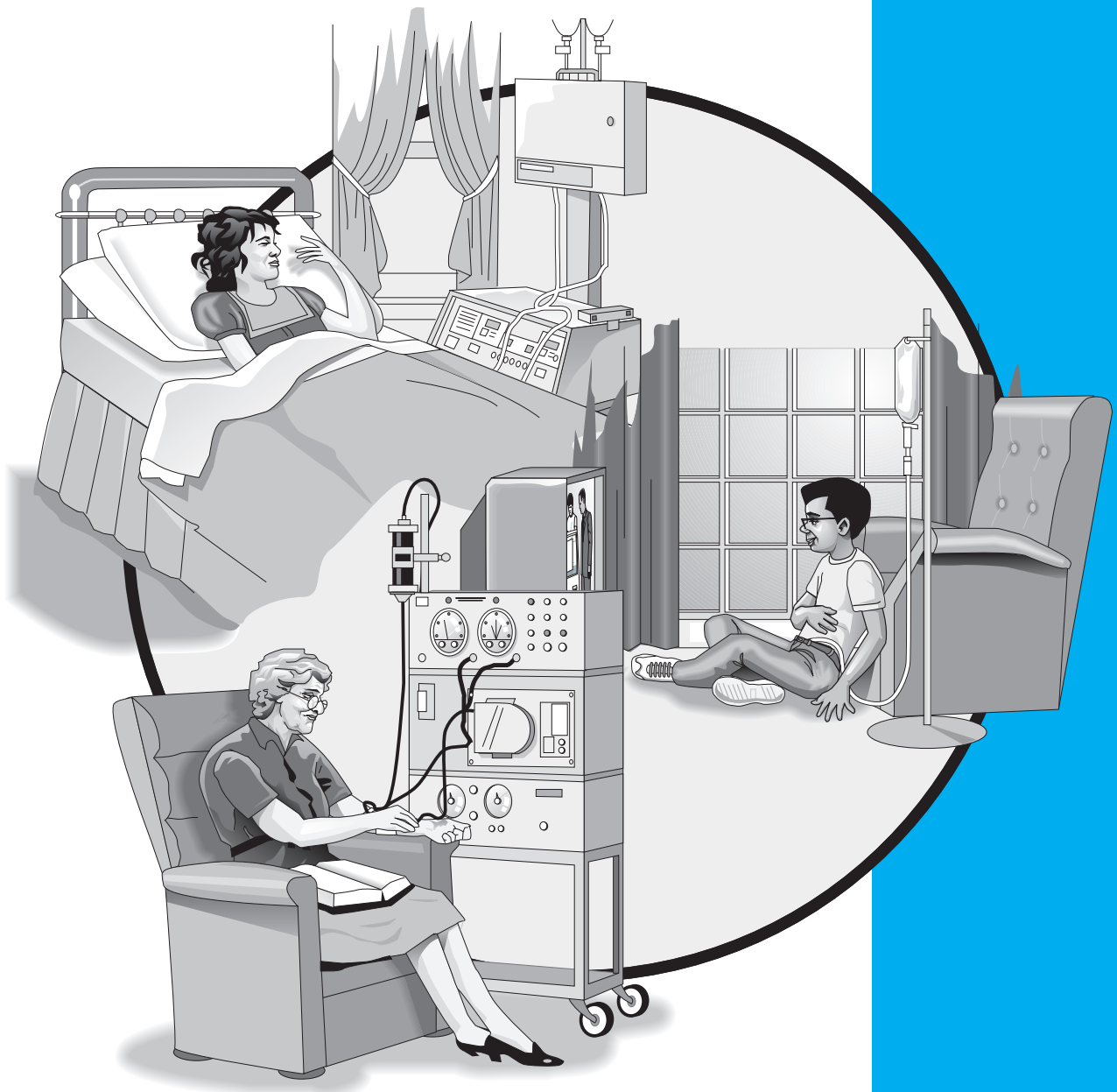


UNDERSTANDING KIDNEY FAILURE

AND SELECTING A TREATMENT MODALITY



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INTRODUCTION

For over 250,000 men, women and children in the United States, kidney failure is a condition that must be lived with each day. At the time of kidney failure or end-stage renal disease (ESRD), a patient faces several treatment options for renal replacement. This booklet has been written for you, the renal patient and your family in an effort to promote better understanding of the treatment options available. There is a strong belief by those involved in the development of this material that each patient should have the opportunity to choose the treatment modality or type that best suits the lifestyle he or she leads. By being better educated and more informed on choices that are available, the modality decision becomes less difficult.

Each treatment option is addressed in this booklet and advantages and disadvantages of each modality are listed. **These are the opinions of specific patients in the Network 8 area and may not apply in every situation to every patient. It is important for you to talk to other patients, as well as to the members of the medical team, before making a decision or forming an opinion on the various treatment choices.**

This booklet also includes basic information regarding other treatment matters such as dialysis access placement and care, dietary changes, medications, as well as other information which will enable you to make informed decisions regarding your care. Personal involvement in your care is an important factor in rehabilitation, and it may be the key to adapting to life with renal failure. This information is intended to relieve some of your anxiety, answer many of your initial questions, and stimulate the desire to learn more and become more involved in your care.

KIDNEY FUNCTIONS AND KIDNEY FAILURE

What are kidneys?

Kidneys are the twin organs shaped like kidney beans that are located below the rib cage in the middle of the back. In the adult, each kidney weighs a quarter of a pound and is about the size of a fist. Most people are born with two kidneys, however, some are born with only one kidney and can live a normal life. If someone is born with both kidneys and one fails, the person can usually live a normal life without fear of the remaining kidney failing too. In fact, a person can live without difficulty with as little as 10% of their total kidney function.

What are the functions of the kidneys?

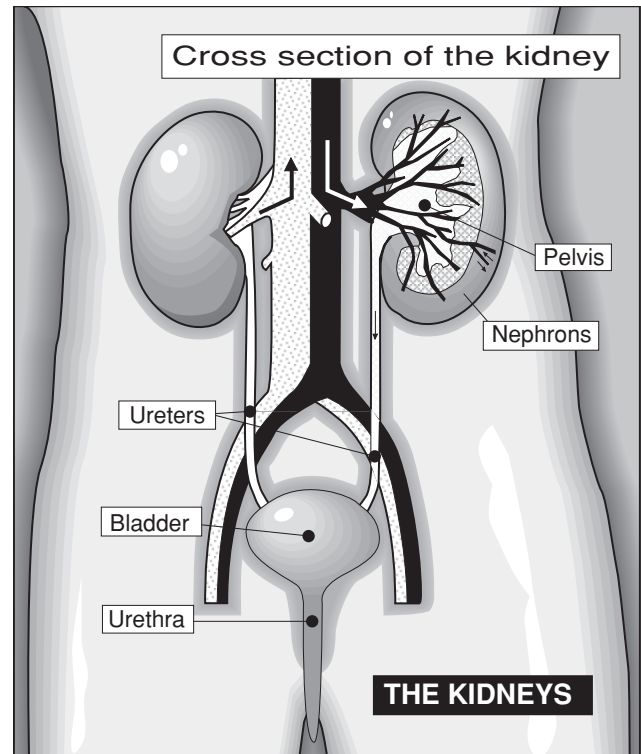
The kidneys perform life-maintaining functions that include the following:

1. Remove waste products from the bloodstream.
2. Remove excess fluid.
3. Adjust levels of minerals and other chemicals.
4. Produce hormones that regulate blood pressure and aid in the formation of red blood cells by producing the hormone, erythropoietin.

The work that kidneys do make them very special organs, but they are seldom understood or appreciated, until something goes wrong.

What causes kidney failure?

Kidney failure occurs whenever the kidneys stop cleaning the blood of wastes and toxins, removing excess fluid, or helping to maintain the balance of the body's chemistry. Chronic kidney failure or end stage renal disease (ESRD) happens gradually and is caused by damage to the kidneys. Certain infections, blockages, diabetes, high blood pressure, and diseases of the kidney can cause the kidneys to fail. Toxic drugs or chemicals may damage the kidneys to the point of failure. Some kidney diseases are



inherited, such as polycystic kidney disease. Often, the cause of kidney failure is unknown.

In ESRD, normal kidney function does not return; therefore, it is essential to obtain medical treatment. This treatment comes in the form of dialysis, which removes waste products and fluid from your blood, or kidney transplantation, in which a healthy kidney is placed in your body.

A second type of failure, acute renal (kidney) failure, is the rapid halt of kidney function which can occur for a temporary period. This may be caused by such things as severe shock from loss of blood or burn injury, or certain types of poisoning. With acute renal failure, normal kidney function may return in a few days, weeks or months.

What are the symptoms or signs of kidney failure?

Many symptoms can occur when the kidneys are not working properly. Signs and symptoms which can be related to kidney

failure include:

1. Edema - swelling of the face, feet or abdomen
2. High blood pressure
3. Loss of appetite, nausea
4. Bad taste in mouth
5. Tiredness or weakness
6. Shortness of breath
7. Mental changes such as inability to concentrate, confusion

Kidney failure may occur without warning or prior symptoms. Very often physical examinations and laboratory tests are needed to detect the problem. Other symptoms of chronic kidney disease may be present, such as: dizziness, restlessness, inability to sleep at night, itchiness all over the body, weight loss, numbness in arms and legs, and headaches. A person should always be aware of any unusual symptoms that appear and see a physician as soon as possible to find out the cause for those symptoms.

Some signs and symptoms may be related to problems other than kidney failure such as a kidney or bladder infection. These symptoms include: a change in the frequency or pattern of urination, burning during urination, and lower back pain.

What happens when the kidneys fail?

