Your dialysis staff will tell you how much fluid you should drink each day. If you drink too much, you may become quite ill. Some problems include increased blood pressure, swelling (edema) of your arms/hands, legs/feet, and/or face, and shortness of breath. In severe cases, you may get congestive heart failure and fluid may build up in your lungs requiring emergency dialysis and possibly hospitalization.

Low Blood Pressure (Hemodialysis)

Low blood pressure, or hypotension, may occur at any time during your dialysis treatment. Hypotension most often occurs at the end of your treatment. It may be caused by a variety of problems. However, it happens most often when you have reached or are below your desired dry weight. You may experience some of these symptoms: blurred vision, light-headedness, dizziness, hot flashes, muscle cramping, nausea, and vomiting. Your dialysis staff will most likely put your feet up to increase blood flow to your head, then give you some saline or other fluid to replace the volume in your blood. They may also change the settings on your machine to avoid taking off any more fluid.

In general, most patients have only moderate changes in their blood pressure. To help maintain adequate blood pressure, the staff will frequently take your blood pressure, adjust the dialysis rate (how the machine removes fluid from your blood), and give you saline or other medications, as necessary.

Muscle Cramping (Hemodialysis)

Muscle cramping of the hands, feet, and legs is fairly common on hemodialysis. The cause of muscle cramping is unknown. However, three conditions that seem to increase cramping are: 1) hypotension; 2) the patient being below dry weight; and 3) use of low sodium dialysis solution.

Muscle cramps are more commonly associated with low blood pressure. However, some cramping continues even after a normal blood pressure is obtained. In fact, muscle cramping can occur even without a fall in blood pressure.

Muscle cramps also can occur when you are below your dry weight. The severe muscle cramping experienced near the end of the dialysis treatment and persisting for a time after dialysis often is due to dehydration.

If you are cramping, let the dialysis staff know. Treatment for cramping vary from unit to unit. When you are cramping and have low blood pressure, the staff may give normal saline. This will increase the fluid in your body and muscle cramping may be relieved. In addition, hypertonic saline or glucose may be given. Heat and massage for the cramping muscle can ease the pain. Ask your doctor and staff what treatments are available to you. For chronic leg cramps they may prescribe Quinine, Carnitine, or another medication.

To avoid cramping, be sure to stick to your fluid and sodium restrictions every day. Maintaining a balance between your dry weight and fluid gains and avoiding foods that make you thirsty and give rise to higher fluid intake are your best defense against muscle cramping.

Also try a program of gentle stretching and toning exercises targeted at the muscles which may tend to cramp during dialysis. Before starting any exercise program, consult with your doctor.

Anemia

Anemia is weak or “low” blood. In dialysis patients, the common causes of weak blood are:

- Not enough red blood cells. Healthy kidneys produce a hormone called erythropoietin. This hormone helps the bone marrow make more red blood cells. For dialysis patients, the kidneys no longer make as much of this hormone.
- Not enough iron. Although you may be eating good amounts of iron, your system may not absorb enough of it.
- Red blood cells don’t live as long due to the toxins in your blood.
- Some blood is lost with every dialysis treatment.

Some signs of anemia in dialysis patients are tiredness, paleness, decreased ability to exercise and a feeling of coldness. If anemia becomes severe, you may experience shortness of breath, become easily tired, or have chest pains (angina).

To help prevent anemia, you must eat a balanced diet. Your doctor may prescribe a vitamin-mineral supplement that includes iron and folic acid to help keep your blood as strong as possible.

Your doctor may prescribe **Epogen (EPO)**, a synthetic erythropoietin. This is a medication that can correct anemia by raising red blood cell levels. Before EPO was approved in 1989, blood transfusions were often used to treat anemia. For patients who do not respond to EPO or whose anemia is severe, a blood transfusion still may be required. It is very important for most people to take iron when on EPO, because iron is necessary for the EPO to work. You may be given iron as a pill, or in your machine during your dialysis treatment. Many patients on EPO say they feel more energetic, less cold and fatigued, and they may note an increase in appetite. Because of this improved appetite, you may also have an increase in potassium and blood pressure. Ask your doctor about the advantages and disadvantages of EPO for you.

High Blood Pressure

If you drink too much fluid and eat foods with too much salt, you may develop high blood pressure (hypertension). Dialysis will be adjusted to take off the extra fluid and salt. The best cure for this type of high blood pressure is prevention. Watch your fluid and salt intake carefully.

Some patients develop high blood pressure during hemodialysis. As fluid is removed, the heart pumps more efficiently. This may cause a rise in blood pressure. If the rise is severe, your doctor may prescribe medication.

Infection

Dialysis patients are at greater risk for infection because their white blood cells are slow to attack the infectious bacteria or viruses. Dialysis patients seem to more easily catch a cold, flu or whatever else is going around.

Also, patients run the risk of infection at the access sites. That is why the staff will thoroughly explain how important it is for you to be careful when touching an open site or other wound.

If you get an infection, a blood test will be performed to determine which type of infection you have and what medicine you need. Often, a general antibiotic medication is prescribed immediately.

In general, dialysis patients are less able to resist infection. It may now be necessary to avoid exposure to others who are ill, to avoid crowds during flu epidemics and cold season, and to boost your immune system by getting a flu shot or pneumonia vaccine. Also, you need to eat properly and get plenty of rest. These general guidelines should help you avoid getting sick.

Bone Disease

Kidney patients often get bone disease because the body's calcium and phosphorus are not in balance. When the phosphorus level is too high, the calcium level may be too low. When this happens, your body pulls calcium out of your bones, causing your bones to become weak.

To keep your phosphorus level normal, you may need to limit the amount of phosphorus that you eat. Some foods high in phosphorus are dairy products, meats, nuts, whole grain breads and cereals, and some soft drinks (colas). Also, you may need to take medicine (called phosphate binders) that bind with phosphorus to lower its absorption in your body. Some types of phosphate binders must be taken during the meal and others must be taken immediately after you finish a meal. It is important to take the phosphate binder exactly as your dietitian or doctor tells you.

Bone problems are easier to prevent than to cure. Take time to learn about your diet and keep your calcium and phosphorus at acceptable levels. Know your blood levels and take all of your medications according to the doctor's order. By learning about these aspects of your treatment, you can make good choices and help prevent bone disease.

Itching

Itching is a common complaint among dialysis patients, although not all patients are troubled by it. While no one knows the exact cause(s), itching may be brought about by:

- Dry skin
- High Phosphorus Levels
- Allergic Reactions
- High Blood Levels of Parathyroid Hormone (PTH)

Among dialysis patients, itching is most often caused by dry skin. It occurs because the skin is not making enough oil to moisturize itself. It is important to keep the skin clean and moisturized. It may help to use a moisturizing soap when you bathe, to apply unscented body oil, and to use body lotions.

Another factor related to itching may be your diet. In your blood, phosphorus combines with calcium to form phosphorus-calcium products. Some of these phosphorus-calcium products are excreted through your skin and this may cause you to itch. The best way to avoid this is to keep your phosphorus level normal. Maintain your dialysis diet and take phosphorus binders with each meal or large snack as directed.

Allergic reactions to the dialyzer, blood tubing or medications may occur during the hemodialysis treatment. Keep a record of how you feel during your treatment. Maintaining such a log may help you to pinpoint the causes of your itching. Discuss how you feel with your doctor or nurse. There are medications available that may help you.

A blood test can tell if you have a high level of parathyroid hormone (PTH). PTH levels are often elevated in dialysis patients due mainly to a decreased calcium level and an increased phosphorus level. This condition stimulates the parathyroid gland to secrete excessive hormones. This can lead to bone disease. Symptoms may or may not occur. If symptoms appear, the bone disease may already be severe.

The most common symptoms are bone pain, joint discomfort and itching. Treatment includes controlling calcium and phosphorus levels with phosphate binders and taking Vitamin D.

Nervous Movements

Some kidney patients may experience a slowing of nerve function, called neuropathy. Symptoms include restless legs, tingling or painful burning of the feet, and weakness of the legs and arms. It is often described as an irritating sensation, especially in the calf muscles that can be relieved only by moving the legs and feet. It often happens at bedtime or when the patient is resting.

The cause is not known. There is no cure. However, more dialysis may prevent the condition from becoming worse. Your doctor may increase your dialysis time or increase the type and size of the artificial kidney so your treatment is more effective. Some medications may be helpful.

Blood Leaks (Hemodialysis)

Although rare, blood leaks at the needle sites may occur or a blood line can actually separate or pull apart. All needles and blood tubing should be securely taped to help prevent this. Sometimes a blood leak may occur inside the dialyzer itself. If any of these blood leaks should happen, the staff will evaluate the amount of blood loss. The doctor may be notified if the loss is substantial.

KIDNEY TRANSPLANTATION

Kidney transplantation is a major treatment option for many patients with kidney failure. It involves an operation in which a kidney is removed from a donor and is placed into a patient with kidney failure.

Kidneys for transplantation come from three sources:

1. Living related family donors.
2. Living, non-related donors.

3. Individuals that die and, through their own choice or their families, donate their kidneys for transplantation. These donors are called cadaver or non-living donors.

Most doctors agree that kidney transplants from a closely related living donor offer the best results. However, less than half of kidneys donated are from family members. Generally speaking, there is a 95% chance that a kidney transplant from a living-donor kidney will be functioning two years after the time of transplant. A cadaver transplant will usually continue to function in 85% of patients after the one-year mark.

Nonetheless, both living donor and cadaver transplants can function for many years. A successful transplant means that the kidney function is normal and that dialysis is not required. Discuss this option and its cost with your doctor, nurses, or social worker.

Donor

Over 20 percent of the kidney transplants performed are from living related donors, such as a mother, father, sister or brother, or occasionally an adult child of a patient. The potential donors undergo a rigid screening and evaluation. This helps to determine compatibility and any potential risks. Among those individuals who have donated kidneys, serious complications are rare.

There are several ways of removing a kidney from a volunteer donor. The surgery can be through an incision on the side or in the front of the abdomen. A simple nephrectomy performed for transplant purposes requires removal of the kidney and a section of the attached ureter. The surgical procedure can take up to three hours, depending on the type of nephrectomy being performed.

Laparoscopic nephrectomy is a form of minimally invasive surgery. Although laparoscopic surgery has been available for 10 - 15 years, it has only recently been used to remove kidneys from a living donor. With this type of surgery the incision is smaller and the hospital stay can be as little as two to three days with a recovery time that is reduced to an average of two to three weeks. The donor's remaining kidney has extreme reserve power. Most often normal function occurs

very soon after surgery. The donor does run a slightly increased risk of kidney failure if injury, tumors, or blood vessel disease occurs. Life expectancy is no different from someone with two kidneys, and the quality of life is unchanged. Donors usually have no restrictions of any kind after recovery from surgery. Hopefully such positive results will encourage more individuals, whether related or non-related, to become donors.

If the kidney patient does not have a suitable living donor to donate a kidney, the kidney may be obtained from a non-living donor. A non-living or cadaver donor is an individual who has donated his/her kidneys after death. The kidneys are maintained on a special machine or packed on ice until a suitable recipient is located.

In May of 1999, the United Network for Organ Sharing (UNOS) reported that there were over 43,000 individuals on the list awaiting a kidney transplant. In 1998, only 8,939 individuals received a cadaver kidney transplant. Generally the waiting period for a cadaver kidney depends upon the availability of a suitable kidney and the health of the recipient. The average waiting period is six to 12 months but can be as short as two to three weeks.

Kidney Pancreas Transplants

Many patients with diabetes mellitus will eventually experience complications. Poor kidney function is one of them. In fact, diabetes is one of the leading causes of chronic kidney failure. For patients with diabetes who also have reached the dialysis stage, a successful kidney transplant can give them a better quality of life and improved rate of survival. A kidney transplant, however, does not stop the progress of the diabetes. Kidney transplant patients with diabetes will continue to suffer symptoms, such as, impaired vision and circulatory problems. That is because diabetes involves the pancreas as well as the kidney. Simultaneous kidney-pancreas transplantation is recommended as a means to both replace kidneys damaged by diabetes and to provide a healthy pancreas capable of normal insulin production.