When kidneys fail, toxins, waste products and excess fluid will build up in the body and make you very sick. Treatment will be necessary, either in the form of dialysis or kidney transplantation, to replace kidney function which is necessary for life. Although non-treatment is also an option, this choice will lead to death. The time at which a person begins dialysis will be determined by the physician after blood tests and other physical assessments have been performed. With ESRD, dialysis treatments must continue for life unless a kidney transplant is received.

TREATMENT CHOICES

Which type of treatment is best for me?

Each of the three types of treatments, **hemodialysis, peritoneal dialysis and kidney transplantation**, have advantages and disadvantages. Not all treatments are suitable for all patients due to certain conditions and situations. Patients and families should discuss all choices carefully with the physician and healthcare team members. The option for non-treatment may be considered by patients or families of patients who have been seriously ill for some time, and have little quality of life remaining. This can be a very difficult decision for the patient and the family. The healthcare team can provide the needed support if this option is chosen.

Listed below are things which should be considered when choosing a treatment option:

1. **Physical condition** - Your doctor will suggest a treatment suitable for your medical condition. Every patient is not suitable for each modality. If you disagree with his suggestion, ask about other options. Are you physically able to get to the dialysis unit or perform tasks for home dialysis?
2. **Emotional condition** - Do all of the treatment options scare you? As you learn more about each treatment modality, your anxieties and fears should decrease, making the treatment options more appealing.
3. **Lifestyle** - Do you work? Do you travel? Do you go to school? Do you have small children to care for at home?
4. **Location of nearest dialysis center** - Would you have reliable transportation? The dialysis center can sometimes assist you with this.
5. **Home conditions** - Is your home suitable for home dialysis? Minor changes may need to be made in the plumbing and electrical systems for home hemodialysis.

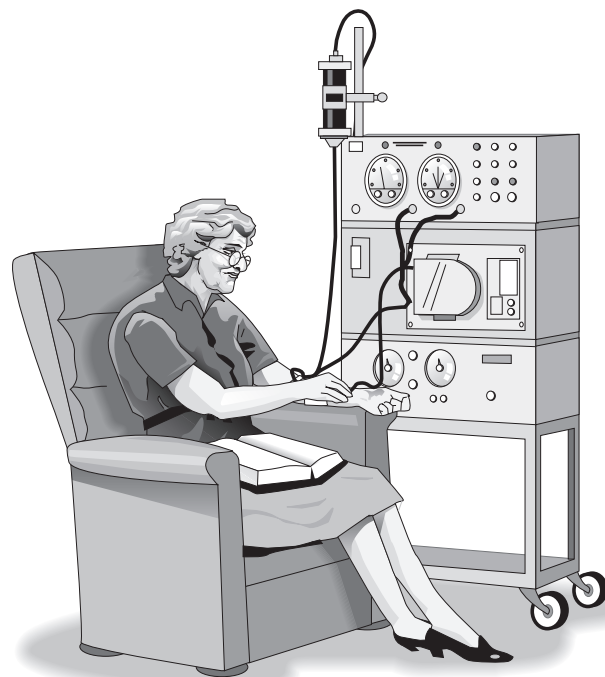
6. **Availability of support** - Do you have a family member or friend to train and help you with home dialysis? Is your family supportive of your treatment choice?

Once a decision is made, it may not be final. If a patient finds his choice unsuitable, other treatment methods will be offered if possible. Also, during the course of treatment, certain conditions may require a change in treatment modality. The physician will notify you if this occurs and discuss other treatment options with you.

HEMODIALYSIS

What is hemodialysis?

“Hemo” means blood, and “dialysis” means the movement of substances through a semipermeable membrane. A semiperme-



able membrane is a filter with tiny holes, which allows some substances to pass through. In other words, hemodialysis is a process in which substances are removed from the blood through the use of a filter.

This process is achieved by the use of an artificial kidney, or dialyzer. The dialyzer has membranes which contain filtering holes. Blood flows into the inside of the membrane and a fluid called dialysate flows around the outside of the membrane. The chemicals in the dialysate closely resemble those in the normal blood. Waste products, toxins and excess fluid in the blood pass through the membrane and are washed away. Due to the size of filtering holes, some substances, such as blood cells, do not pass through the membrane. The dialysis machine controls the rate at which the blood flows through the artificial kidney, the flow of the dialysate, and the amount of fluid removed from the blood. The dialysis machine has alarms and features which help make treatments safe. The machine noises and alarms can be frightening at first, but as you learn more about them and how the machine works, you will feel more comfortable.

Where and when will I have my dialysis treatments?

Hemodialysis can be done in the hospital, an outpatient clinic, or in the patient's home. The frequency and length of treatment time will depend on the patient's individual needs and is always determined by the physician, usually a nephrologist, who specializes in the treatment of kidney failure. The treatments are usually done three times a week for four to five hours each. If a patient chooses dialysis at home, he will need to have a helper and go through training in order to learn all about the dialysis machine and what dialysis involves.

What is self-care dialysis?

Self-care dialysis originally involved the patient managing his treatment at home with the assistance of a trained helper, usually a family member. Now patients who dialyze in a facility (in-center) frequently have the opportunity of participating in self-care dialysis. This does not always mean that the in-

center patient is completely in charge of his care, but he does have the opportunity to manage a good deal of his own care while at the facility for his dialysis treatments. For instance, he may set up his dialysis machine, insert needles into his access and put himself on the machine. There are other things he may do such as check his own blood pressure and weight during his dialysis treatment. This idea may seem frightening, but many patients enjoy self-care, and feel more in control of their disease. Many patients who learn to stick themselves find that it is much easier than having a nurse to stick them, when he or she may be unfamiliar with the access. Patients are encouraged to participate in self-care programs where available.

IN-CENTER HEMODIALYSIS

Advantages

- More intensive medical care and supervision
- Social outlet provided by clinic environment
- Ability to forget about dialysis day after treatment (no machine to look at in home)
- Support available from other patients
- Treatments only three times a week compared to daily PD

Disadvantages

- Having to be stuck by staff unfamiliar with graft, unless self-care is done
- Reuse of artificial kidneys by many dialysis facilities
- Dialysis schedule set by facility, schedule may conflict with work schedule if you have a job
- Must follow rules of facility such as eating restrictions and limitations on visitors
- More dietary and fluid restrictions than peritoneal dialysis
- Risk of access problems

HOME HEMODIALYSIS

Advantages

- Select own time for treatment
- Not required to dress or leave house
- Allowed to have unlimited visitors
- Allowed to eat while on dialysis
- Able to watch TV as desired
- No time involved for travel
- Same person assists
- Use of new artificial kidney each time
- Only three treatments a week compared to daily PD
- Have greater control

Disadvantages

- No professional medical assistance on site in an emergency situation as in in-center hemodialysis
- Less personal contact with staff and other patients
- Room needed to store supplies and machine
- Must have dependable helper
- May cause added stress on family

HEMODIALYSIS ACCESS

How does my blood get into the artificial kidney?

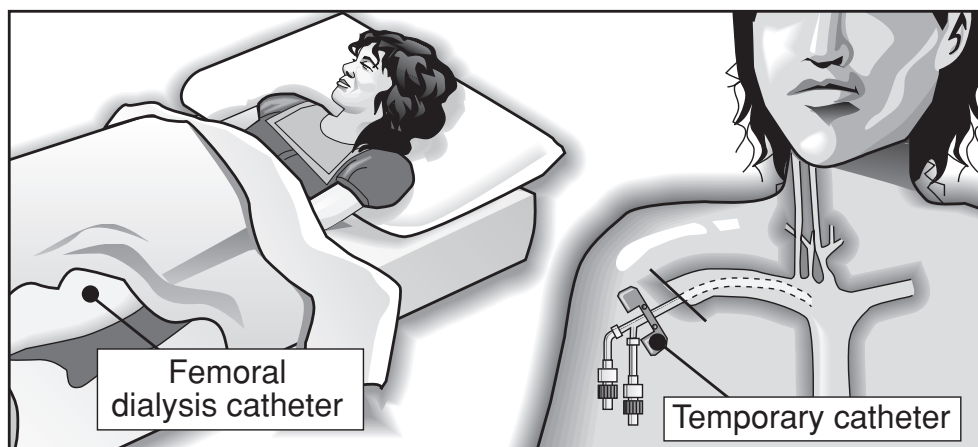
To gain entry to your blood stream, an **access** (entrance) will need to be created by a surgical procedure. The access is required because your own veins are not large enough or strong enough to withstand the blood flow required for dialysis. Usually the access is created in the arm using a local anesthetic to prevent pain. The two access types which are most common are the **native arterio-venous (AV) fistula** and the **synthetic or artificial graft**. Once a permanent access is created and is ready for use, two needles can be placed in it when a hemodialysis treatment is due. One needle is placed in the arterial end to pull blood out, and one is placed in the venous end to return the blood. Plastic tubing called bloodlines will be connected to the needles during the treatment so that your blood may enter the artificial kidney for dialysis to take place, and then return to you once it is cleaned.

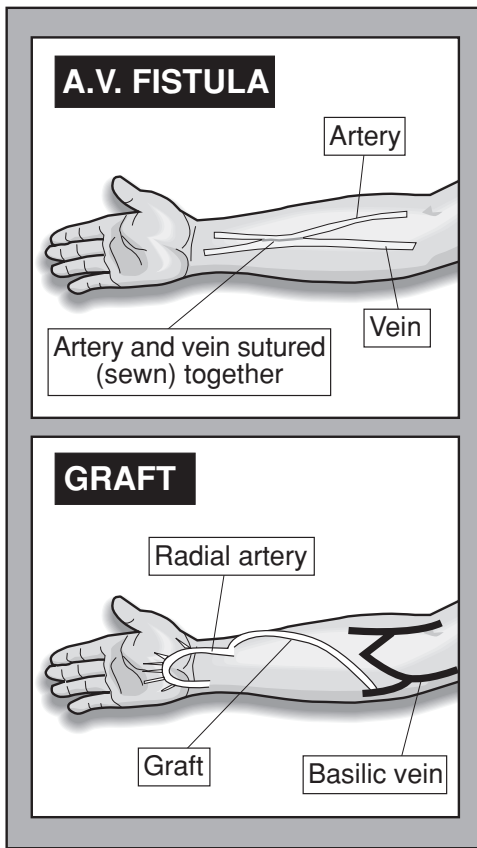
If you are diagnosed with kidney failure before you need dialysis, an access should be placed so that it will be healed, or ready for use, when dialysis has to be started. Ideally, patients should be referred for surgery to have an AV fistula placed within one year of an anticipated need for dialysis. Synthetic grafts ideally should be placed 3 to 6 weeks prior to an anticipated need for hemodialysis. Many patients do not feel this is necessary

since they are not “sick enough” at this point to need dialysis treatments. However, early placement of the access makes it much easier to use and prevents many complications.

If you require hemodialysis before a permanent access is created or has healed, your doctor may have to place a **temporary access**. The most common type of temporary access is a catheter, which is a tube placed in a large vein in the neck or groin area (femoral catheter). The catheter is stitched into place and covered with a sterile dressing. The catheter has two ports or openings which the bloodlines will be connected to. The blood will come out one port and be returned through the other. The catheter will remain in place until a permanent access is ready for use. The temporary catheter should however, be removed as soon as possible to avoid the possibility of it becoming infected. In some cases catheters may be the only access possible, due to the patient’s poor arteries and veins. In these cases, a **permanent catheter** may be placed. These catheters have “cuffs” on them which help the tissue close around it to prevent infection. These catheters often do not provide enough blood flow, causing treatments to be inadequate; therefore, they should only be used as a last resort.

A **native AV fistula** is the surgical connection of one of your own arteries to a vein, normally on the underside of the forearm. This surgical connection results in the blood from the artery flowing directly into the vein.





This pressure from the arterial blood flowing through the vein causes the vein to enlarge and strengthen. It takes several months for the veins to become large enough for dialysis, and the patient is often given exercises to do in order to speed the process. **The AV fistula is the access of**

choice because of fewer complications such as infection and clotting associated with it. However, some patients do not have adequate blood vessels to allow fistula placement, and must therefore have a graft placement.

A **graft** is made of a synthetic material in the shape of a hollow tube which is placed under the skin and is used to connect an artery to a vein. A graft may be placed in a straight line or in a loop. If your graft is a loop, you should learn which side is the arterial side and which side is the venous side. This determines how the needles will be placed. Since the graft is synthetic, complications such as infection and clotting may occur.

It is important to know that needle sites must be rotated, particularly for synthetic grafts. Many patients are more comfortable having the needles placed in the same sites with each treatment. However, if needles are continuously placed in the same sites, the access may become infected or weakened at the site, and permanent damage to the graft material will occur. These complications can lead to access failure and require replacement or creation of a new access. You can extend the life of your access by helping the nurses select new sites for needle placement.

NATIVE ARTERIO-VENOUS FISTULA

Advantages

- lower rate of complications such as clotting, infection, stenosis and steal syndrome
- have greater longevity than other accesses if well developed (works longer)
- lower morbidity (sickness) associated with the fistula, less hospitalizations related to access problems
- improved performance over time

Disadvantages

- length of time to heal before fistula may be stuck safely
- must have adequate blood vessels for fistula to be created
- some patients find the enlarged fistula physically unattractive

SYNTHETIC GRAFT

Advantages

- shorter maturation time, can be used sooner than A-V fistula
- may be easier to stick than a poorly developed fistula

Disadvantages

- higher incidence of complications such as clotting, infection, stenosis
- higher incidence of morbidity (sickness) associated with graft, may lead to more hospitalizations
- complications may require graft replacement or revision

How do I care for my access?

Instructions will be given to you once you have had an access placed. **Temporary accesses** must be kept clean and dry. Showers should be avoided, and care must be taken when bathing to avoid getting the dressing wet. The dressing will be changed by the dialysis staff each dialysis treatment. The catheter should not be pulled on or allowed to become kinked. If the site begins to bleed, leak or have drainage, notify your doctor or dialysis unit. If the catheter should fall out or be pulled out, hold pressure to the site and go to the hospital.

If you have a **permanent access**, your nurse will teach you how to make sure your access is working each day. You will be able to feel a “buzz” or “thrill” in the area of your access because of the blood flowing through it. You should get in the habit of checking this each morning, after each dialysis treatment, and several times a day. Your dialysis unit should be notified immediately if you cannot feel the “buzz”. If this occurs, it means your access is clotted and is not working.

Other measures to use to care for your graft include:

- 1) Do not allow anyone to take your blood

pressure in your access arm. Do not allow anyone except dialysis staff to start an IV or draw blood from your access arm.

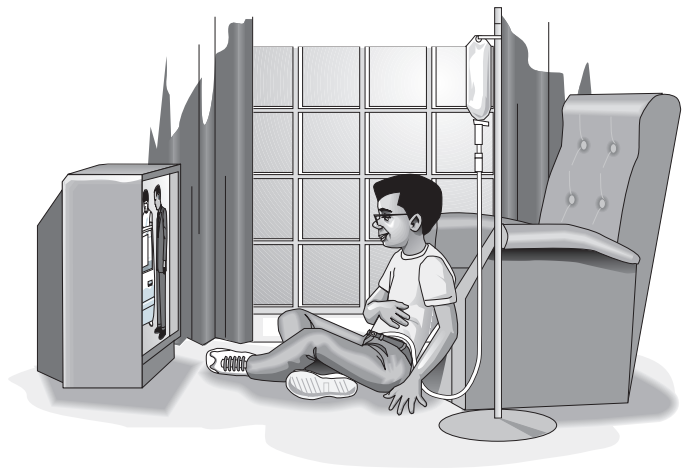
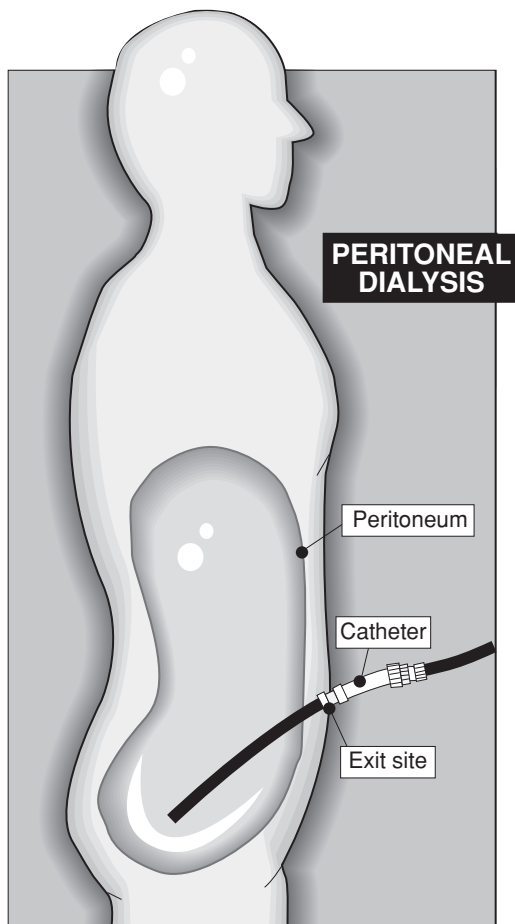
- 2) Do not wear tight sleeves, watches, or carry a purse on your access arm.
- 3) Do not sleep on your arm or with your arm tightly bent.
- 4) Report immediately any signs of access infection such as fever, redness, pain, drainage or swelling in your access arm.
- 5) If bleeding reoccurs from needle sites, apply light pressure at once until bleeding stops. If bleeding is heavy or continues for an extended period of time, continue to hold pressure and report to the emergency room.
- 6) Report any signs of low blood pressure, such as dizziness, lightheadedness, or palpitations (irregular heartbeat) to the dialysis staff. Low blood pressure can slow the blood flow in your graft and allow it to clot.
- 7) Wash your arm with soap and water prior to your dialysis treatment. Make sure the nurse cleans your access site with antiseptic before placing the needles.

PERITONEAL DIALYSIS

What is peritoneal dialysis?

Peritoneal dialysis involves the use of the peritoneum as a means of removing wastes and excess fluid from the body. The **peritoneum** is the lining of the abdominal cavity and surrounds the intestines and other organs in the abdominal area. It functions like the membrane of the dialyzer or artificial kidney in hemodialysis. The many tiny holes in the peritoneal membrane filter out the waste products and other chemicals.

Access to the peritoneal cavity is created by surgically placing a catheter or tube in the abdominal wall. This is commonly done under local anesthesia. During treatments this catheter is used to fill the peritoneal cavity with a special solution called dialysate. The dialysate is allowed to remain in the peritoneal cavity for several hours. During this time, waste products and fluids move from your blood, through the peritoneal



CAPD

(Continuous ambulatory peritoneal dialysis)

membrane, into the dialysate which will be drained from your abdominal cavity later.

There are three different forms of peritoneal dialysis: continuous ambulatory peritoneal dialysis (CAPD), continuous cycling peritoneal dialysis (CCPD), and intermittent peritoneal dialysis (IPD). Both CAPD and CCPD are performed at home while IPD is performed in a hospital.

What is Continuous Ambulatory Peritoneal Dialysis (CAPD)?