Selection Criteria

To determine if you are a good candidate to receive a transplant, your doctor will consider many factors.

Disease: Your kidneys must be unable to support life.

Associated Illness: You must not have an illness or disease that would affect the success of the transplant.

Age: Many older patients have illnesses that might hurt the success of the transplant, so age may be a consideration. In the younger patient (children), body size and emotional maturity are major considerations.

Urinary Tract Evaluation: You will have a complete examination of your urologic system to find any problem which might complicate the transplant. Surgical corrections may be required prior to the actual transplant.

Psychological Preparation: You should seriously consider whether or not you want a transplant. Talk with your doctors, nurses, social workers, family, the transplant center, your potential living donor, and your family members. Ask questions. Know what is expected of you after a transplant. Many transplant programs have long lists of transplant patients who are willing to discuss all aspects of transplantation with you. Potential transplant patients need a sense of commitment to the transplant process. This means being prepared to make the necessary sacrifices in time and health maintenance, including diet and regular exercise, both before and after the transplant.

Compliance: Poor medical compliance is a major risk factor for morbidity and mortality both before and after transplantation. After transplantation compliance is critical to proper functioning of the kidney. It will be helpful if you exercise regularly, monitor your blood pressure, take all of your immunosuppressive medications, stop smoking, maintain a good diet, have your blood work completed as required, attend clinic as scheduled, and avoid drinking alcohol.

Financial Responsibility: Patients and their families have many concerns regarding financial responsibilities related to transplant surgery and maintenance.

It is important for the patient to understand Medicare coverage for kidney transplant especially if the patient has commercial insurance through an employer group health plan. Finding out what is covered, how long the coverage lasts and how other expenses will be met are critical to the transplant process. The unit social worker or transplant center financial adviser will be able to help you obtain the most accurate information. Keep your health insurance information up-to-date and make sure to let the transplant center know of any changes.

It is important for patients and their families to make a long-term commitment to managing the financial responsibilities of a kidney transplant. There are state programs as well as patient assistance programs offered by drug manufacturers that offer assistance. There are also transplant associations and foundations that offer resources to patients.

The key is to learn about these options early and establish eligibility in a timely manner.

Laboratory Testing (Initial)

Tissue Typing: One of the most important factors affecting kidney transplantation is tissue matching. Whether you receive a cadaver or living donor kidney, the transplant center works to find the best possible match for you. Blood samples are taken from both you and potential donors for this test.

Miscellaneous Lab Studies: These include a complete blood count, blood typing, urinalysis and culture, liver function studies, EKG, and chest X-ray. Additional studies may include nerve conduction studies, kidney angiography, and tissue biopsy of the kidney. While you are on dialysis, blood is taken and analyzed to follow your progress. You should report any problems to your doctor so these can be treated promptly.

For some patients, surgery might be necessary before transplantation. Examples include removal of kidneys, spleen, appendix, parathyroid glands, or gall bladder. Every effort is made to help you be as healthy as possible before transplantation.

Surgery And Hospital Stay

The transplant operation usually takes two to four hours. You will go to the recovery room after surgery to wake up and then be transferred to a special unit.

The transplanted kidney is placed in the lower part of your abdomen, and not in the position of your original kidney.

For the transplanted patient, the usual stay is about one to three weeks after the transplant. During this period, the doctors and nurses will watch you very closely and adjust your medicines to prevent and/or treat complications.

After you are discharged from the hospital you will need to take your medicine, follow your diet, and visit the transplant clinic. Do not visit crowded areas such as shopping centers or movies, and avoid anyone with any kind of infection. You are encouraged to return to meaningful activities and employment as soon as the doctor gives the OK.

Rejection

Your body recognizes and destroys foreign substances. This remarkable ability is called immunity. When harmful bacteria or other foreign substances enter the body, certain tissues make a protein antibody, which helps destroy the foreign substance.

Your body sees the transplanted kidney as a foreign body. It treats the new kidney as it would any other foreign substance. When the immune system attacks the transplanted kidney, it is called rejection. The types of rejection are:

Hyperacute Rejection: This is very rare and occurs within minutes or hours after transplantation. The rejection is permanent. The rejected kidney is removed and you return to dialysis.

Acute Rejection: This usually occurs after the person has recovered from surgery. Acute rejection is the most common form of rejection and occurs in 50 to 60 percent of cadaver donor transplants and in 10 to 15 percent of living donor transplants. Acute rejection can be reversed in more than 80 percent of cases.

Chronic Rejection: This occurs at any time. Your body has a continuous tendency to reject the new kidney. This rejection does not happen to every patient.

If your body totally rejects the transplanted kidney in the first few months, or if the new kidney does not function, the transplanted kidney may need to be surgically removed from your body. You will then return to dialysis and, if you choose, wait for another kidney. Late failure of the transplant may not require its removal.

Rejection is a common problem in transplantation. The medicines that help prevent rejections are called immunosuppressive or anti-rejection medications. You will take these medicines as long as your new kidney functions. Medicines that help prevent rejection make you prone to infection, because there is a weakening of the body's immune system. Most of these infections can be treated. If an infection threatens your life, your anti-rejection drugs may be stopped. This usually will cause the transplanted kidney to fail. You will need to return to dialysis treatments.

Medications

After transplantation, you will need to take immunosuppressive or anti-rejection medicines. As with many drugs, these anti-rejection drugs have side effects. Some of these may be:

1. Increase in infections
2. Weight gain
3. Acne
4. Fluid retention

5. Irritation of stomach
6. Bone problems
7. High blood pressure
8. Increased blood sugars
9. Increased cholesterol (or lipid) levels

These side effects do not occur in all patients. They are mentioned for your information.

You will also be given antacids, stool softeners, and other medicine as needed. Your transplant doctor will set the dosage you need to take.

Diet

After the transplant, it will be necessary to limit fat and cholesterol in the diet because some of the anti-rejection medicines can increase blood sugar levels. This could also necessitate following a diabetic diet and/or using insulin.

The anti-rejection medicines may cause fluid retention and high blood pressure which may need to be controlled with a low sodium diet, as well as medication. A registered dietitian, who specifically works in the transplant area, will tailor the diet to the transplant recipient's needs.

Advantages And Disadvantages

The advantages of transplants are improved physical and mental health, no more dialysis treatments, and a better quality of life.

The disadvantages include frequent visits to see a doctor, chance of rejection, and low tolerance to infection. Ask your doctor if you are a suitable candidate for transplantation. Please feel free to contact transplant centers for any information concerning transplantation.

Your doctor, nurses, and social workers have the telephone numbers of transplant hospitals in your area if you wish to speak with the staff in these hospitals.

NUTRITION AND KIDNEY DISEASE

As the body uses nutrients from the foods we eat, wastes are made. Many of these wastes are carried by the blood to the kidneys so they can be removed from the blood. When the kidneys stop working, they no longer remove these wastes. Wastes and fluids will then build up in the blood.

The build up of wastes and fluids will make the person with kidney failure feel ill. This is why people with kidney failure need to change their eating habits. By eating controlled amounts of foods and fluids, you can have better health. You will need to monitor your protein intake and limit the amounts of sodium, potassium, phosphorus and fluids in your diet. A dietitian will help you make the necessary changes in your eating habits.

Protein, Fat And Carbohydrate

Foods have different amounts of protein, fats, and carbohydrates. Your body uses all three of these nutrients for energy. Protein, however, is used for more than energy. Protein is used by your body for growth, maintenance and repair. It is important that you eat enough high quality protein to stay well nourished. However, eating large amounts of protein (defined as more than your body can adequately use) will cause high levels of the protein waste product, blood urea nitrogen, or “BUN.”

Some proteins are called high quality proteins. Milk, cheese, eggs and meats are examples of foods containing high quality proteins. Beans, peas, lentils, nuts, grains and vegetables contain some protein. The proteins in these foods are considered low quality proteins. Your body does not use these proteins as well as the high quality proteins. The amount of protein you should eat will be determined by your type of kidney disease, your treatment plan and your body weight. A dietitian will give you guidelines for high and low quality protein foods.

Carbohydrates and fats provide calories or “fuel” for your body. Calories from carbohydrates and fats are important to keep body tissues from being broken down for energy. Carbohydrates and fats

do not cause a build up of wastes. If you do not eat enough calories, your body will take calories from your muscle protein. This makes protein wastes that will build up in your blood.

Breads, cereals, fruits, sugar, jam, jelly, and honey are examples of carbohydrates. Fats are in milk, meats, cream, butter, margarine, salad dressings and oils. The amount of calories you need will be determined by your sex, height, weight, age, and activity level. Your dietitian will help you to choose food sources for carbohydrates and fats.

Phosphorus (P)

Phosphorus is a mineral that helps to maintain strong bones. The level of phosphorus is controlled by your kidneys. High levels of phosphorus cause calcium to be taken from bones. When calcium is lost, bones become weak and joints become painful. Keeping a normal blood phosphorus level is important to prevent bone damage. High phosphorus levels can also cause calcium deposits in muscles, organs, blood vessels and other areas of the body which can be painful and dangerous. Calcium deposits in the skin also can cause severe itching.

Phosphorus is found in many foods. Most foods that are high in calcium contain phosphorus. Dairy foods are high in phosphorus. Meats, eggs, legumes, and bran cereals also have high amounts. Medicines called phosphorus binders help to control phosphorus levels in your blood. It is important that you take your medication and work with the dietitian to keep your phosphorus level in control.

Sodium (Na) And Water

Sodium helps with nerve activity, muscle contraction, and fluid balance. Everyone needs some sodium, but since sodium is found naturally in foods, most people consume more sodium than they need. When kidneys fail, the extra sodium is not removed. With extra sodium in your body, you will feel thirsty and may drink more fluids.

One teaspoon of salt has 2,000 milligrams of sodium! You can see why it's important to eliminate table salt as much as possible, and to limit salty foods. Too much salt can lead to greater thirst which may cause you to drink more water and become fluid overloaded. Too much fluid can cause high blood pressure, difficulty breathing, and swelling of hands, feet and legs. Taking off the excess fluid can cause severe muscle cramping and low blood pressure during dialysis treatments. Drinking too much fluid, which causes large water weight gains between dialysis treatments, is a dangerous habit. Frequent fluid overloading can lead to lung congestion and chronic heart failure. Weigh yourself daily to keep fluid weight gain under control. If you see a one to two pound weight gain in a day's time, you must limit fluid **and** sodium intake.

The best way to control thirst is to limit sodium. This means you need to restrict your use of table salt, avoid salty foods and softened water. Read food labels carefully. Watch for the words "sodium," "salt," and "soda." A dietitian will give you guidelines for sodium and fluids.

Potassium (K)

Potassium is a mineral. It helps with nerve activity, muscle contractions, and fluid balance. When kidneys are not working, potassium will build up in the blood. This can be dangerous. Too much potassium can cause muscle weakness. Since your heart is a muscle, high potassium levels could cause it to beat abnormally or to stop. There are no warning signs of high potassium in the blood, so potassium intake must be closely controlled.

Potassium can be controlled by the foods you eat. Potassium is found in almost all foods. Fats and sugars are the only potassium free foods. Milk, bananas, oranges, potatoes (especially potato chips), tomatoes, and dried beans are high in potassium. Salt substitutes and sodium-free baking powder are also very high in potassium.

High potassium in the blood is called "hyperkalemia." If blood levels cannot be maintained at an appropriate level, your physician may prescribe a combination of medications called Kayexalate and Sorbitol. Kayexalate binds potassium in the intestine and Sorbitol acts as a laxative to help to move the Kayexalate+potassium through the body.

The amount of potassium your body can handle depends on your level of kidney function. Your doctor will prescribe the amount that is right for you and a dietitian will help you to plan changes in the foods you eat.

Summary

Keeping a diet, which calls for protein management and limits sodium, potassium, phosphorus, and fluids may be difficult. It is, however, in your control, and it is something you can do for yourself. Be sure to talk with your doctor and dietitian when you have questions about your diet.

Following your renal diet, taking your medications properly, and maintaining your treatment schedule are all important to keep you feeling good. Your dietitian may have suggestions and specialized renal recipe cookbooks to help make adjusting to the new diet easier—just ask.