CAPD is usually done every four to six hours. The bag of dialysate is first drained into the abdomen by positioning the bag above the head and releasing a clamp on the tubing. When the bag is completely drained, the tubing is clamped off and the bag is either folded and stored inside the clothing or detached completely and used later to drain the fluid. The fluid is allowed to remain in the abdomen about 4-6 hours, long enough for dialysis to take place. When it is time to drain the fluid, the empty bag is placed on the floor, and the fluid is drained through the peritoneal catheter into the bag. The process is then repeated with fresh dialysate again drained into the peritoneal cavity. Each process is called an exchange and requires about half an hour to complete. For CAPD patients, exchanges are usually done four

times per day beginning first thing in the morning and ending right before bedtime.

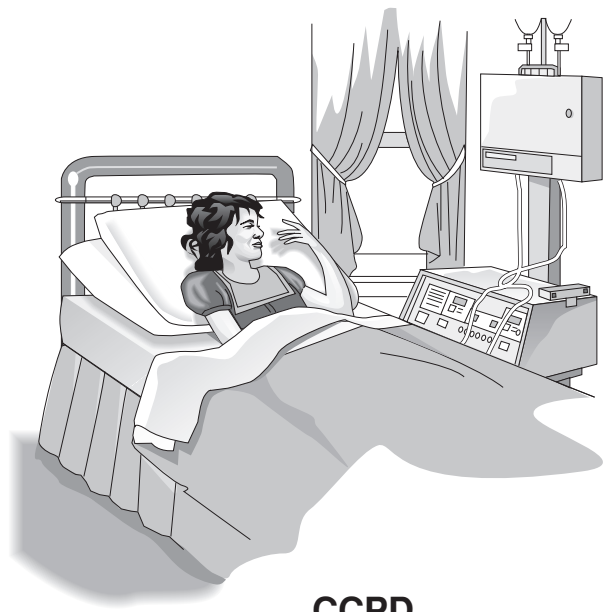
What is Continuous Cycling Peritoneal Dialysis (CCPD)?

This form of dialysis is a variation of CAPD and is achieved using a machine called a cyclor. The procedure is done at night while the patient sleeps, and is an eight to ten hour process. The catheter is connected to the cyclor machine, and during the night the cyclor continuously fills and drains the dialysate from the abdominal cavity. The dialysate is left in the abdomen during the day, and the process is repeated each night. One to two manual exchanges during the day may be ordered by your physician to increase the adequacy of the treatment.

Many patients like this type of dialysis because they are only hooked up to the machine while sleeping, and their daytime hours are generally free. It allows them to “forget” about dialysis at least for a short period of time.

What is Intermittent Peritoneal Dialysis (IPD)?

This type of dialysis may be done in a hospital setting and is also another form of peritoneal dialysis. A solution is cycled by a machine like CCPD. The treatments occur several times per week, usually for ten to fourteen hours each time. The process is the same as other forms of peritoneal dialysis in that it works to remove waste products and excess fluid from the body. A form of IPD is occasionally done at home, using the cyclor nightly. This is called NIPD. The cyclor is disconnected in the morning after the abdomen is drained, and the abdomen remains dry during the day. Because of adequacy concerns, many physicians favor CCPD over NIPD.



CCPD
(Continuous cyclor peritoneal dialysis)

CONTINUOUS AMBULATORY PERITONEAL DIALYSIS (CAPD)

Advantages

- More liberalized diet (more food choices allowed)
- Fluid restriction less
- Does not require machine
- Schedule more flexible
- More freedom to travel
- Can be done in many locations
- No use of needles

Disadvantages

- More prone to infections than with hemodialysis
- Not offered by all facilities
- Must have treatments daily every 4-6 hours
- Abdomen full of fluid all the time
- Everything must be sterile during exchanges
- Requires a tube (catheter) in the abdominal wall

CONTINUOUS CYCLING PERITONEAL DIALYSIS (CCPD)

Advantages

- Daytime usually is not taken up with any form of dialysis
- Patient normally asleep during treatment
- More liberalized diet (more choices) than with hemodialysis
- Fluid restriction less
- Can switch to CAPD when traveling
- No use of needles

Disadvantages

- More prone to infections than hemodialysis
- Feeling confined to a machine
- Machine waking patient during the night

PERITONEAL DIALYSIS ACCESS

How do I care for my peritoneal dialysis catheter?

Specific instructions for catheter care will be given to you by your doctor after it has been placed. These should be followed closely in order to prevent complications. Generally, immediately following insertion, the site is covered with a sterile dressing which is not changed for several days. Movement of the catheter should be avoided. Dressing changes are to be performed as instructed, usually using an antiseptic scrub to clean the exit site. The catheter may be taped to the abdomen to prevent pulling or twisting the catheter. Once the site is healed, daily site care is begun, using an antiseptic scrub or soap and water, depending on your doctor's preference.

Some patients are instructed to cover the site, while others are advised to leave the site open to air. Patients can start showering and cleaning the exit site 2 to 8 weeks after insertion, depending on the doctor's instructions. Patients should be aware of signs and symptoms of infection and report these immediately to the doctor or home-training nurse. Infection can occur at the exit site, in the catheter tunnel, and in the peritoneal cavity, itself. These signs and symptoms include:

- redness at exit site
- purulent drainage or pus at exit site
- pain or tenderness at exit site
- abdominal pain, fever and cloudy dialysate (fluid drained from abdomen) may indicate peritonitis or infection of the peritoneum or peritoneal cavity

KIDNEY TRANSPLANTATION

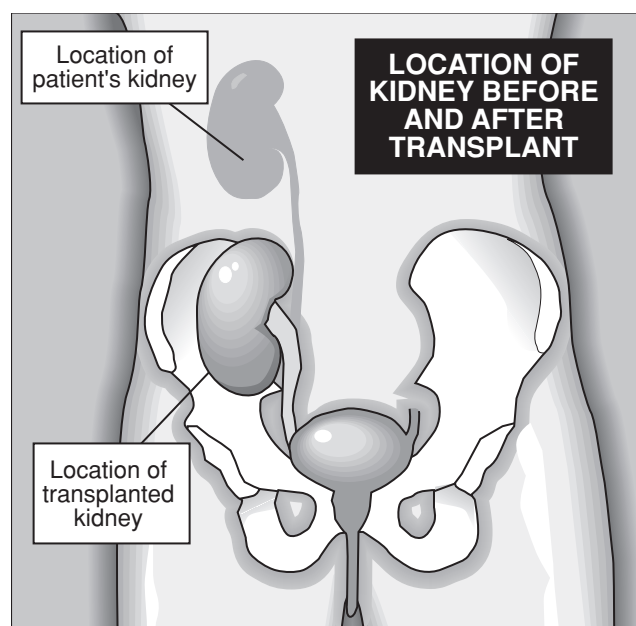
What is a kidney transplant?

A kidney transplant is the surgical placement of a healthy human kidney into the body of a patient with kidney failure. Its goal is to replace kidney function with the donor kidney and improve the quality of life for the patient. Many people think of a kidney transplant as the absolute cure for kidney failure, and though a transplant does improve the quality of life and life expectancy for a patient, it is considered a treatment rather than a cure.

How is a kidney transplant achieved?

A healthy kidney from another person (**donor**) is placed near your hip bone through a surgical procedure and joined to an artery and vein in that area. Generally, your own kidneys are not removed. However, in some cases this may be required to control persistent infection or high blood pressure. The donated kidney can perform all of the functions that your damaged kidneys are unable to do.

Each patient who is interested in transplantation will have a complete evaluation done by his physician. This includes a screening process and medical workup to determine if the patient is a good candidate for this form of treatment. Transplantation may not be appropriate for every patient because of certain medical problems and health complications. Age may also be a factor in determining if a person is a good candidate for transplant. The upper age limit for transplantation is usually 65 to 70 years of age. Older patients may have a greater risk of developing medical complications; but, these patients should not be excluded from transplant screening. Many transplant programs require that dialysis patients be compliant or follow their hemodialysis (or peritoneal) treatment orders in order to be considered for transplantation.



Where do donor kidneys come from?

There are two major sources from which donor kidneys may come, and a third source becoming more common. The first is from a **living-related donor**, who is a healthy family member with no history of kidney problems. The blood and tissue of both the donor and the recipient (patient receiving the kidney) are tested to find if they match or are compatible.

The second and largest source of donor kidneys is through a **cadaveric donor**. A cadaveric kidney comes from someone who has died or is braindead, usually from a stroke or head injury. The donor's family has consented to organ donation and given permission to remove the kidneys from the patient and donate them to someone else. If a dialysis patient does not have a relative who is able or willing to donate, he or she may be placed on a waiting list at a chosen transplant center to receive a cadaveric kidney. The patient will then be called when a possible match with a cadaveric donor has been found. The length of time that a patient remains on this list may vary from a few months to several years, depending on the availability of organs and the difficulty of matching.

The third and final source for donor kid-

neys is through a **living non-related donor**, such as a spouse or close friend. This type of transplant has just recently become a more common practice. Generally, family members are considered to be the closest tissue match, but successful transplants are common with non-related living donors as well as with cadaveric donors.

What medications will be required after being transplanted?

Once a patient has been given a new kidney, he will be required to take several medications in order to keep the body from rejecting the transplanted organ. These drugs are taken to suppress or overpower the immune system of the patient's body. These drugs, called immunosuppressives, restrict the natural response of the body to reject the newly transplanted kidney as a foreign object. The drugs must be taken throughout the life of the transplanted kidney.

Occasionally, there are problems associated with the medications needed to keep the body from rejecting the transplanted kidney. For instance, a patient may become unprotected against infections or may develop stomach problems. Normally, medication is given to the patient to keep him from developing stomach problems such as ulcers. Some other effects of the medication may be weight gain, growth of facial hair and fullness in the face. Weight gain may be due to an increased appetite since dialysis has been stopped and the patient generally feels better. Most of these side effects are temporary and decrease as the dose of medication is reduced.

Overall, the patient's health and quality of life are dramatically improved after transplantation. The diet and fluid intake is much less restrictive after transplantation, and patients are able to lead a fairly normal life.

After a successful transplant, the patient will be closely examined at specific intervals to assure that the kidney is working proper-

ly and to evaluate medication dosages. It is very important for a transplant patient to remember that his physician should be notified at the earliest sign of any problems with the transplanted kidney. Some patients experience bouts of acute rejection and these can often be controlled by a change in medication. If rejection does take place and cannot be corrected, the transplanted kidney may or may not be removed, and the patient returns to dialysis.

Some kidney patients have been transplanted more than one time during their lives. If the transplanted kidney fails, the patient may be able to go back on the waiting list and will dialyze while waiting for another kidney.

KIDNEY TRANSPLANTATION

Advantages

- Feel healthier
- More energy
- Live almost normal life
- Frees patient from dialysis
- Able to work full time without regard to treatment schedule

Disadvantages

- Possible side effects of medications
- Possible weight gain and body changes
- Required to take medication daily, medications costly
- Current limitations on Medicare coverage of medications
- Rejection risk

RENAL FAILURE IN CHILDREN

Although treatment for kidney failure is basically the same in children and adults, the causes of kidney failure, potential complications and special needs are unique in children. The most common causes of kidney failure in younger children are malformed kidneys and urinary system obstruction or blockage. Chronic glomerulonephritis is the most common cause of kidney failure in older children and adolescents. Glomerulonephritis is a disease caused by chronic inflammation of the glomeruli which are the filters of the kidney.

Both peritoneal and hemodialysis may be started at any age, however different factors are considered in the choice of treatment modality in a child. The child's age and wishes, if old enough, as well as the parents' desires and abilities will be considered in the decision. In adults, both peritoneal dialysis and hemodialysis have advantages and disadvantages. Basically they are the same in children. Peritoneal dialysis is usually the modality of choice for children since it may be less technically and psychologically difficult for the child. Peritoneal dialysis can be performed at home by the parents or other adults on the infant or younger child. An older child or adolescent may be able to perform his own treatments. Hemodialysis treatments may also be done at home or at a dialysis facility.

A kidney transplant should always be considered in children. Transplantation in children can greatly reduce and even reverse some of the complications that long term kidney failure may cause. Along with the complications which occur in adults such as high blood pressure, anemia, heart and bone disease, unique complications of renal failure occur in children. These include: failure to thrive in infants, reduced growth rates, delayed puberty and infertility. Careful attention to diet and administration of

growth hormones can help minimize these complications.

Careful attention must also be given to the psychosocial development of the child. Fear, depression, and the feeling of being different from other children can lead to isolation. While there may be times when the child is too sick to attend school, the child should not be allowed to use kidney failure as an excuse to continually miss school or avoid doing homework. It is important for the child to remain involved in activities he enjoyed prior to kidney failure. Peer support from other children and parents affected by kidney disease can provide help with coping. Patient organizations, as listed in this booklet, can provide information and support beneficial to both patients and family members. Summer camps are available to children with renal failure. Coping with a child's chronic illness is very difficult for both the child and the family. Your healthcare team and patient organizations are always available for support and assistance.



DIALYSIS ADEQUACY

Dialysis treatments, both hemo and peritoneal, replace only a small part of normal kidney function. Therefore, it is very important that **adequate or enough** dialysis is received. Recent studies have shown that some dialysis patients are underdialyzed. These patients feel sick, are unhealthy, and do not live as long as those receiving adequate treatments. Inadequate treatments do not remove enough waste products from your blood, resulting in symptoms such as weakness, poor appetite, nausea and weight loss. Underdialysis may also lead to serious complications such as malnutrition, infections, prolonged bleeding and inflammation of the heart. These complications can lead to hospitalizations and in some cases, death.

Doctors have developed several ways to determine the amount of hemodialysis or peritoneal dialysis that is actually delivered. They have also done studies and have evidence to support the recommended amount of dialysis a patient should receive. These recommendations which follow have been established or agreed upon by the Renal Physicians Association (RPA), the National Kidney Foundation (NKF), and the American Association of Kidney Patients (AAKP). You should be aware that the following are minimum standards and individual patients may require greater levels than those listed.

HEMODIALYSIS ADEQUACY MEASUREMENT:

1. **URR (Urea Reduction Ratio)** - determines how much urea (a waste product) was removed from your blood during the dialysis treatment. Blood is drawn before and after your dialysis treatment to determine the “pre” and “post” blood urea nitrogen concentration (BUN). For adequate dialysis, your **URR should be 65% or greater**.

2. **KT/V** - a more complicated formula used to determine the amount of dialysis

needed (prescribed) and received (delivered). This formula can determine the amount of your protein intake and the amount of the protein waste products (urea) removed by your dialysis treatment, by using the “pre” and “post” BUN levels drawn. For adequate dialysis, your **KT/V should be 1.2 or greater**. Hemodialysis adequacy should be measured every month.

PERITONEAL DIALYSIS ADEQUACY MEASUREMENT:

1. **Weekly KT/V** - describes the amount of urea removed by your PD treatments plus any removed by the remaining (residual) function of your kidneys. If you are on CAPD, your **KT/V should be 2.0 or greater**. A slightly higher KT/V is recommended for CCPD and NIPD.

2. **Weekly Creatinine Clearance** - describes the amount of creatinine (another waste product) removed by your PD treatments plus any removed by the residual function of your kidneys. If you are on CAPD, your weekly **creatinine clearance (CrCl) should be 60L (liters) or more**. If you are on CCPD or NIPD, a slightly higher creatinine clearance is recommended.

Suggested frequency of measurement for peritoneal dialysis adequacy is every four months.

How can I find out if my treatments are adequate?

You can ask your nurse, dietitian or doctor at your dialysis unit for your adequacy numbers.

What can cause my treatments to be inadequate?

If you are on hemodialysis:

- Cutting your treatment time short, missing treatments, turning down your blood pump speed, or not following your diet can lead to inadequate treatments.

- Other factors related to inadequate treatments are access problems or clotting dialyzers.
- Your initial prescription may become inadequate over time due to factors such as weight changes, diet changes, or decrease in urine output. The doctor may increase your treatment time, the size of your dialyzer, and/or the rate of your blood pump speed to make the prescription adequate.

If you are on peritoneal dialysis:

- Inadequate treatments can be caused by failure to follow your dialysis prescription by skipping exchanges, reducing fill volumes (the amount of fluid you fill your belly with), or shortening dwell times (the length of time fluid remains in your belly).
- Inadequate treatments may be the result of the prescription itself, requiring the doctor to make adjustments in it.

- Other factors related to inadequate treatments are peritonitis (infection of your belly), catheter problems, and peritoneal membrane changes.

What can I do to keep my treatments adequate?

- Follow all doctor's orders regarding dialysis treatments, diet and medications. Do not cut your treatment time short. Every minute counts for a better treatment.
- Notify your nurse, doctor, or dietitian if you are experiencing uremic symptoms such as weakness, always feeling tired, nausea or poor appetite.
- Know your numbers and talk to your doctor, nurse or dietitian if they are too low.

**REMEMBER: ADEQUATE DIALYSIS
LEADS TO BETTER, HEALTHIER,
LONGER LIVES!**

OTHER IMPORTANT NUMBERS

As a dialysis patient, you will have many routine lab tests performed. These tests will not only reveal the adequacy of your dialysis treatments, but they will reveal information regarding your nutritional status and your hematologic (blood) status. Your dialysis nurse, dietitian and/or physician should review this lab work with you on a routine basis.

Nutrition

Dialysis patients may become malnourished at times for several reasons. Malnutrition may be due to inadequate (not enough) protein intake due to a poor appetite or restricted diet, or protein losses during dialysis or any serious illness. The lab value which monitors nutritional status is the **albumin level**. Your albumin level should be **3.8 - 4.0 g/dl or higher**. If your albumin falls below this level, your diet may need some adjustments; nutritional supplements may need to be ordered; or your dialysis prescription may need to be changed.

Anemia

Dialysis patients may also become anemic. Being anemic means your blood count is too low. Anemia can result in such symptoms as fatigue (weakness or tiredness), inability to concentrate, shortness of breath, and chest pain. If left untreated, complications such as enlargement of the heart and heart failure may occur. Several factors contribute to anemia in dialysis patients. Normal kidneys produce a hormone (erythropoietin) which helps make red blood cells. When your kidneys fail, this function is reduced, and less blood cells are made. Iron deficiency is another contributing factor to anemia. Your body must have enough iron to produce red blood cells.

Many lab tests can reveal information relating to anemia. The primary tests to monitor are hematocrit and hemoglobin levels

and iron studies. Hematocrit is the percentage of whole blood made up of red blood cells. Your **hematocrit** should be in the range of **33% - 36%**. If your hematocrit is below this level, your doctor will most likely prescribe Epogen (EPO) - a medicine which helps the body make red blood cells. Hematocrits will be monitored weekly to twice monthly, and your EPO dose should be adjusted as needed to keep your hematocrit in this range. There is also another measure called hemoglobin, which is similar to hematocrit, which may be used by some physicians to measure the amount of red blood cells. Your **hemoglobin** level should be **11-12g/dl**.

Two lab tests which monitor iron levels are: ferritin and transferrin saturation. These tests are usually monitored monthly to quarterly. Your **ferritin level** should be greater than **100ng/ml**. Your **transferrin saturation** should be at least **20%**. If your iron studies indicate your levels are too low, the doctor may prescribe iron supplements which may be taken by mouth, or given intravenously through your bloodlines during hemodialysis. With the use of EPO and iron supplements, anemia can be corrected, your energy level will increase, and your overall well-being may improve. Through the development and use of these medications, patients are no longer dependent on blood transfusions, as in the past, to correct anemia.