KIDNEY FAILURE IN CHILDREN

Kidney failure is also called chronic renal disease (CRD) or end-stage renal disease (ESRD). When a child has been diagnosed with end-stage renal disease, his/her kidneys are no longer working properly. The kidneys have two major jobs: to remove fluid and to clear the body of waste products. If the kidneys no longer work, dialysis or a new kidney (transplantation) is needed to keep the patient alive. Diseases that cause kidney failure in children vary by the age of the child.

Renal failure in childhood is very different from renal failure in adults. While kidney disease is a complicated chronic illness affecting many aspects of a child's life, it is a manageable condition. The goal of treatment is to have the patient lead a normal life.

Renal failure is less common in children than adults: new cases of pediatric kidney failure occur at a rate of approximately 11 children per million Americans, compared to almost 200 adult cases per million for the entire U.S. population.

The causes of kidney disease are also different for children than adults. Among the children under the age of 12, the most common causes of kidney failure are problems with the structure of the kidney, bladder, or anywhere along the urinary tract. Most children are born with these problems. In many cases of structural kidney disease, surgery is required either to preserve kidney function, to manage urinary problems, or to prepare patients for renal transplantation. In children over the age of 12, glomerulonephritis (inflammation of the kidneys) is the most frequent cause of kidney failure.

Glomerulonephritis can also occur in younger children under 12. Not all kinds of glomerulonephritis lead to kidney failure, but some do. One type of glomerulonephritis is focal segmental glomerulosclerosis, which can lead to renal failure by causing scarring of the kidneys. In contrast to adults, high blood pressure and diabetes mellitus are extremely rare causes of kidney failure in children. High blood pressure does not usually cause kidney failure in children, but often is caused by the renal failure.

Treatment

Treatment of a child with **ESRD** involves a team of professionals headed by a pediatric nephrologist (a doctor who specializes in pediatric kidney diseases) who knows about the care of children with kidney failure. Other members of the ESRD team include nurses experienced in pediatric dialysis and transplantation, a pediatric renal dietitian and social worker. Pediatric urologists, pediatric surgeons, psychiatrists, and psychologists are often closely involved in the care of these children. Physical therapists, occupational therapists and speech therapists are also sometimes needed.

Any form of treatment provided must meet the medical and social needs of each child. The goal of treatment is to provide the most normal lifestyle possible to allow the child to grow and mature. Failure to grow has been a common problem among children with chronic kidney disease, but improved medications such as recombinant growth hormone, nutritional supplements, and human recombinant erythropoietin have allowed for normal growth in many patients.

Transplantation (placing another person's kidney into the abdomen of the patient) is generally the treatment of choice for children with ESRD. The new kidney would function as though it were the patient's own kidney and can be provided by a cadaveric donor (a person who dies has donated his or her kidney) or from a living person (most people have two kidneys and only need one to live). However, 38 percent of children with kidney failure are on dialysis either because they are awaiting a kidney transplant, have a failed kidney transplant, or are considered not ready or appropriate for renal transplantation.

Hemodialysis

Hemodialysis is performed in an in-center unit for children of all ages and sizes. During hemodialysis, the patient is attached to a machine which removes blood from the patient, cleans the blood, removes extra fluid from the blood and returns the patient's own blood back to the body. The technical part of dialysis is similar to those used for adult patients, but there are some parts that are different.

Some patients receive dialysis by having a permanent catheter, similar to a large IV placed in their neck, chest or leg. Other patients have a graft or fistula which is a connection under the skin which is used for dialysis by placing a needle into it. Although needle insertion, a necessary part of hemodialysis, may be uncomfortable, the treatment itself is not painful. Many children read, do homework, sleep, or play during the hemodialysis treatment. Some small children may require more intensive monitoring during dialysis.

Peritoneal Dialysis

Peritoneal dialysis (PD) is done at the patient's home through a peritoneal catheter.

PD is performed by patients and families in their homes and allows more regular school attendance and may interfere less with activities. Patients and families are trained in PD by dialysis nurses and seen regularly in the office setting for ongoing care.

There are several ways to do peritoneal dialysis. All types of peritoneal dialysis used in adults are available for children, including CAPD (continuous ambulatory peritoneal dialysis) and CCPD (continuous cycling peritoneal dialysis). First, a PD catheter appropriate to the size of the patient is placed surgically into the patient's abdomen.

In CAPD, a patient would place a special fluid into his or her abdomen, allow that fluid to sit for a specific amount of time, then drain the fluid. This process is continued at regular time periods throughout the day. In CCPD, the patient is attached to a machine overnight and the machine puts the specialized fluid into the patient's abdomen, rests for a specific amount of time, and then drains the fluid out of the abdomen. The patient's nephrology team can determine which type of peritoneal dialysis is the best for each individual patient.

Transplantation

Transplantation is the treatment of choice for nearly all children with ESRD. A renal transplant may allow the child an opportunity for better growth than dialysis treatments and for more normal participation in school and activities with peers. In addition, there may not be as many diet restrictions once the patient has a new kidney.

Many parts of renal transplantation in children are no different from those in adults: the patient and the donor must have blood types that match and must be able to undergo surgery to have the kidney removed from the donor and put into the patient. The donor for a kidney transplant to a child may be a living relative, cadaver, or a living unrelated adult. At one time, it was believed that kidneys from very small donors were better for children, but it is now known that the chance of success is greater when a child receives a kidney from a donor who is at least six years old. Usually adult kidneys are transplanted into small children. If possible, a living related kidney transplant is preferred because there is a lower chance of rejection and better long-term kidney survival. Also, the waiting time is predictable since the transplant can be scheduled in advance. Parents may be donors, as can brothers or sisters who are over the age of 18 and are thereby able to give consent. Younger siblings may also be considered as donors under special circumstances.

Preparation for a kidney transplant is complex and requires a full range of medical services. The child is tested to assure that he is healthy and prepared for the procedure. Immunizations are updated. The child is tested for infections. In some cases, surgery to correct bladder problems may be necessary before transplantation. Psychologists and social workers are important in the evaluation of transplantation both to help the patient and patient's family, and the medical team. This part of the preparation for transplant will help to anticipate potential problems after transplant. The evaluation of the potential living donor is a separate process from that of preparing the child.

Medications, known as immunosuppressive drugs, are necessary to prevent the patient's body from rejecting a kidney transplant. These medications are required lifelong after transplant, whether a cadaver or living related transplant. Patients and families must understand the absolute importance of taking immunosuppressive medications reliably as they are prescribed or the transplant may be lost to rejection. Not taking medications is, sadly, a very common way for kidney transplants to be lost in children and adults.

Helping Children And Families Cope With Renal Disease

Children with kidney failure have special medical, social and emotional needs. They need to be informed about their condition and treatment so that they can understand their disease. This helps children cope with the normal feelings and fears that come with illness. It is important to help young people continue with their regular activities and to feel as much "like other kids" as possible.

School attendance is extremely important for children, both while on dialysis and after transplantation, to avoid falling behind their peers. Parents should keep the school updated about treatments, hospitalizations and office visits. Often tutoring can be provided if a child cannot attend school on a regular basis.

Dietary restrictions may be especially difficult for children and teenagers. Many social activities revolve around food and it is not always easy to supervise children under those circumstances.

Peer pressure can be very strong, and adolescents have a strong need to feel that they are part of a group. Being aware of this issue and discussing it with your child will help. Dietitians are available to answer your questions and discuss problems your child may have with his/her diet or medication compliance.

Once the diagnosis of ESRD is made or anticipated, the child and his/her family will have an opportunity to meet with the medical, nursing staff, dietitian and social worker. They will be shown the dialysis center, the equipment and procedures. The patient and family should not hesitate to seek professional advice and to ask questions directly of the nurses, physicians, social workers and dietitians. It may also be helpful to talk with other dialysis patients and their families.

Coping with a child's illness is very stressful to a family. The day-to-day demands of medical care, the financial burden, the worry and the stress place a tremendous strain on the parent's relationship with each other and the rest of the family members. Like most chronic diseases, renal disease is a family affair. Learning how to cope and reaching out for support when it is needed is essential to maintaining a strong and healthy family life. The social worker will be able to help with needed resources and support. The social worker may also be able to help find additional financial resources to help the family during the medical process.

The most important factor in helping an infant, child or teenager adjust to dialysis and transplantation is the continued love, understanding and support of the family.

LIVING WITH RENAL DISEASE

Kidney disease forces patients and their families into new situations, feelings, and relationships. Facing and adjusting to your kidney disease is one of the biggest challenges you have ever faced. You have asked the question, "Why me?" You may have to cope with financial, emotional, and physical experiences that you have never experienced before.

A lot of stress is put on you and your family when your kidneys fail. Understanding and dealing with that stress will make a difference and provide a happier, more normal life. A good way to start is for you and your family to learn as much as you can about your disease. Knowing what to expect from your illness will make it easier to cope.

Know your limitations. Realize that you may not be able to do all of the things that you did before you became ill. Don't feel guilty. Concentrate on what you can do.

The most important point is to follow the care plan that your doctor has prescribed. This means taking your medications as prescribed, following your diet, and dialyzing the correct amount of time at each treatment session. When you correctly follow your care plan, you will feel better and will be able to handle problems that may arise.

Each dialysis and transplant unit has a team of doctors, nurses, social workers, and dietitians to help you become a successful dialysis or transplant patient. It is important for you to discuss with them what is happening to you and how you feel. Be honest about your feelings. They can be a great source of support and information.

Many services and sources of help are available for dialysis and transplant patients. Check with your health care team for more information. Ultimately, your life will be what you make of it. Some patients may choose to sit back and feel sorry for themselves, and some may choose to use every resource available to build a new life. The choice is yours.

Psychosocial Aspects

Kidney disease affects you not only physically but also emotionally, socially, and spiritually.

When you learned you would need dialysis, you may have found it hard to believe. Even if you experienced unpleasant side effects, general fatigue, or lack of energy before you started dialysis, it is hard to accept the fact that you may need this treatment for the rest of your life.

Many people experience sadness, anger and feelings of helplessness and hopelessness at this time. This is a natural grieving process for the freedom and independence that you may find profoundly altered.

Diet and fluid restrictions may seem almost impossible at first. Many things that used to be simple become difficult.

It may be hard to keep a positive attitude. You may be irritable, confused, experience sleep disturbances, or changes in your appetite.

At first, you may find it hard to understand the overwhelming amount of information you receive. During this time, remember that your life has changed and that it may take a while to adjust. To wish and hope the changes away is impossible.

Even after this information begins to fall into place, you may find that it is many months before you feel at ease with your new life. And know that it is “OK” to have highs and lows. Some days you will be ready to tackle the world and other days you will think about giving up. The choice of a positive or negative attitude belongs to you.

Remember that you and your family have you own individual ways to deal with stress, and personality strengths and weaknesses. Some habits may be difficult to change. If you can choose to take control of those things, which will enhance your life, you are likely to find yourself strengthened by this experience.

Living With The Renal Diet

The renal diet is probably one of the most complex diets anyone must follow.

The following suggestions are intended to help make it easier for you to follow you diet and to allow the rest of the family to eat what they like at the same time.

First of all, remember you should avoid certain foods due to high sodium content (such as ham), or due to high potassium (such as bananas, tomatoes, potatoes and soup beans).

However, if family members really want these foods, you can work in a small amount if you know that your weight and/or serum potassium level is acceptable and you can stop at just a small serving. Usually the best time to have a “forbidden” food is the meal just prior to your next dialysis treatment, or at least within the day before you next dialysis time. If you know you cannot limit yourself to the small serving, you should prepare something different for yourself that meal. Every dialysis patient is different, so you must remember you may not be able to work in “forbidden” food as often as someone else.

Secondly, most food can be prepared without added salt. Your family members can add salt once the food is on their plates. It is usually easier for you if the salt shaker is not on the table at all. Keep other favorite seasonings on the table instead, such as pepper, vinegar, tobasco sauce and seasoning blends, such as Mrs. Dash or Molly McButter. Avoid all salt substitutes and “lite salt” since these contain potassium in very concentrated amounts. Garlic powder and onion powder (instead of garlic salt and onion salt) are also popular and acceptable to use.