These numbers as well as your adequacy numbers reflect how healthy you are, and how well your treatments are working. Ask your dialysis staff to discuss all of them with you. You can be the key to receiving quality care. Remember, your life depends on it!

MEDICATIONS FOR DIALYSIS PATIENTS

Your kidney doctor will prescribe routine medications for you to take. These medications play an important role in your dialysis therapy. Therefore they should be taken exactly as prescribed. Medications prescribed by other doctors, and over-the-counter medications such as laxatives, cold, fever, headache or pain medicines should not be taken without the approval of your dialysis nurse or kidney doctor. Listed below are commonly prescribed medications for dialysis patients.

Vitamins - prescribed due to restrictive diet and removal of some vitamins during dialysis.

Iron - prescribed to increase iron stores needed for red blood cell production. Iron may be given by mouth or intravenously (through your bloodlines) during hemodialysis.

Epogen - prescribed to help make red blood cells. Epogen (Epoetin alfa or EPO) may be given subcutaneously (a shot just under the skin, like an insulin injection) or intravenously during hemodialysis.

Phosphate Binders - used to bind excess phosphorus in your food before it gets to the blood. Excess phosphorus is normally excreted by your kidneys. With kidney failure, the excess phosphorus is not removed and can cause bone disease and other problems. Phosphate binders are taken with each meal.

Calcium Supplements - may be prescribed if your calcium level is too low. Calcium is important in bone production and normal function of your heart and muscles. Calcium supplements may be given by mouth or intravenously when on hemodialysis.

Vitamin D Supplements - aid in absorption of calcium. May be given by mouth or intravenously during hemodialysis.

Anti-hypertensives - prescribed if your blood pressure is too high and uncontrolled after excess fluid removal.

Antibiotics - prescribed for any type of infection. May be given by mouth or intravenously during hemodialysis. Commonly given for access infections.

MEDICATIONS GIVEN DURING HEMODIALYSIS TREATMENTS

Some medications are routinely used during a hemodialysis treatment, while others are available for use to prevent or treat mild side effects resulting from the treatment. Not all dialysis facilities use or stock the same medications. Listed below are those commonly used.

Normal Saline - an intravenous solution routinely used by all facilities to clear the air from the artificial kidney and bloodlines prior to the dialysis treatment. Also used to rinse back your blood upon completion of the treatment. May be used to replace fluid if side effects (such as muscle cramps) occur with fluid removal.

Heparin - used to prevent clotting of your blood in the artificial kidney (dialyzer). May be given as a bolus (large dose) at the beginning of the treatment or as a bolus and then throughout the treatment.

Hypertonics - strong saline or glucose solutions used to aid in fluid removal and prevention of side effects which may occur with excess fluid removal.

Other medicines commonly used as needed are medications for nausea, medications for headaches or fever, and medications for itching.

RECOMMENDED VACCINATIONS FOR DIALYSIS/ TRANSPLANT PATIENTS

Dialysis and transplant patients have a weakened ability to fight infection. Therefore it is recommended that they receive the following vaccinations. Ask your doctor or nurse about them.

- **Hepatitis B vaccine** - for prevention of Hepatitis B virus. This vaccine is given in a series of three injections usually when starting dialysis. The vaccination lasts for life.
- **Influenza vaccine** - given yearly for prevention of the flu.
- **Pneumococcal vaccine** - for prevention of pneumonia. The vaccination usually lasts for life.

THE RENAL DIET

Why is it important to change the diet of a kidney patient?

Normally, healthy kidneys control and manage levels of certain substances in the bloodstream. The most important substances are protein, sodium, potassium, and phosphorus. When the kidneys do not function, these substances can build up to dangerous levels in the bloodstream and cause uremia and other serious problems. Dialysis removes only some of these waste products. Fluid is another concern related to the renal diet. When kidneys fail, excess fluid cannot be removed. Fluid builds up in the body and collects in the bloodstream, tissues and lungs, causing heart problems, breathing problems, and high blood pressure. Fluid intake, therefore, must be limited. Normal kidneys work 24 hours a day removing waste products and excess fluids. Since dialysis cannot replace all the work that the normal kidneys did, dialysis patients must follow a restricted diet and limit fluid intake in order to help manage their kidney disease. The following text briefly describes the renal diet. Your dietitian will fully explain the diet to you.

What is the importance of protein?

Protein is necessary for building, maintaining, and repairing body tissues. A certain amount of protein is necessary for all of these, especially in dialysis patients. The waste product of protein is called urea. Failed kidneys cannot remove enough urea from the body, causing it to build up in the blood stream. The blood urea nitrogen (BUN) level is the amount of protein waste products in the blood. If this level is too high, symptoms of uremia may occur. These symptoms include nausea, vomiting, tiredness and confusion. The amount or type of protein intake may be restricted in your diet to avoid these problems. On the other hand, if your body does not get enough protein,

muscle wasting, reduced energy levels, and slow healing of wounds can occur. Your dietitian will monitor your protein and BUN levels to provide dietary instructions.

What is sodium and why is it restricted in the renal diet?

Sodium, a mineral found in the body's tissues, helps regulate the fluid content of the body's tissues. If the kidney patient has high blood pressure, sodium intake is already restricted. Since excess sodium cannot be excreted because the kidneys have failed, it is moderately to strictly controlled in the diet. Excess sodium can cause fluid to build up in the tissues. This places extra strain on the heart and causes high blood pressure.

Many people think that salt and sodium are the same thing, but in fact, they are not. Salt does contain sodium, however, and is the most common source of sodium in the diet. While some foods contain some sodium they do not all have added salt.

Foods high in sodium include:

- canned and processed meats such as ham, bacon, sausage, and cold cuts
- potato chips, nuts, pickles, olives, and other salty tasting foods

There are other foods too numerous to list; information on these may be obtained from the dialysis facility's dietitian.

Will I be able to use salt substitutes instead of table salt?

Unfortunately, the main ingredient in most salt substitutes is potassium. Potassium is also restricted in the renal diet. For this reason salt substitutes should never be used. Your dietitian may suggest alternative ways to season your food.

What is potassium and why must it be monitored?

Potassium is a mineral needed for normal

muscle and nerve function. Since the heart is a muscle, potassium has a direct effect on the heart beat. With normal kidney function, excessive amounts of potassium are excreted in the urine. When a person has no kidney function, potassium builds up in the blood until it is removed by dialysis. If the level of potassium becomes too high, it can cause muscle weakness and affect the beating of the heart. This abnormal heart beat can be so dangerous that it may cause cardiac arrest. This is when the heart stops beating. Occasionally, your potassium level may be too low. This can cause the same problems as when your potassium is too high. This tends to occur more in peritoneal dialysis patients and in malnourished patients. Your potassium level will be monitored routinely. It should be in the range of 3.5 - 5.5 mEq/L. Your dialysis staff will review your labwork with you and instruct you if changes need to be made regarding potassium intake in your diet.

Foods High in Potassium:

- Fruits such as oranges, orange juice, bananas
- Vegetables such as tomatoes and tomato products, broccoli, spinach, dried beans and peas, potatoes
- Chocolate and nuts
- Meats and milk products
- Salt substitute products

Obviously all of these foods cannot be avoided. Your dietitian will teach you how and when to restrict potassium in your diet.

What is phosphorus and what is its importance?

It would be difficult to talk about phosphorus without also talking about calcium. Calcium is the most abundant element in the body, with phosphorus a close second. Both of these elements are needed to form bones. In order for the body to utilize calcium from food, vitamin D must be present. However, since the non-functioning kidneys cannot

activate vitamin D, calcium from food eaten is not absorbed well. This results in a drop in calcium in the bloodstream.

When the kidneys are not functioning, phosphorus can build up in the bloodstream, which causes a decrease in the level of calcium. High levels of phosphorus in the bloodstream can rob the bones of calcium, making the bones weak and brittle. This can lead to bone disease which causes severe pain and also causes bones to break easily. A high phosphorus level can also cause calcification (hardening) in the blood vessels, soft tissues, and skin (which causes itching). Your calcium and phosphorus levels will be monitored routinely. Your phosphorus level should be in the approximate range of 4.5 - 5.5 mg/dl. Your calcium level should be in the approximate range of 9.0 - 11.5 mg/dl. (Acceptable lab values may differ slightly from physician to physician or from unit to unit.) Proper diet and medications will help control the balance of phosphorus and calcium and help prevent complications.

Foods High in Phosphorus:

- Dairy products such as milk, cheeses, ice cream
- Vegetables such as dried beans and peas
- Whole grain breads and cereals
- Protein foods such as meats, peanut butter
- Nuts and chocolate

Again, all of these foods cannot be avoided. Your dietitian will give you detailed instructions regarding phosphorus in your diet.

Why is it important to control fluid intake for a dialysis patient?

Kidneys that are properly working prevent the build up of fluid in the body by removing what the body doesn't need through urination. When the kidneys are not functioning, fluid collects in the tissues (causing edema or swelling) and in the bloodstream, placing

a strain on the heart and causing high blood pressure. In some cases, fluid may also collect in the lungs making breathing difficult. With kidney failure, you may continue to urinate in small amounts. This may allow you to drink more fluids than patients who have no urine output. However, this will not keep you from needing dialysis treatments.

Fluid sources:

- water, tea, coffee, fruit juice, sodas, alcohol, beer
- ice
- ice cream, sherbet, popsicles, milkshakes
- soup, broth
- juice from vegetables and fruits
- jello

Is it possible to not get enough fluid?

There may be times when a person with kidney failure loses fluid through excessive perspiration or sweating, vomiting, or diar-

rhea, causing dehydration, which is not having enough fluid in the body. Symptoms include lightheadedness, weakness, nausea, and muscle cramps. Low blood pressure or hypotension will likely occur with dehydration. These symptoms may also occur if too much fluid is removed during a dialysis treatment. This problem can be corrected by giving fluid intravenously during your hemodialysis treatment or through intake of fluids by mouth.