Another seasoning idea is liquid smoke to season vegetables or other dishes that you would previously seasoned with bacon or ham. Use $\frac{1}{4}$ teaspoon of a natural liquid smoke, without sugar, coloring or other additives, since these leave an aftertaste. You can use $\frac{1}{2}$ teaspoon of liquid vegetable oil with the liquid smoke to enhance the flavor. It is important to cook the food at least 10 minutes before tasting to see if you have enough seasoning; it takes that long for the flavor to adjust itself. If, in 10 to 20 minutes, you need more flavor, add a few more drops of liquid smoke and taste again in 20 minutes.

Butter flavored oil or salt free margarine can also be used freely, unless you are on a weight reduction diet or a diabetic diet.

Vinegar can also add a salty taste to food without adding a grain of salt. Malt vinegar has more of a “salty” taste than white or cider vinegar. Wine vinegar is also a nice change from plain vinegar, as well as is garlic or tarragon vinegar, so try different ones to find which you prefer.

Finally, your family can help make your diet more livable by understanding your diet instructions and how important the diet is to your health! If they understand how dangerous it is for you to have an extra helping or two of high potassium food, they will be less likely to encourage you to “live a little” and go off your diet. It can be difficult for you to say no. Especially when everyone else says, “why not, what can it hurt?” But, it is very important for you to do so.

Use these suggestions as a starting point. Your dietitian will be more than glad to help you work with family members to make your diet a more palatable and positive experience.

Work And Relaxation Activities

Staying active and involved is important. Some of you will be able to continue in your present job with few changes. Others of you may have to find a new line of work. It may take some time or retraining but opportunities do exist for those willing and able to work. And even those of you who are not able to work can find fun and fulfillment in volunteer and leisure activities. Find a new hobby, develop a new skill, join a club – just stay active. Consider the following suggestions:

- Learn about the Americans with Disabilities Act (ADA)
- Contact your local Department of Vocational Rehabilitation for information on skills evaluation, job training, and career alternatives.
- Discuss your leisure interests with your hospital occupational therapist. He or she can assist you in developing new hobbies, work methods, and techniques to use your physical energy wisely.
- Ask your social worker to put you in touch with community agencies regarding job hunting, volunteer opportunities, recreational, and educational activities. Your social worker is a trained counselor who can discuss a variety of personal issues with you as you adjust to your new way of life. He or she may also teach relaxation techniques to help you lower your anxiety and to make more productive use of your time.
- Visit your local library and rediscover the pleasures of reading. Talking Book programs for the visually impaired are available.

- After talking with your physician, start and maintain a program of regular exercise. Moderate exercise improves physical well-being. It can have a very positive effect on your mental outlook and attitude.
- Your church or synagogue may have many programs in which you can be actively involved.
- Contact your local volunteer bureau to find out about organizations that need you. Volunteering provides an opportunity to meet people with similar interests, learn new skills, and become involved in causes that affect our society. This also helps you to take the focus off yourself as you help others.

Patients with a fully developed life outside of the dialysis routine are better able to cope with the stress and strain of chronic illness. Your life will be made fuller by pursuing those activities that bring you meaning and pleasure.

Exercise

Regular exercise can improve your heart function, increase your hematocrit and hemoglobin levels, improve your glucose control, and decrease your blood pressure. Improved exercise tolerance can improve your overall physical wellbeing and lower your level of anxiety and stress. These changes will occur at different rates in different individuals, depending on your age, health, type and frequency of exercise and fitness level. First consult your doctor and remember to start gradually, exercise regularly and have fun!

Choose an activity that is both convenient and enjoyable to you, whether it be floor exercises, walking, swimming or bicycling. Stationary bicycles are practical for all weather conditions. If you are a CAPD or CCPD patient, be sure to check with your doctor for special precautions when swimming.

Frequency. Exercise - should be a minimum of three days per week. Many hemodialysis patients prefer to exercise on the days they are off dialysis.

Duration. During the first week, exercise five minutes each session, then add one or two minutes per session each week until you gradually work up to one half hour. At the beginning, a short walk twice a day might be very effective. For weight control and increased benefits, try longer walks (one hour).

Intensity. Guidelines:

- Your breathing should not be so labored that you cannot talk with someone.
- You should feel completely recovered within one hour after exercising.
- You should feel muscles that have not been used for some time the next day, but no soreness.
- Exercise at a comfortable push level.
- Exercise slowly at the beginning of each session to warm up, then increase the pace. Decrease the pace to cool down toward the end of the session.

When to Exercise

- Schedule your exercise into your regular daily routine.
- Wait one hour after a large meal before exercising.
- Try to exercise with someone (a neighbor, another dialysis patient, your pet, etc.)
- In hot weather, exercise in the morning and/or evening when it is cooler.

Do Not Exercise Under Any of These Conditions:

- If you have a fever.
- If your dialysis schedule is changed.
- If the weather is very hot and humid (temperature higher than 80 degrees).
- If you have any orthopedic conditions that may be worsened by exercise.

Stop Exercising if You Feel:

- Excessively fatigued
- Short of breath
- Chest pains
- Irregular or rapid heart beats

- Nauseated
- Leg cramps
- Dizzy or lightheaded

Final Note: Let common sense be your guide in your exercise program. Use moderation especially in the beginning of your program. Report any changes in your condition to your dialysis medical staff.

Dialysis While Traveling

Being on dialysis is no longer a reason not to travel. It is now possible for a person to travel to visit relatives or just to explore a new place.

Dialysis in a unit away from home while traveling is commonly referred to as transient dialysis. The key to a smooth, successful vacation is planning in advance. For common tourist areas such as Arizona, Florida, or California, several months notice may be necessary. When you set your vacation dates, contact your unit nurse or social worker for assistance in making necessary contacts and arrangements. Your unit may have a list of units and phone numbers in your vacation area. It is a matter of calling the units to see if a space is available.

The transient unit will request medical and financial information prior to accepting you as a patient. Your nurse or social worker can help to gather and send this information.

Most units bill Medicare directly but some may ask you to pay the remaining 20 percent at the time your are dialyzed. You are then responsible for billing your supplemental insurance for reimbursement when your return home.

If you are a CAPD patient, you should also contact your unit nurse or social worker for assistance with travel arrangements. A CAPD unit near your vacation spot will be notified that you may be calling them if you have problems. In many cases, if you plan to be gone for several weeks, your CAPD supplies can be shipped to you at your vacation address.

Many kidney patients continue to enjoy vacations with their families by dialyzing successfully in units around the country and even overseas (Medicare does not pay for dialysis treatment received outside of the USA). But remember – plan ahead!

Impact On Families

Kidney disease is a family affair. Everyone in the family feels its impact. The well spouse often goes through stages of the grieving process as he/she accepts the illness of the patient and takes on the role of caregiver. Family members often need to readjust who does what chores and take on different responsibilities as family roles change. Learning about kidney disease is important as is making the dialysis diet and treatment time a part of their lives.

The caregiver may find it helpful to keep a notebook close at hand. It can be used to write down questions for the doctor and dialysis staff, as well as their answers. A notebook also can be used to vent feelings in a safe and private way, which can relieve a lot of personal stress and tension. Family members usually appreciate meeting other families who are coping well with kidney disease in their families. Support from others is very important and decreases the feelings of “being out there all alone.”

Children who have a parent with kidney disease need to be told about the illness at an age-appropriate level. The dialysis staff can assist with this. Children may have a lot of fear and anger about what is happening to their families. Understanding the illness can help them deal with it better. Keeping some of their same routines is helpful and adding new routines that include the illness is good, too. In addition, having a plan in place for emergencies can help children feel more secure.

Intimacy

Intimacy is one area where many problems or concerns may develop with individuals in renal failure. Renal patients may experience some of the changes discussed below. If you experience any concerns, speak with a health professional.

The changes that take place may have a direct affect on your desire for any sexual activity. This may be a normal, but not necessarily permanent change. The way you feel will determine how often you want to have sex. Your medications, diet, sleep and physical changes can influence your sexual desire.

The mind and body work closely together and may influence your desire for sex. As you adjust to your new life on dialysis some of the psychological obstacles to sexual fulfillment will probably disappear.

Many dialysis and transplant patients have fulfilling relationships. Sexuality remains a positive part of their lives. If there are changes in your sex life, it is important to keep your communication open and honest. Changes in your sex life will require your time, patience, and some compromises between you and your partner.

Sometimes just talking may help the situation. If you have concerns, you may want to discuss them with your physician, nurse or social worker. They can refer you to someone outside of your facility if necessary.

For more information about intimacy you may want to read the following books:

Sex and Intimacy for Dialysis and Transplanted Patients
Virgil Smirnow Associates, Inc., P.O. Box 55109, Lexington, KY
40555; (606) 299-8475.

Understanding your New Life with Dialysis
by E.T. Oberley and T.D. Oberley; Charles C. Thomas Publishing,
2600 S. First St., Springfield, IL, 62794-9265; (217) 789-8980.

Sexuality and Chronic Kidney Failure
Publication Order #05-04PP; The National Kidney Foundation, 30 E.
33rd St., New York, NY 10016; 1-800-622-9010.

Hepatitis B

Hepatitis is a viral infection of the liver. It is transmitted by exposure to infected blood or body fluids. Symptoms, when present, include fatigue, loss of appetite, nausea, vomiting, abdominal pain and jaundice. Most outbreaks among hemodialysis patients have been due to cross contamination to patients from supplies or equipment.

This is why blood work should be routinely drawn to test for hepatitis, and patients found to be positive should be isolated. Staff taking care of a patient in isolation for hepatitis should not be taking care of other patients in the unit (who do not have hepatitis) at the same time. The occurrence of this infection in hemodialysis patients has declined over the years, perhaps because there is better screening of the blood supply and less need for transfusions due to the development of Epogen.

All dialysis patients are recommended to receive the hepatitis B vaccination. It is given as three injections over 6 months time. If you have questions about receiving the vaccine you should ask your dialysis staff.

Aids And The Dialysis Patient

AIDS stands for acquired immunodeficiency syndrome. It is a disease caused by a virus that enters the blood. Human immunodeficiency virus (HIV) is the virus that causes AIDS. HIV destroys a person's ability to fight infections.

HIV is spread through blood and certain body fluids, such as semen and vaginal fluids, from infected individuals. You cannot "catch" it like a cold or the flu. HIV is usually spread by having oral, anal, or vaginal sex with someone who is infected with HIV or by using drug needles previously used by a person infected with HIV. It can also be spread to babies from their infected mothers before or during birth.

HIV can spread in a dialysis unit through direct exposure to infected blood or body fluids on broken skin and mucous membranes (for example, mouth, nose, anus, and vagina).

HIV cannot be spread through contact with equipment or other surfaces in the dialysis unit. The spread of HIV in the dialysis unit can be prevented by the following routine infection control procedures that have been used for many years. Dialysis staff members take precautions to keep you and themselves safe from the spread of all infection.

Examples of the precautions staff take are:

- Wearing gloves, scrub suits, lab coats or aprons.
- Wearing gowns and protective eyewear and masks when blood splashes are likely.
- Washing hands and putting on a fresh pair of gloves for each patient.
- Cleaning and disinfecting equipment and other surfaces in the dialysis unit.
- Disposing of needles or other sharp instruments in puncture-resistant containers located close to dialysis areas.
- Never recapping needles.

There is very little chance that you will get HIV from a health care worker. Staff members take proper steps to prevent the spread of infection.

Reuse of dialyzers will not spread HIV. Specific dialyzers are assigned to specific patients. Each patient reuses his or her own dialyzer after it has been properly disinfected by staff members. This prevents the chance for HIV and other blood-borne infections from spreading to other patients. Check your dialyzer to be sure it has your name on it before your treatment begins.

Many local and national organizations have information about AIDS, including the following:

- National AIDS Information Clearinghouse: **301-762-5111**
- National AIDS Hotline: **800-342-AIDS**
- American Association of Kidney Patients: **800-749-2257**
- National Kidney Foundation: **800-622-9010**

FINANCES

Medicare And Dialysis

Medicare is available for individuals with chronic renal disease who require dialysis. The effective date of coverage depends on the type of treatment chosen by the patient. Transplantation and home dialysis patients have coverage from the start of their therapy. With in-center dialysis, the patient's coverage begins the first day of the month following the third month of treatment.