Are all of these dietary changes necessary for hemodialysis, peritoneal dialysis, and transplant patients?

Each type of dialysis will require different dietary changes. Each person is different and may have different nutrient needs. There are fewer dietary changes required for peritoneal dialysis patients than for hemodialysis patients and even fewer for the transplant patient.

QUALITY OF LIFE

COPING WITH KIDNEY FAILURE

Since each individual is different, each patient's response to kidney failure will not be the same. Some patients find the challenge extremely demanding, while others make fairly simple adjustments. Many lifestyle changes will occur that not only affect you, the patient, but others around you such as your spouse, children, friends and co-workers. Diet restrictions, new medications, treatment schedules, anxieties, fears and physical changes are only a few issues that you will have to face. Adjusting to these changes will take time, but you can do it!

A strong support system with family members and friends is important to have. Talk about your concerns and feelings with your family and allow them to talk about their feelings also. Seek out other patients with kidney failure and share your questions and concerns with them. They can be a valuable resource since they have experienced many of the same concerns. Utilize your social worker and patient groups for support.

Don't let kidney disease take control of your life. You can take control of it by learning as much about it as possible and by remaining active. Study the information given to you by your doctor, nurses and dietitians. Attend patient meetings and educational seminars. Ask questions when you don't understand something, or something seems wrong. Take responsibility for your care by following your diet, taking your medicines and watching your labwork. You may want to consider self-care or become a leader in your facility as a patient advocate. Continue to participate in outside activities which you enjoyed prior to having kidney failure, such as work, school, church, clubs, and hobbies.

Remember this is not the end of your life, but the beginning of a new one. It will be a life filled with challenges, but ones you can

meet! You do not have to face them alone, but you must learn to ask for support when you need it. As time passes, your fears and anxieties will decrease and your body will adjust to your treatments. You will begin to feel better, both mentally and physically. Remember to stay positive for good things still lie ahead.

Can dialysis patients travel?

Both hemodialysis and CAPD patients can travel with little difficulty. Hemodialysis patients will need to arrange for dialysis at a facility in the city they are visiting. Normally, the social worker arranges for this and plans should be made several weeks in advance to assure space at a facility. PD patients have to carry their supplies and locate sanitary places to do fluid exchanges.

Will kidney disease affect my ability to have children?

In women, kidney disease commonly disrupts the menstrual cycle making it difficult to become pregnant. If the woman continues to menstruate and does not wish to become pregnant, she should use contraception. If a woman on dialysis wishes to become pregnant, she should discuss this with her physi-



cian. Pregnancy is possible, but it is not recommended. It is much more difficult to manage than a “normal” pregnancy due to increased risks of complications for both mother and baby.

Many men have fathered children after the onset of kidney disease. However, infertility can be a problem for men on dialysis and impotence is common. This may be due to medical causes such as anemia, uremia or side effects of medications the patient is taking. Emotional reasons can also affect sexual functions for both males and females. Patients experiencing any of these problems should discuss them with their doctor or nurse. Some of these problems may be treated medically or through professional counseling.

REHABILITATION

Can dialysis patients continue to work?

When you first begin dialysis, you may feel too sick to work or return to school. However, many patients find that they are

able to continue working or return to school after they have made an adjustment to dialysis. Some people who have jobs requiring much physical labor may need to alter their work. In many instances, patients have benefited from the use of vocational rehabilitation services in getting back to work after starting dialysis. Each state has a vocational rehabilitation department and the dialysis center social worker can be helpful in making the referral for an interested patient.

Certain laws passed by Congress help protect the employment rights of patients and families. These laws include:

- The Americans with Disabilities Act (ADA) - requires employers to make “reasonable accommodations” to allow disabled persons to work. Accommodations for renal patients may include flexible schedules, or a clean private room to perform CAPD exchanges.
- The Family and Medical Leave Act (FMLA) - if you cannot perform the duties of your job for a period of time due to kidney failure, you can qualify for up to 12 weeks of unpaid leave. If a family member (spouse, parent, child) is needed to help care for the person with kidney failure, he or she may also be able to take unpaid leave under this law.

How will working affect my social security insurance (SSDI) and Supplemental Security Income (SSI)?

Some people receiving SSDI and SSI benefits feel uncertain about accepting a job because of the fear of losing these benefits. You can test your ability to work by taking a full- or part-time job on a trial basis. You can continue to receive benefits for up to nine months while you are working. This trial period will not affect your benefits regardless of how much you earn. The nine months that comprise the trial work period need not be consecutive. Also, only the months in which you earn over \$200 gross wages count as trial work months.



At the end of the trial work period, a decision will be made as to whether you are able to perform “substantial gainful work”. Usually if your earnings do not average more than \$500 a month, benefits can continue. If earnings do average more than \$500 per month, benefits will continue for a three-month grace period before they stop.

Are there opportunities for job training?

There are several kinds of job and job-training settings you may consider, depending upon your needs and skills.

Supported employment is a special type of placement which offers job training programs and assists individuals in establishing vocational goals while at the job site. It also includes training that can lead to employment. The training program enables you to establish vocational goals and identify a job in paid, competitive employment. Supported employment offers job matching. This means placing you in a job that matches your skills and aptitudes. Once you are placed on the job, a job coach may work side by side with you to teach you how to perform the job. The job coach may also assist you in learning the proper behavior for an employee in that company. He/she may alert your co-workers to the areas in which you may need assistance. This will leave you with some additional supports (such as certain types of reminders) when the job coach is no longer with you.

Transitional Employment helps prepare an individual for full-time employment in the community. Usually, individuals in transitional employment work part-time in the community. Training and support are offered to do the job. Transitional employment is for a limited period of time, generally no longer than six months.

Competitive (paid) Employment is the last step toward complete vocational independence. It means holding down a job with minimum or no support. The employee is held to the same standard of job performance as any other employee, and it is



expected that with reasonable accommodations, the employee can achieve and/or maintain that standard independently.

What is the difference in renal rehabilitation and vocational rehabilitation?

Renal rehabilitation focuses on improving all aspects of the life of a renal patient. Vocational rehabilitation is a part of renal rehabilitation which focuses on helping the patient continue his education, keep his job, or get a new job. A group of patients, doctors, nurses, government representatives, researchers, and private business individuals formed the Life Options Rehabilitation Advisory Council, which has developed goals for renal rehabilitation. These goals include:

- Jobs for those who are able to work, including patients over age 65 who wish to work
- Better fitness to improve physical functioning for all patients
- Increased control over the effects of kidney disease and dialysis
- Return to activities enjoyed prior to dialysis

Many advances have been made in dialysis technology which have improved the well-being of the dialysis patient. These advances have made it possible to improve abilities as well as quality of life. Therefore we encourage you to use these abilities as you did before your kidneys failed. Ask your dialysis

center's staff about programs available which may help you reach these goals.

EXERCISE

People with kidney failure **can** lead healthy lives filled with many of the activities they enjoyed before they became sick. One activity which should be continued or started, if not done before, is exercise. Exercise has many benefits for the renal patient.

- It strengthens your heart and reduces the risk of heart attack.
- It gives you more energy.
- It can lower your blood pressure and reduce the number of medicines needed.
- It can strengthen your muscles and make your joints more flexible.
- It can reduce depression, anxiety and stress.
- It can help control your blood sugar.
- It can lower the level of fat or cholesterol in your blood.

Many patients feel they are too weak or too sick to exercise. This does not mean that exercise should be avoided. It may be the very thing your body needs. Your muscles and heart become weak when you are inac-



tive and your joints get stiff. Exercise can reverse this and make you feel healthy again.

You should check with your physician before starting an exercise program to determine if any limitations should be set. High impact exercises are usually avoided in dialysis patients due to the risk of bone problems. Your doctor can help you develop a program which best suits your needs. Every patient's prescription for exercise will differ according to individual needs and physical limitations.

Several types of exercise are recommended for renal patients. They include:

- 1) **flexibility/stretching exercises** - help you move more easily
- 2) **strengthening exercises** - make your muscles stronger with the use of weights or other resistance techniques
- 3) **cardiovascular exercises or aerobics** - strengthen your heart and lungs and improve your circulation, can also improve your endurance

Many dialysis units have started exercise programs within their facility. Exercises may be done during your dialysis treatment. Your facility may have a stationary bicycle you may "ride" during your treatment, or small hand weights you may use. Other stretching exercises may be done while in the dialysis chair during your treatment.

Exercise does not have to be limited to programs only within your facility. There are other programs available in most communities such as YMCA or YWCA, hospital based classes, gyms, and Mall Walkers. Physical therapists are also available to help you get started. If your doctor refers you to one, Medicare may pay for several visits. You really don't need fancy gyms and equipment or special clothes to exercise, although a good pair of exercise shoes may a worthwhile investment. Just remember, whatever plan of exercise you choose, have your doctor approve it.

To exercise successfully follow these steps:

- Have a positive attitude toward exercise.
- Set reasonable goals.
- Record your progress.
- Have patience with your progress.
- Reward yourself for your accomplishments.
- Make it as enjoyable as possible.
- Be flexible.
- Don't overestimate your limitations.

Remember, exercise is one of the most important things you can do for yourself. You may not begin to run marathons or even walk one, but your exercise program may lead you back to activities you enjoyed and took for granted in the past. You may have forgotten what it was like to walk to your mailbox, or play with your children without getting tired. You may have become dependent on others to help you dress, or get in and out of the bed. You may have even become wheelchair or walker dependent. Exercise may not change every situation above, but it has been known to change many. It is a vital part of your rehabilitation that will lead you to a better, healthier, more satisfying life. So, get started, and good luck!