Medicare has two parts. Part A pays for hospital care and related expenses. It has an annual deductible; there is no monthly premium for the patient. Part B is medical insurance and has a monthly premium. Part B has an annual deductible as well. The premium for Part B is either paid monthly by the patient or is deducted from Social Security Disability if you are receiving monthly benefits. Part B pays for doctor's services and outpatient services, including dialysis. It is critical that this payment is kept up. If you do not pay Part B premiums, Medicare will not pay for your dialysis. In some areas, Medicaid may pay for your Part B coverage.

To be eligible for Medicare you must have worked for a required amount of time under Social Security or be the spouse or dependent child of an individual who has worked for the required amount of time to be eligible Medicare benefits. (Contact the Social Security Administration for more information about the required amount of time needed under social Security to be eligible for ESRD Medicare.)

Only the individual with chronic renal disease requiring dialysis is eligible to be covered; your family is not covered. The social worker or patient accounts individual in your facility will help you complete the forms to enroll in Medicare. A Medicare handbook, which explains coverage in far more detail, is available at your Social Security office or on the Internet (www.medicare.gov).

Social Security Disability

If you have paid into Social Security, you may be entitled to Social Security Disability benefits. A person is disabled if he or she has a physical or mental condition which:

- a) prevents him or her from doing any substantial gainful work and
- b) is expected to last for at least 12 months or is expected to result in death.

You must fill out a lengthy application form, which can be obtained from your local Social Security office. Your physician will also have to fill out a medical evidence report. The application process can take up to five months. Monthly checks start with the sixth full month of disability. Along with the medical evidence provided from your doctor, you must have worked at least five out of the previous 10 years to qualify.

Supplemental Social Security Income (SSI)

This is a federal program that pays monthly checks to aged, disabled and blind individuals who have limited income and assets. This can be a temporary measure while awaiting Social Security Disability or you can receive supplemental benefits as a permanent source of income. Application is made through your local Social Security office.

Veteran Affairs

VA offers various benefits to veterans. Some of these benefits help with living expenses, medications, and medical care. To find out if you qualify for assistance, talk with your social worker or contact the Veterans Affairs - Health Benefits Service Center (877-222-VETS [8387]). This service provides you with help to determine eligibility, coverage, and closest VA facility.

Vocational Rehabilitation

To help individuals with disabilities find employment, state governments have established agencies, which can assist in identifying job skills, arrange training in new job skills, and assist in job placement. This process is called vocational rehabilitation.

Though the programs are called by different names in the four states of the Network, they operate by the same basic guidelines. To qualify for these programs, applicants must first meet the eligibility criteria:

- The individual must have a disability, which poses a substantial handicap to employment.
- The individual must have realistic expectations to be helped by the program.
- The individual's condition must be stable.

Decisions on acceptance are individualized to each person applying to the vocational rehabilitation program. Once the person is eligible for the program, he or she will undergo an evaluation, which may ask questions about the individual's medical, psychological and vocational background.

Participants in the vocational rehabilitation programs are encouraged to contribute to the cost of their program if possible. A benefit search can be done by the agency to look for additional sources to pay for training.

Special rules make it possible for individuals with disabilities receiving Social Security or Supplemental Security Income (SSI) to work and still receive monthly cash payments and Medicare and Medicaid. Social Security calls these rules "work incentives." The rules are different for Social Security and SSI beneficiaries.

For more information on the work incentives, ask the social worker at your unit or contact the local Social Security office and ask for the work incentives expert.

For more information on vocational rehabilitation services available in The Renal Network 9/10 area, contact the following:

Illinois

Department of Rehabilitation Services

100 W. Randolph
Chicago, IL 60601
312-814-2934
800-843-6154

Department of Rehabilitation Services

623 E. Adams Street
P.O. Box 19429
Springfield, IL 62794-9429
217-782-2093
800-252-8635

Indiana

Division of Vocational Rehabilitation Services

Indiana Government Center
402 W. Washington Street, Room W453
P.O. Box 7083
Indianapolis, IN 46207-7083
317-232-1319
800-545-7763 ext. 1319

Kentucky

Department of Vocational Rehabilitation

209 St. Claire Street
Frankfort, KY 40601
502-564-4440
800-372-7172

Ohio

Rehabilitation Services Commission

400 E. Campus View Blvd.
Columbus, OH 43235-4604
614-438-1210
800-282-4536

PATIENT SERVICE AND INFORMATION

Many non-profit organizations and government-funded agencies are available to help kidney patients in different ways. These non-profit organizations may provide research for kidney diseases, professional education, patient services and public education. Call the numbers listed for more information. This section provides a state-specific listing of important contact numbers followed by a partial listing of national organizations that impact the lives of renal patients.

ILLINOIS

Circuit Breaker and Pharmaceutical Assistance Program (CB/PA)

800-624-2459 (in-state calls only)
Web site: www.revenue.state.il.us/resources

This program is administered through the Department of Revenue. It provides tax relief and pharmaceutical assistance for qualifying seniors and disabled persons. The program provides assistance for those age 65 and older or are disabled.

Comprehensive Health Insurance Plan

400 W. Monroe Street, Suite 202
Springfield, IL 62704
800-962-8384 ICHIP
Web site: www.chip.state.il.us/chip.htm

A program for people who have been denied insurance - (Blue Cross Blue Shield administers this program)

Department of Insurance

100W. Randolph Suite 15-100
Chicago, IL 60601
312-814-2420
312-814-2427 Consumer Line
312-814-2603 TTY
Web site: www.state.il.us/ins

This office is the same as Springfield, just a different office. They can answer questions about Medigap policies available in your area.

Dept of Insurance Springfield

320 W. Washington
Springfield, IL 62767-3001
866-445-5364 Consumer Assistance Hot Line
877-527-9431 Office of Consumer Health Insurance

National Kidney Foundation of Illinois, Inc.

215 W Illinois Suite 1C
Chicago, IL 60610
312-321-1500
Web site: www.nkfi.org

Department of Public Aid

100 West Randolph - Suite 10300
Chicago, IL 60601
312-793-4706

Department of Public Aid

100 South Grand Avenue East
Springfield, IL
800-252-8635 (in-state calls only)

Illinois Medicare Contact Numbers**Medicare Fiscal Intermediary**

Anthem Insurance Companies
877-602-2426
866-737-8930 TTY

They can answer questions about Part A bills and services, hospital care and skilled nursing care.

Medicare Carrier

Wisconsin Physicians Service

800-642-6930

800-535-6152 TTY

312-938-8000

They can answer questions about Part A bills and services, hospital care and skilled nursing care

Medicare Coordination of Benefits Contractor

800-999-1118

800-318-8782 TTY

They can answer questions about Medicare Secondary Payer and who pays first.

PRO - Illinois Foundation for Quality Health Care

800-647-8089

They help with complaints about quality care, and filing an appeal or complaint.

Medicare Regional Office

Region B DMERC

AdminaStar

P.O. Box 6128

8115 Knue Road

Indianapolis, IN 46250

877-299-7900

Region B includes services for Illinois, Indiana, and Ohio and will answer questions about transplant coverage.

SHIP State Health Insurance Programs

800-548-9034 (in-state calls only)

217-785-9021

217-524-4872 TTY

This program offers counseling and assistance on Medicare and related insurance programs. They can answer questions about: a) understanding your Medicare right/protections, b) how to understand your Medicare bill, c) understanding how to appeal payment denials, and d) how/whether to purchase additional health insurance (Medigap policy, long-term care insurance, etc.).

Illinois State Survey Agency

Along with the ESRD Networks, the following state agencies are also responsible for monitoring patient care, investigating complaints and making sure that dialysis facilities meet Medicare standards.

Office of Health Care Regulation

Illinois Department of Public Health
Central Complaint Registry - Contact Person: Rose Hutchcraft
525 West Jefferson St., Ground Floor
Springfield, IL 62761
800-252-4343 (in-state calls only)
217-785-0321 Local
800-547-0466 TTY (in-state calls only)
217-524-8885 Fax

INDIANA

Crippled Children's Services

These services are provided through the local county welfare department. This program helps with catastrophic disease and the medical expenses they incur. Application must be made at the local welfare department.

Department of Insurance

311 West Washington Street, Suite 300
Indianapolis, IN 46204
800-622-4461 (in-state calls only)
317-232-2395
Web site: www.ai.prg/idoi/index.html

State Renal Disease Program

National Kidney Foundation of Indiana
800-382-9971(for questions)

This program receives funds from legislature for patients with chronic renal disease. Patients are eligible based on income, residency, and resources. The program assists with insurance premiums, immunosuppressive drugs for transplant patients or outpatient dialysis charges. An application must be completed by your social worker annually.

National Kidney Foundation of Indiana, Inc.

911 East 86th Street Suite 100
Indianapolis, IN 46240
800-382-9971
Web site: www.in.net/nkfi

Indiana Medicare Contact Numbers

Medicare Fiscal Intermediary

Anthem Insurance Companies
800-622-4792
317-841-4677 TTY

They can answer questions about Part A bills and services, hospital care and skilled nursing care.

Medicare Carrier

AdminaStar Federal
800-622-4792
317-841-4677 TTY

They can answer questions about Part B bills and services.

Medicare Coordination of Benefits Contractor

800-999-1118
800-318-8782 TTY

They can answer questions about Medicare Secondary Payer and who pays first.

PRO's - Health Care Excel, Inc.

800-288-1499

812-234-1499

They help with complaints about quality of care, and filing an appeal or complaint.)

Medicare Regional Office

Region B DMERC

AdminaStar

P.O. Box 6128

8115 Knue Road

Indianapolis, IN 46250

877-299-7900

Region B includes services for Illinois, Indiana, and Ohio - answer questions about transplant coverage

Indiana SHIP State Health Insurance Programs

800-452-4800 Insurance Counseling - in-state calls only

317-233-3475

Sponsored by Indiana Department of Insurance this program offers counseling and assistance on Medicare and related insurance program. They can answer questions about: a) understanding your Medicare right/protections, b) how to understand your Medicare bill, c) understanding how to appeal payment denials, and d) how/whether to purchase additional health insurance (Medigap policy, long-term care insurance, etc.).

Indiana Supplemental Insurance

Since Medicare pays 80% of the covered charges, the best possible situation is to have a group or individual plan when you begin dialysis that will pay the remaining 20% of the Medicare covered charges plus the uncovered charges. (Currently no insurance company in the State of Indiana offers supplemental insurance to individuals under age 65 who have Medicare.)

OASYS - (Outsource Administrative Systems, Inc.)

4550 Victory Lane

Beach Grove, IN 46203

317-614-2133

800-5527921 (Option #9 bypasses Internet info.)

Web site: www.onlinehealthplan.com

Formerly Adminastar Solution - (a source for high risk insurance policies).

Indiana State Survey Agency

Along with the ESRD networks, the following state agencies are also responsible for monitoring patient care, investigating complaints and making sure that dialysis facilities meet Medicare standards.

Health Care Regulatory Services Commission

Indiana State Department of Health

2 North Meridian St., Section 4A

Indianapolis, IN 46204

317-233-1286 Division Director: Mary Azdill

317-233-7742 Contact Person: Lana Richmond

317-233-7157 Fax

KENTUCKY

Kentucky State Department of Insurance

215 West Main Street

P.O. Box 517

Frankfort, KY 40602

800-595-6053 (in-state calls only)

800-462-2081 TTY (in-state calls only)

502-564-3630

Web site: www.doi.state.ky.us

National Kidney Foundation of Kentucky, Inc.

250 E. Liberty Street, Suite 710

Louisville, KY 40202

800-737-5433

502-585-5433

Web site: www.nkfk.org

Kidney Foundation of Central Kentucky, Inc.

2417 Regency Road

Lexington, KY 40503

859-277-8259

Kentucky Medicare Contact Numbers

Medicare Fiscal Intermediary

Anthem Insurance Companies

800-999-7608

866-284-0881

They can answer questions about Part A bills and services, hospital care and skilled nursing care.

Medicare Carrier

AdminaStar Federal

800-999-7608

317-841-4677 TTY

They can answer questions about Part B bills and services.

Medicare Coordination of Benefits Contractor

800-999-1118

800-318-8782 TTY

They can answer questions about Medicare Secondary Payer and who pays first.

PRO - Health Care Excel, Inc.

800-288-1499

502-339-7442

They help with complaints about quality care, and filing an appeal or complaint.

Medicare Regional Office

Region C DMERC

17 Tech. Circle
Columbia, SC 29202
800-583-2236

Kentucky - SHIP State Health Insurance Programs

877-293-7447 (in-state calls only)
888-642-1137 TTY
502-564-2347

This program offers counseling and assistance on Medicare and related insurance programs. They can answer questions about: a) understanding your Medicare right/protections, b) how to understand your Medicare bill, c) understanding how to appeal payment denials, and d) how/whether to purchase additional health insurance (Medigap policy, long-term care insurance, etc.)

Kentucky State Survey Agency

Along with the ESRD Networks, the following state agencies are also responsible for monitoring patient care, investigating complaints and making sure that dialysis facilities meet Medicare standards.

Division of Licensing and Regulation

Kentucky Cabinet for Health Services
Office of Inspector General
275 East Main St., 4E-A
Frankfort, KY 40621-0001
502-564-2800
502-564-6546 Fax

OHIO

Ohio State Department of Insurance

Consumer Services Division

2100 Stella Court

Columbus, OH 43215

800-686-1526 (in-state calls only)

800-686-1578 Senior and Disabled (in-state calls only)

614-644-2673

Web site: www.ohioinsurance.gov

National Kidney Foundation of Ohio, Inc.

1373 Grandview Avenue, Suite 200

Columbus, OH 43212

800-242-2133 (in-state calls only)

614-481-4030

Web site: www.nkfofohio.org

Eastern Regional Kidney Foundation

8515 Four Seasons Trail

Poland, OH 44514

330-707-1910

Web site: www.erkidney.com

This is a volunteer organization that promotes the interest and welfare of kidney patients. Assistance with transportation and prescription medication, information on support groups, finding dialysis centers when traveling, and education.

Kidney Foundation of Northwestern Ohio, Inc.

1545 Holland Rd., Suite B

Maumee, OH 43537

877-893-5512

419-893-5512

West Central Ohio Kidney Foundation

1001 Bellefontaine Ave.

Lima, OH 45804

419-226-5051

They office patient assistance with transportation, medication, and small equipment.

Kidney Foundation of Greater Cincinnati, Inc.

2200 Victory Parkway, Suite 510

Cincinnati, OH 45206

513-961-8105

Web site: www.kidneycincinnati.org

This organization promotes kidney health care and quality of life for patients with kidney disease by providing a) direct services to patients, b) community health education, and c) professional education.

Kidney Foundation of Ohio, Inc.

1370 W. 6th Street. Suite 201

Cleveland, OH 44113

216-771-2700

Web site: www.kfohio.org

This organization fosters a broad program of assistance and education for persons with kidney disease and their families.

Ohio Medicare Contact Numbers

Medicare Fiscal Intermediary

Anthem Insurance Companies

877-602-2430

866-737-8930 TTY

They can answer questions about Part A bills and services, hospital care and skilled nursing care.

Medicare Carrier

Nationwide Mutual Insurance Company

800-282-0530

800-542-5250 TTY

They can answer questions about Part B bills and services.

Medicare Coordination of Benefits Contractor

800-999-1118

800-318-8782 TTY

They can answer questions about Medicare Secondary Payer and who pays first.

PRO - Ohio KePRO, Inc.

800-589-7337

216-447-9604

They help with complaints about quality care, and filing an appeal or complaint.

Medicare Regional Office

Region B DMERC

AdminaStar

P.O. Box 6128

8115 Knue Road

Indianapolis, IN 46250

877-299-7900

Region B includes services for Illinois, Indiana, and Ohio - answers questions about transplant coverage.

Ohio - SHIP State Health Insurance Programs

800-686-1578 (in-state calls only)

614-644-3458

This program offers counseling and assistance on Medicare and related insurance programs. They can answer questions about: a) understanding your Medicare right/protections, b) how to understand your Medicare bill, c) understanding how to appeal payment denials, and d) how/whether to purchase additional health insurance (Medigap policy, long-term care insurance, etc.).

Ohio Supplemental Insurance

Since Medicare pays 80 percent of the cost of dialysis, it is necessary to have supplemental insurance to cover the remaining 20 percent or to have Medicaid if you qualify for it. The availability of supplemental insurance varies through out the State of Ohio but is generally difficult to acquire with a pre-existing illness such as chronic kidney disease. The social worker at your dialysis center can best advise you concerning supplemental insurance.

Ohio State Survey Agency

Along with the ESRD Networks, the following state agencies are also responsible for monitoring patient care, investigating complaints and making sure that dialysis facilities meet Medicare standards.

Division of Quality Assurance

Bureau of Information & Operational Support

Ohio Department of Health

246 North High Street

Columbus, OH 43266-0118

614-752-8832

614-466-8692 Fax

800-342-0553 (in-state calls only)

614-644-1845

RESOURCES AVAILABLE TO ALL FOUR STATES

Renal Organizations

American Kidney Fund (AKF)

6110 Executive Blvd., Suite 1010

Rockville, MD 20852

301-881-3052

800-638-8299

301-881-0898 (fax)

E-mail: helpline@akfinc.org

Web site: <http://www.arbon.com/kidney>

The American Kidney Fund is an organization founded in 1971 to provide the following services: a) financial assistance to community programs to cover emergencies and transportation costs, b) public and professional education publication of educational materials, and c) direct financial assistance to patients. They help with treatment-related necessities such as medications, transportation, special dietary needs, and other expenses that are not covered by any other source. This financial assistance falls into two categories: a) monthly grants when the need for assistance is on-going and b) one time grants awarded in one payment. An application for financial assistance must be completed with the help of your social worker. You can obtain an application by contacting your social worker or call the 800 number.

National Kidney Foundation (NKF)

30 East 33rd Street
New York, NY 10016
800-622-9010
212-689-9261 (fax)
Web site: <http://www.kidney.org>

Non-profit organizations may provide research for kidney diseases, professional education, patient services and public education. Their web site has links to all NKF Offices nationwide

American Association of Kidney Patients (AAKP)

100 S. Ashley Drive, Suite 280
Tampa, FL 33602
813-223-7099
800-749-2257
813-223-0001 (fax)
E-mail: AAKPnat@aol.com
Web site: <http://www.aakp.org>

The AAKP is a voluntary patient organization of more than 12,000 members. They help patients and their families cope with the emotional, physical and social impact of kidney disease, leading to more normal productive and satisfying lives; publish a patient magazine and educational information publications; sponsors an annual patient conference; and provides patient advocacy.

National Kidney and Urologic Diseases Information Clearinghouse

3 Information Way

Bethesda, MD 20892-3580

Email: nkuic@info.niddk.nih.gov

Web site: www.niddk.nih.gov/health/kidney/nkudic.htm

Polycystic Kidney Research (PKR) Foundation

4901 Main Street, Suite 200

Kansas City, MO 64112-2674

816-931-2600

800-PKD-CURE

E-mail: pdkcure@pkrfoundation.org

Web site: <http://www.pkdcure.org>

The William B. Dessner Memorial Fund, Inc.

1056 Fifth Avenue, #4D

New York, NY 10128

212-831-0265

This is an organization that provides small grants (one time only per patient of \$50.00) to be used to help meet a need of the patient. A letter must be sent by the patient's social worker stating the age, income, marital status, number of children, a brief history of the medical condition, and how the requested money will be used. The information can be brief (a couple of paragraphs) and should include the patient's home address since the money is sent directly to the patient. In the past, grants have been given to assist with medications, utility bills, groceries, bus fare, car repairs, and medical equipment.

UNOS

1100 Boulders Pkwy

Suite 500

P.O. Box 13770

Richmond, VA 23225-8770

Patient/Public Information 1-888-TXINFO1

The transplant community is joined under a nationwide umbrella: The United Network for Organ Sharing (UNOS), a nonprofit charitable organization maintains the nation's organ transplant waiting list under

contract with the Health Resources and Services Administration of the U.S. Department of Health and Human Services. Located in Richmond, Virginia, UNOS brings together, under that contract and on behalf of the Organ Procurement and Transplantation Network (OPTN), medical professionals, transplant recipients and donor families to develop organ transplantation policy. UNOS provides the OPTN with a functional, effective management system incorporating the UNOS Board of Directors, committees and regional membership structure to operate OPTN elements and activities.

Government or Government-funded Agencies

Medicare

800- MEDICARE (800-633-4227)

877-486-2048 TTY/TDD

Web site: www.medicare.gov

Available 24 hours a day including weekends

Medicare Rights Center

1460 Broadway, 11th floor

New York, NY 10036

212-869-3850

They will answer questions about doctor bills under Medicare and have booklets about Medicare options (available for a small fee).

The Center for Medicare Advocacy

P.O. Box 350

Williamantic, CT 06226

860-456-7790

National AIDS & Other Sexually Transmitted Diseases

800-342-AIDS Hotline

800-344-7432 Spanish Speaking

800-243-7889 TTY

The National Organization on Disability

910 16th Street NW - Suite 600

Washington, DC 20006

202-293-5960

Web site: www.nod.org

Information and Referral

The CDC National Prevention Information Network

800-458-5231 Monday - Friday 9-6 Eastern Time

Web site: www.cdcnpin.org

Social Security Administration (SSA)

800-772-1213

800-325-0778 TTY

Web site: www.ssa.gov

They can answer questions on Social Security benefits and Medicare Part A or Part B issues.

Veterans Affairs

VA offers various benefits to veterans. Some of these benefits include help with living expenses, medications, and medical care. To find out if you qualify for assistance, talk with your social worker or contact Health Benefits Service Center.

Veterans Affairs - Health Benefits Service Center

877-222-VETS (8387)

This service provides you with help to determine eligibility, coverage, and closest VA facility.

Of General Interest

American Association of Retired Persons (AARP)

Provides information about AARP member (people 50 years of age and older) services, insurance program, pharmacy program and publications on topics such as finances, medical treatment, employment planning, American With Disabilities Act (ADA), writing

resumes, housing, life transitions, transportation, and how to handle legal matters, call:

800-424-3410 (Will help you find the closest chapter)

Web site: www.aarp.org

AARP Midwest Office (Serving Illinois, Indiana, and Ohio)

Midwest Regional Office

8750 W. Bryn Mawr Ave. Suite 600

Chicago, IL 60631

773-714-9800

773-714-9927 Fax

773-714-9995 TTY

AARP Southeastern Office (Serving Kentucky)

Southeast Regional Office

999 Peachtree St. N. E. Suite 600

Atlanta, GA 30309

404-888-0077

404-888-0902 Fax

404-888-7742 TTY

The American Diabetes Association

American Diabetes Association

ATTN: Customer Service

1701 North Beauregard Street

Alexandria, VA 22311

800-DIABETES (1-800-342-2383).

The American Diabetes Association is the nation's leading nonprofit health organization providing diabetes research, information and advocacy. The mission of the organization is to prevent and cure diabetes and to improve the lives of all people affected by diabetes. To fulfill this mission, the American Diabetes Association funds research, publishes scientific findings, provides information and other services to people with diabetes, their families, health care professionals and the public. The Association is also actively involved in advocating for scientific research and for the rights of people with diabetes.

American Society of Hypertension

515 Madison Ave, Suite # 1212,

New York, NY 10022

212-644-0650

Fax: 212-644-0658

E-mail: ash@ash-us.org

THE RENAL NETWORK, INC. (ESRD Network 9/10)

The Renal Network is an agency, which monitors the treatment of kidney patients in the states of Illinois, Ohio, Kentucky and Indiana. There are several ways that the Network helps kidney patients:

- Renal Outreach is a newsletter written for patients. It is mailed four times per year to patients and dialysis units at no cost.
- The Patient Leadership Committee (PLC) is a dynamic group of patients, family members and facility staff that works to respond directly to patient needs through the creation of high quality patient resources. The PLC also helps The Renal Network understand which areas of patient needs are most salient, which service delivery processes work and where to fine tune.
- Patient Advisory Committees are active in each of the Renal Network four-state area. Each is made up of patients from dialysis units and transplant centers in that state. Patient representatives provide information, Network materials and often help plan educational and recreational activities such as health fairs, workshops and picnics.
- Treatment data is published by the Network in its annual report. This information is free and available to the patients.
- Grievance Policy. The Renal Network promotes high-quality care in all facilities. If a patient feels he or she has problem that can't be solved in the facility, a grievance may be filed with the Network by the patient. A grievance is simply a written description of the problem. When a grievance is received, it is reviewed by the Network, with ideas on ways to solve the problem. The Network may go between the facility and the patient to help solve the problem, if necessary.

- Web sites making up-to-date information readily available through internet access. The Renal Network provides a site geared specifically for renal patients and family members at www.kidneypatientnews.org. The Network also maintains a site at www.therenalnetwork.org where it maintains data, policy and governance materials and reports.

Contact Address: The Renal Network, Inc.
 911 E. 86th Street, Suite 202
 Indianapolis, IN 46240
 800-456-6919 (toll free for patients only)
 317-257-8265

APPENDIX I – PATIENT RIGHTS AND RESPONSIBILITIES

MODEL STATEMENT OF PATIENT RIGHTS AND RESPONSIBILITIES

The Renal Network Patient Rights & Responsibilities

A goal of The Renal Network is to make sure that all ESRD patients in Illinois, Indiana, Kentucky, and Ohio are able to receive medical care and are treated with dignity and respect. The following Rights and Responsibilities have been revised by the Network's Patient's Leadership Committee and approved by the Board of Trustees.

Your Patient Rights are to:

1. Know your rights and responsibilities.
2. Know how to protect your rights and responsibilities.
3. Receive quality, competent care and be treated with respect and dignity no matter what your age, color, culture, race, religion, or how your medical expenses are being paid.
4. Be told about your kidney disease and other medical problems that may concern you.
5. Be told about all the types of treatment that could be used to do the work your kidneys did before they stopped working; and for you to help decide which treatment might be best for you.
6. Be given the help you need for any difficulty or problem that keeps you from fully understanding your medical care (be it physical like a hearing or vision loss, or social like speaking a language other than English), or not understanding technical or complicated terms.

7. Expect that all healthcare workers responsible for your care will talk to each other about important medical information they need to know about your care like your medications, treatments, allergies, etc.
8. Have your personal and medical records be open only those people who have to know about your care. You can decide who can see your records outside of the unit where you are treated, except if you change to another unit. If you change to another unit, your records must be given to the new unit according to government regulations and the law.
9. Be told the reasons for all tests, and have test results explained to you when the results are known.
10. Make sure you are told how, and that you understand why, things are done to you.
11. Know your primary doctor.
12. Know that you can meet privately with your doctor on a regular basis.
13. Be able to get another doctor's opinion about your healthcare and know how much it will cost you.
14. Be told about how much your care will cost, about ways to get help paying for these costs, and about how much should be paid by you and your family.
15. Be able to choose or change doctors, type of treatment, and/or the place where you dialyze. However, this does not mean that the staff has to change the type of treatment to match your choice.
16. Be able to see the social worker, dietician, rehabilitation caseworker, psychologist, or other healthcare worker in a timely manner as needed.

17. Write down a concern or grievance and give it to the person at your facility who takes care of grievances. You can also send your grievance to The Renal Network. Filing a complaint will not have an effect on your care.
18. Be told exactly what to do in case of emergency while you are being treated.
19. Be given help to find a place to dialyze when you are planning to travel.
20. Be told about new treatments that might help you, and be told the good points and bad points of those new treatments.
21. Decide if you want to be part of a research study.
22. (If you choose to be part of a research study), you must understand what the research study is about and the results of the study.
23. Refuse to have someone watch you if they are not part of the staff giving you care.
24. Refuse treatment (as allowed by law) and be told what will happen to your body if you do so.

Your Patient Responsibilities are to:

1. Learn as much as you can about your disease, treatments, medicines, possible problems that could happen, and your rights and responsibilities as a kidney patient.
2. Bring as much information as you can when you are giving your medical history to the healthcare workers caring for you.
3. Tell your doctor or healthcare workers if you do not understand something.
4. Follow the diet the doctor and dietician order for you.

5. Get and take the medications the doctor orders for you. Also, tell the doctor if the medications are not working or cause problems for you.
6. Make an appointment, as needed, to see your doctor at his/her office and not just at the unit.
7. Arrive on time for your treatments, appointments, and meetings. Stay the entire time for your treatment; don't leave early. You need to call if you are going to be late or cannot make it in that day.

APPENDIX II – FACILITY RULES AND REGULATIONS

Most dialysis units and transplant centers receive payments from Medicare for the treatments provided to Medicare patients. To make sure Medicare patients are receiving proper treatment, the federal government has written and adopted regulations on how the dialysis facilities should be run. (These rules apply only to dialysis facilities and transplant centers, which accept Medicare payments.)

These regulations may be obtained by contacting:

**Superintendent of Documents
Government Printing Office
Washington, D.C. 20402
(202) 783-3238**

If you contact this agency, be sure to state that you want the regulations for the operation of dialysis facilities and transplant centers.

To be sure that these regulations are followed, the government inspects the dialysis facilities periodically. This inspection is done for the federal government by the state boards of health within each state. Additionally, each state has specific health rules which must be followed by all dialysis facilities and transplant centers in that state, whether the facility or center receives Medicare payments or not. More information on these state rules may be obtained by contacting the state board of health in your state.

The Renal Network promotes high quality care in all renal facilities. The Network has written and adopted a “Criteria and Standards of ESRD Care.” These standards list guidelines which dialysis facilities and transplant centers should follow in Illinois, Indiana, Kentucky and Ohio. These standards may be obtained by contacting the Network office at **1-800-456-6919**, or online at **www.therenalnetwork.org**.

If a patient feels he or she has a problem which can't be solved in the facility, a grievance may be filed with the Network by the patient. A grievance is simply a formal statement of the problem with a request for help. When a grievance is received, it is reviewed by the Network; suggestions may be made for ideas to solve the problem. A copy of the grievance procedure may be obtained by contacting the Network office at **1-800-456-6919**.

APPENDIX II – Glossary of Terms

Access	A surgically formed connection of an artery and vein or an implanted artificial conduit in the arm or leg to allow easy access to the bloodstream for processing blood through an artificial kidney and returning to the body. (Also called cannulae, fistula, graft.)
Acute Renal Failure	A sudden short-term loss of kidney function.
Air Detector	A device that is a part of the artificial kidney machine. It will clamp off the venous bloodline if there is any danger of air entering the bloodstream. (Occasionally, this instrument may sound an alarm for no apparent reason).
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.
Antacid	Medicine that neutralizes stomach acid to help prevent ulcers. For dialysis patients, these are used mainly as phosphorus binders.
Antibiotic	A medication used to kill bacteria (germs) that may be causing an infection in the body.
Antibody	A substance in the body that fights disease and foreign substances.
Antigen	A substance in the body that stimulates the production of antibodies.
Anti-hypertensive	A medication that relieves and controls high blood pressure. Examples: Captopril, Clonidine, Diltiazem, Hydralazine, Labetalol, Losartan, Prazosin, Minoxidil, Nifedipine, Verapamil. (List not all inclusive)

Anti-rejection medications	Also called immunosuppressives . A class of medication given to transplant recipients to stop the body's immune system from rejecting a transplanted kidney. Transplant patients are put on a combination of drugs which may include: Predisone, Imuran® (azathioprine), Cellcept® (mycophenolate mofetil), Neoral® (cyclosporine), and Prograf® (tacrolimus or FK506). There are also medications that can be given by injection that are used short-term to prevent rejection, treat rejection, or both (e.g. OKT3, ATG, Zenapax®, and Simulect®).
Arterial Line	The tube carrying blood from the body into the artificial kidney.
Arteriogram	An x-ray test involving injection of dye into the artery. A renal arteriogram injects dye into the artery to the kidneys to see if the blood vessels are normal.
Artery	Vessel carrying blood away from the heart; part of the circulatory system.
Artificial Kidney (same as dialyzer)	A filtering device that removes excessive fluid and waste products from the bloodstream and corrects chemical imbalance of the blood during hemodialysis.
Artificial Kidney Machine	(Hemodialysis machine). A machine that supports and monitors the functioning of the dialysis treatment and the patient while on dialysis.
Ascites	Fluid that is retained in the abdominal cavity.
Aseptic Technique	Very clean procedure used to prevent bacteria from entering the body, thus limiting risk of infection.
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	(Same as dialysate, dialysate fluid) Dialysate fluid or bath is composed of fluids and chemicals similar to body fluids without the waste products. Dialysate is used in both hemodialysis and peritoneal dialysis. The dialysate fluid in hemodialysis bathes the hollow fibers of the artificial kidney. Waste products will flow from the blood into the dialysate and then be flushed away. Dialysate fluid usually consists of two parts, the bicarbonate solution and the “acid” component. The dialysis machine mixes the two with purified water to make the final solution. During peritoneal dialysis, the dialysate is infused into the peritoneal cavity for a period of time where dialysis takes place and then is drained out of the body.
Bilateral Nephrectomy	Surgical removal of both kidneys.
Bladder	The sac in which urine, produced by the kidneys, is collected and stored until the urine is released from the body.
Blood Flow Rate	The amount of blood passing through the artificial kidney each minute. This is determined by the speed at which the blood pump is set.
Blood Pressure	The pressure exerted by the blood upon the walls of the blood vessels. Recorded in two numbers. The larger number is the SYSTOLIC or the pressure when the heart contracts. The second, DIASTOLIC, is the pressure in the blood vessels between heart contractions.
Blood Pump	A pump that is used to pull the blood from the patient through the artificial kidney and back to the body.
Bubble Trap	The larger part of the arterial and venous bloodlines which traps air from the lines and prevents air bubbles or clots from entering the vein by “trapping” them in a filter.

BUN	Abbreviation for “Blood Urea Nitrogen,” which is a waste product normally excreted by the kidneys. This waste product is a breakdown of protein metabolism. In dialysis patients, the BUN levels cannot be properly excreted by the kidneys in the urine, so it must be removed by dialysis.
Cadaver Kidney	A kidney that comes from a donor who has recently died and who has donated the kidney for transplantation.
Calcium	A mineral found in the blood that is important for bone growth and body functioning.
Cannulae	Special tubes that carry blood from an artery directly to a nearby vein.
Catheter	A tube passed through the body for infusing or withdrawing fluids into the body cavities. There are different types of tubes for different procedures.
Chronic Renal Failure	Permanent, irreversible damage to both kidneys. Dialysis and transplant are treatments for chronic renal failure.
Clotting Time	A method of determining the length of time it takes for blood to clot. Heparin dosage may be determined by clotting times.
Compliance	Following doctor’s orders (i.e.: taking medications that are ordered, coming to every treatment, and staying for ordered time at treatment).

Congestive Heart Failure	A condition in which the body retains too much fluid, causing the heart to pump less efficiently than it should. This can result in too much fluid in the lungs and the eventual filling of some of the lungs' airways. Treatment consists of removing the fluid during dialysis, restriction of fluid intake, and other medical measures. Prevention: restrict fluid as advised by dialysis staff.
Contraindications	Something (such as a condition, symptom or behavior) that makes a particular treatment or procedure inadvisable.
Coumadin™	A pill sometimes referred to as a "blood thinner" which interferes with the clotting of blood. It is often used to prevent a vascular access from clotting.
Creatinine	A waste product in the blood that is caused from the breakdown of muscle metabolism. It is used as an indicator of how well the kidneys are functioning (also see BUN).
Cross Matching	The testing of a transplant or blood donor and recipient's blood cells and serum to determine if compatibility exists.
Cytomegalovirus – CMV	Any of several herpes viruses that cause cellular enlargement and formation of inclusion cells. Both Donor and Recipient are tested for this virus before transplantation.
Dialysate	Same as bath or dialysate fluid. (See below)
Dialysate Fluid	Dialysate fluid or bath is composed of fluids and chemicals similar to body fluids without the waste products. Dialysate is used in both hemodialysis and peritoneal dialysis. The dialysate fluid in hemodialysis bathes the hollow fibers of the artificial kidney. Waste products will flow from the blood into the dialysate and then be flushed away. Dialysate fluid usually consists of two parts, the bicarbonate solution and the "acid"

component. The dialysis machine mixes the two with purified water to make the final solution. During peritoneal dialysis, the dialysate is infused into the peritoneal cavity for a period of time where dialysis takes place and then is drained out of the body. (Same as bath or dialysate)

Dialysis Staff

Personnel who care for dialysis patients. These staff members include doctors, nurses, technicians, dietitians, and social workers.

Dialysis Therapy

The process of maintaining the chemical balance of the blood when the kidneys have failed; removal of waste products and fluid from the blood. May refer to hemodialysis or peritoneal dialysis or CAPD (Continuous Ambulatory Peritoneal Dialysis).

Dialyzer

A filtering device that removes excessive fluid and waste products from the bloodstream and corrects chemical imbalance of the blood during hemodialysis. (Same as artificial kidney)

Diaphragm

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

Diffusion

Passage of particles from a solution of high concentration to a solution of low concentration.

Disequilibrium

Term used to describe a condition that may result from rapid dialysis therapy most commonly during the first treatment. Some mild symptoms may be headache, cramps, nausea, or vomiting. More severe symptoms may include confusion and seizures.

Donor

Someone who offers his or her kidney to be transplanted into another person. The donor may be living, or have recently died.

Dry (or Ideal) Weight

The weight at which blood pressure is normal and no swelling is present.

Edema (swelling)	An abnormal accumulation of fluid in the tissues causing swelling in the ankles, face (particularly the eyelids), and sometimes in the abdomen or lung.
End-Stage Renal Disease	Any irreversible kidney disease that 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, not that the condition is terminal.
Epogen™ (EPO)	Synthetic erythropoietin. A genetically engineered medication used to stimulate bone marrow cells to produce red blood cells for the body. It is used in patients to correct anemia. It is administered intravenously (IV) or subcutaneously (SQ).
Erythropoietin	A hormone made in the kidney that stimulates special bone marrow cells to produce red blood cells.
Exchange	Describes the cycle of draining used dialysate and infusing fresh dialysate solution within the abdominal cavity during peritoneal dialysis. Exchanges are commonly done four times a day.
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. This is the first access of choice.
Folic Acid	A substance necessary for red blood cell production.
Glomerulonephritis	Also called nephritis. It is an inflammation of the glomeruli (part of the functional 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 slow, progressive damage which may ultimately lead to dialysis therapy and/or transplantation. Bright's disease is a type of glomerulonephritis; there are several others.

Glucose	A type of sugar found in the body.
Graft	A type of permanent blood access made from a synthetic material to form a conduit between an artery and a vein beneath the skin. It provides blood flows necessary for connection to the artificial kidney machine.
Hematocrit	A measure of the volume of red blood cells in the blood.
Hematoma	A swelling caused by an accumulation of blood in the tissues. A hematoma may occur at the site where the needle has slipped out of the vein. Also called a bruise or “black and blue” mark.
Hemodialysis	The process by which extra body wastes and fluid are removed from the blood when passing through an artificial kidney.
Hemoglobin	The chemical compound in red blood cells which carries oxygen.
Hemostat or Clamp	The instrument used to stop the blood flow in the lines.
Heparin	A medication given to “thin the blood” by prolonging blood clotting time, allowing blood to flow through the artificial kidney without clotting.
Heparin Pump	A pump on the dialysis machine that can be set to give a continuous infusion of Heparin at a specified rate per hour throughout hemodialysis.
Hepatitis	Inflammation of the liver. May be caused by one or more viruses.
Hepatitis Antigen Test	A blood test which determines the presence of an antigen associated with a type of hepatitis.
High Flux/Efficiency Dialysis	Use of a large dialyzer and a high blood flow rate in order to remove larger amounts of molecules and fluid on hemodialysis.

Hollow Fiber Kidney	A dialyzer consisting of thousands of tiny hollow fiber tubes lying parallel to each other. During dialysis, blood runs through the inside of the fibers while the dialysate fluid bathes the outside of the fibers.
Hyperkalemia	A high level of potassium in the blood that can cause an irregular heart beat and ultimately cardiac arrest.
Hyperglycemia	A high level of sugar in the blood often associated with diabetes.
Hypertension	High blood pressure. Some cases of hypertension can result in kidney damage, and some cases of hypertension are caused by kidney damage.
Hypertonic Dialysate	A strong dialysate fluid (4.25 percent dextrose) used in peritoneal dialysis therapy that will pull a large amount of excess fluid from the body.
Hypoglycemia	Low blood sugar.
Hypokalemia	A low level of potassium in the blood that can cause muscle weakness or low blood pressure.
Hypoplastic/ Dysplastic Kidneys	Kidneys that are small in size with defective anatomy.
Hypotension	Low blood pressure. A potential complication during hemodialysis treatments.
Immunosuppressive Drugs	A class of medication given to transplant recipients to stop the body's immune system from rejecting a transplanted kidney. Transplant patients are put on a combination of drugs which may include: Predisone, Imuran® (azathioprine), Cellcept® (mycophenolate mofetil), Neoral® (cyclosporine), and Prograf® (tacrolimus or FK506). There are also medications that can be given by injection that are used short-term to prevent rejection, treat rejection, or both (e.g. OKT3, ATG, Zenapax®, and Simulect®). (Same as antirejection)

Intravenous (IV)	Within a vein. Liquid medications may be given directly into the vein with a needle.
Kayexalate™	Brand name for a medication used to remove excess potassium in the blood. It may be taken orally or given as an enema. It works by exchanging the potassium for sodium so potential sodium excess could occur.
Kidney	One of the two organs located at the back of the abdominal cavity, one on each side of the spinal column. Their function is to maintain the chemical balance, fluid, and waste removal of the body.
Kidney Transplantation	A technique in which a healthy kidney from a qualified donor is surgically implanted to replace kidney function.
Living Non-Related Donor	A living person who is not related to the person who needs a kidney transplant and who donates one kidney.
Living Related Donor	A related donor who offers one kidney to a family member for transplantation.
Malignancy	Having cancer or a cancerous tumor.
Membrane	In hemodialysis, the membrane refers to the material the fibers in the artificial kidney are made of through which wastes and fluid from the blood pass into the dialysate fluid. In peritoneal dialysis, the membrane is the lining of the peritoneal cavity.
Membrane Leak (Blood Leak)	A tear in the fibers of the artificial kidney which causes blood to leak into the dialysis bath. Machines can detect very small amounts of blood and alarm to prevent large blood losses.
Metabolism	Process in which foods are broken down and used for body energy and function.
Monitor	An electronic device used to check, remind, or warn.

Needle Insertion Procedure	A procedure to place large needles through the skin into a fistula or graft. The needles are then connected to the artificial kidney machine. Sometimes referred to as “needle” stick or cannulation.
Negative Pressure	Pulling pressure exerted in the dialysate compartment that causes excess water to be pulled from the blood compartment of the dialyzer across the dialysate compartment.
Nephrectomy	Surgical removal of a kidney(s).
Nephrologist	Doctor specializing in diagnosis and treatment of kidney problems, hypertension and other metabolic abnormalities of the body.
Nephron	The filters in the kidney which act to maintain the body’s chemical balance. There are approximately one million nephrons in each kidney.
Nephrosis	A condition in which there is a large and abnormal leakage of protein into the urine.
Neuropathy	Refers to any disease of the nerves. Sensitivity of the nerves is usually decreased as a result.
Nocturnal Dialysis	Hemodialysis performed at night for 8-10 hours while the patient is asleep. May be done nightly or three times per week. Improved adequacy from increased time on dialysis should ensure improved quality of life.
Non-Compliance	Not following doctor’s orders.
Osmosis	The passage of fluid through a membrane separating solutions of different concentrations. The fluid passes through the membrane from the region of lower to region of higher concentration of 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 part or all of the parathyroid glands.
Perfusion Machine	A machine that keeps a donor kidney in the best possible condition outside the body until it is transplanted into a recipient.
Peritoneal Dialysis	A process in which dialysate is put into the peritoneal (abdominal) cavity, dwelled for a prescribed amount of time, then drained. The peritoneal membrane in the abdomen functions in the same way as the membrane in the artificial kidney. Also called CAPD or CCPD.
Peritonitis	Infection in peritoneal cavity. A complication of peritoneal dialysis.
Phosphorus Binders	Medication used to prevent phosphorus absorption in persons with kidney disease (i.e., Calcium Carbonate, (Cal-Carb, Os-Cal, Tums); Calcium Acetate, (Phos-Lo, Phos-Ex); Aluminum based (Alternagel™, Aludrox™, Amphogel™, Basaljel™, Nephrox™), and Renagel, etc. These medications may help to prevent bone disease.
Plasma	The fluid portion of the blood.
Polycystic Kidney Disease	A 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	In hemodialysis, referred to as “back pressure” or “venous resistance.” Pressure exerted on the artificial kidney to cause removal of water from the blood. Increasing the positive pressure increases fluid removal. (See venous resistance.)

Posterior Urethral Valves	Found in male children; it is an obstruction in the urethra which slows the free flow of urine.
Potassium	A mineral necessary to the body, but harmful when found in excess. Hyperkalemia is a condition in which there is too much potassium in the body. Too low potassium also can be harmful.
Prime	The normal saline used to fill the lines and dialyzer prior to dialysis.
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 gross disturbances of kidney function.
Recipient	The person who is receiving the kidney transplant.
Renal	Referring to the kidney.
Renin	Hormone produced by the kidney which may cause high blood pressure.
Reuse	Reprocessing of dialyzers. After a dialyzer is used on hemodialysis, it is rinsed free of blood, chemically cleaned and disinfected. Testing is performed to measure fiber bundle volume and to check for leaks. The dialyzer may then be reused on the same patient. The number of times a dialyzer may be reused varies from unit to unit.
Saline	A salt water solution often given intravenously to patients during hemodialysis.
Semi-permeable Membrane	A material through which only certain particles may pass, and through which other particles will not pass. Dialyzers are semi-permeable membranes.
Serum	The fluid portion of the blood remaining after a clot has formed.

Sodium	One of the major chemicals of the body, found and taken into the body most commonly as table salt. When too much sodium 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. Salt substitutes contain potassium.
Steroid Drugs	Natural or synthetic chemicals closely related to certain hormones manufactured by the adrenal gland (located on top of each kidney). These powerful compounds are effective in the management of a variety of kidney diseases.
Tenckhoff™	A catheter for peritoneal dialysis.
Thrill	Vibration or buzzing sensation felt over the vein of a fistula or graft.
Tissue Typing	Refers to matching cells of individuals who are to undergo transplantation with their potential donors. The success of the transplant may be related to the closeness of the tissue match.
Toxins	Wastes that accumulate in the blood of dialysis patients that are harmful to the body's metabolic systems.
Triple Drug Therapy	The use of three drugs to treat transplant rejection. Some of these immunosuppressive medications include: Prednisone, Imuran®, Cellcept®, Neoral®, and Prograf®. Most patients will be on a combination of three of the above meds which will be chosen by the physicians based on each patients' individual needs. Each of the medications work differently to lower the body's immune response and prevent or treat rejection. All of the medications have potential side effects, most of which can be prevented or managed by your physician with other medications and/or by lowering the dosage.

Ultrafiltration	The process of removing water from the blood during dialysis by exerting positive or negative pressure on the blood in the artificial kidney.
Uremic Syndrome or Uremia	Signs and symptoms that occur as a result of the toxic effects of waste products in the body. (Nausea and vomiting, poor appetite, itching, edema, shortness of breath.)
Ureter	One or two tubes within the body that carries urine from the kidney to the bladder.
Urethra	A tube for the discharge of urine from the bladder.
Urinary Tract	The system in the body containing the kidneys, the ureters, the bladder and the urethra. The urinary tract produces urine, stores it and carries it to the outside.
Vein	A blood vessel that carries blood back to the heart from the other parts of the body.
Venous Line	The tube carrying the blood back into the body from the artificial kidney machine.
Venous Resistance	The opposing force to blood flow in the vein. (Pressure of pushing the blood from the dialyzer back into the body.)
Xylocaine™	A local anesthetic. (Same as Lidocaine)



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