ADVANCE DIRECTIVES

What is an advance directive?

In December 1991, the Patient Self-

Determination Act was passed which gives all legally competent adults the right to make decisions in advance, about their future healthcare. These are decisions which could not be made on their own in the future due to their medical condition. This law requires hospitals, nursing homes, and other health agencies to give all patients information about advance directives. An advance directive is a legal paper or document which tells your wishes for medical care. There are two basic kinds of advance directives: the living will, and a durable power of attorney for health care decisions.

The **living will** is a written statement which tells your doctor or health care provider what type of medical care you do or do not want if you can not make these decisions at times of crisis. Possible decisions you could make are to accept all recommended treatments, to accept only some of the recommended treatments, or to refuse all treatments. These treatments may include cardiopulmonary resuscitation (CPR), to revive a dying person; tube feedings, nutrition given through a tube in the stomach or vein when a person is unable to eat; mechanical or artificial respiration (respirator or ventilator, a machine which breathes for the patient); medications for infections, irregular heart beats, or blood pressure problems; blood transfusions; surgery; or kidney dialysis.

A **durable power of attorney** for health care decisions or a health care proxy is a document in which you name someone such as a spouse or close family member or friend to make these decisions for you if you become unable. You must ask this person if he/she is willing to do this for you, and then discuss your wishes with them. Your state's laws may allow both types of advance directives or may combine the two.

Am I required by law to have an advance directive?

No, the law only requires certain health

care providers to give you information concerning advance directives. It is however, important to have one. First, it allows you to make your own decisions regarding your medical care. Second, it allows your family to know your wishes and relieves them of the burden of making difficult decisions in such a stressful time.

How do I get an advance directive?

Your social worker at the dialysis facility should be able to help you obtain an advance directive. If not, you can get copies from your state or local bar association. You do not need to see a lawyer to obtain an advance directive. However, since state laws vary, you may want to speak to a lawyer to discuss your state's specific laws. Also you should

discuss the treatment options with your doctor before filling out the form.

Once you have completed an advance directive, you should tell your doctor and other health care providers, family and friends. You may also want to make them a copy of the record. Some states require that they be filed with the State Department of Health. If you change your mind in the future, your advance directive may be changed or canceled. You should then tell everyone again and give them the new copies or retrieve the old copies if you cancel.

To get more information on advance directives, speak to your health care team at the dialysis facility.

PAYING FOR TREATMENT

Much of the treatment expense for ESRD (including dialysis and transplant) is paid for by the Federal Government. Often, private insurance or state programs pay the rest.

Medicare pays for 80 percent of the cost of your dialysis treatments or transplant, no matter how old you are. To qualify, you must have worked long enough to be insured under Social Security (or be the child of someone who has), or you already must be receiving Social Security benefits. A social worker at your hospital or dialysis facility can help you apply for Medicare as soon as possible after starting dialysis.

Private insurance often pays for the entire cost of treatment, or it may pay the 20 percent that Medicare does not cover. It may also help pay for your prescription drugs. Group health policies are responsible for 80% of treatment costs during the first 30 months of treatment.

Medicaid is a state program which may pay for your treatments if you cannot receive Medicare, or it may pay the 20 percent that Medicare does not cover. Your income must be below a certain level to receive Medicaid funds. To apply for Medicaid, talk with your social worker or contact your local health department.

If you are a veteran, the VA can help pay for treatment. Contact your local VA office for more information.

Other benefits available from the Social Security Administration are Social Security Income (SSI) and Social Security Disability Income (SSDI). These benefits can assist you with the costs of daily living. To find out if you qualify, talk with your social worker or call the Social Security office.

RIGHTS AND RESPONSIBILITIES

What are my rights and responsibilities as a patient?

Patients' rights and responsibilities are set as standards as part of Public Law 92-603 of the federal Medicare program and ensure, at a minimum, the following:

Standard: Informed Patients.

All patients in the facility:

- 1) Are fully informed of these rights and responsibilities, and of all rules and regulations governing patient conduct and responsibilities;
- 2) Are fully informed of services available in the facility and of related charges including any charges for services not covered under title XVIII of the Social Security Act;
- 3) Are fully informed by a physician of their medical condition unless medically contraindicated.

Standard: Participation in Planning.

All patients treated in facility:

- 1) Are afforded the opportunity to participate in the planning of their medical treatment and to refuse to participate in experimental research;
- 2) Are transferred or discharged only for medical reasons or for the patient's welfare or that of other patients, or for nonpayment of fees (except as prohibited by title XVIII of the Social Security Act), and are given advance notice to ensure orderly transfer or discharge.

Standard: Respect and Dignity.

All patients are treated with consideration, respect, and full recognition of their individuality and personal needs, including the need for privacy in treatment. Provision is made for translators where a significant number of patients exhibit language barriers.

Standard: Confidentiality.

All patients are ensured confidential treatment of their personal and medical records, and may approve or refuse release of such records to any individual outside the facility, except in case of their transfer to another healthcare institution or as required by federal, state or local law and the secretary for proper administration of the program.

Standard: Grievance Mechanism.

All patients are encouraged and assisted to understand and exercise their rights. Grievances and recommended changes in policies and services may be addressed to facility staff, administration, the Network Council, and agencies or regulatory bodies with jurisdiction over the facility, through any representative of the patient's choice, without restraint or interference, and without fear of discrimination or reprisal.

Although not outlined in federal legislation as above, many facilities have a list of **patient responsibilities** that they expect the patient to follow. These responsibilities should be given to you when you begin dialysis. These responsibilities are for your own benefit, and are an important part of your care.

Examples of responsibilities are:

- To choose a doctor and treatment center that best meets your needs
- To follow prescribed medical orders for diet, medications, dialysis and activities
- To learn all you can about your disease and its treatment
- To identify your strengths and needs to help in planning your long term care treatment and rehabilitation
- To provide the required medical, social and financial information needed for your dialysis program, promptly and completely

- To arrive at your scheduled dialysis appointments on time or to notify your dialysis unit's office if you will be late or unable to come
- To avoid acting in any way that would infringe upon the rights of other patients or the duties of the staff
- To let the dialysis staff know of any changes in your condition before beginning each treatment
- To tell the nursing staff, social worker, dietitian or doctor when you are having trouble dealing with some dialysis related problem
- To try to resolve problems you have with the facility through outlined grievance procedures, both local and otherwise if necessary

What do I do if I have problems with my dialysis facility?

Occasionally a dialysis patient will have concerns regarding his dialysis facility, and wonder how to handle them. Fortunately, there are processes for dealing with these problems which can usually be separated into two groups: those that deal with quality of care issues, and those that deal with personal likes and dislikes or problems in getting along with staff members or other patients.

Quality of care problems are those which could affect the health of patients. Examples are equipment problems, improperly trained staff, poor infection control methods, lack of timely response to medical problems, and inadequate dialysis. Problems dealing with personal preferences, or likes and dislikes, usually involve facility policies or rules regarding such things as chair assignments, treatment schedules, television use, rules concerning eating and drinking during treatments, visitors in the unit, and temperature of the unit. These issues usually do not affect the health of the patient.

Issues related to patient preferences should always be addressed within the facili-

ty itself. Each facility has its own policies and rules which are not regulated by outside sources. Issues related to quality of care can be addressed within the facility through discussion with appropriate staff, or they may be referred to the Network office if the patient feels uncomfortable addressing the facility staff.

Network 8 supports the use of the **local** facility grievance process **first**, because facility staff who are closest to the problem are usually in the best position to offer a solution. In most cases if the problem cannot be resolved at the facility, the local grievance process allows a patient to move up the line to an administrator who can be called on to work things out. Ask to see your facility's written grievance procedure if your problem cannot be resolved by talking it over.

At the Network level, formal grievances are reviewed by a committee of the Medical Review Board. Network staff assist the committee by gathering information from the patient and facility personnel. The committee generally limits its activity to quality of care problems. If the matter does not fall into this category, the Network will still make every effort to help patient and facility staff to work together in resolving the problem.

Remember, that while you have the right to express your concerns and have them resolved, you also have the responsibility to be accurate in your complaints and reasonable in your expectations for the outcome of your concern. Some things simply may not be open to change, while others can be changed, but will take time.

NETWORK 8, INC PATIENT GRIEVANCE POLICY

1. Each facility shall have a written procedure posted in a location accessible to patients for resolution of patient grievances at the facility level. (If you do not find this posted, ask your dialysis staff about it.)

2. The above procedure should include the following statement: **If the patients' com-**

plaint is not resolved to his/her satisfaction or if the patient does not wish to file a grievance with the facility, the patient may file a grievance with Network 8, Inc. at P.O. Box 55868, Jackson, Mississippi 39296-5868 in writing or by phoning 1-601-936-9260.

3. Patients contacting the Network who have a complaint concerning conditions of patient care will initially be advised to contact the medical director and/or administrator or patient representative within the facility and inform them of the nature of the grievance. The patient may then request a hearing or other similar procedure under the facility's established grievance procedure. If the complaint is not handled to the satisfaction of the patients or if the patient does not wish to file a grievance with the facility, the individual may then choose to file a formal grievance with Network 8. The Medical Review Board encourages active patient participation in the facility grievance procedure since most concerns are more effectively resolved at the facility level.

4. The policies for handling grievances at the Network level shall be maintained at each facility and made available to the patient upon request.

5. All formal patient complaints presented, either in writing, in person, or by telephone to the Network will be evaluated immediately to determine whether it involves the quality of professional medical/surgical services. If the complaint appears to be of an immediate life-threatening nature it will be immediately forwarded to the Health Care Financing Administration (HCFA) Regional Office. The initial contact between the Network and the HCFA Regional Office will be by telephone, then immediately followed by written confirmation. The Network shall inform the patient that his/her grievance has been forwarded to the HCFA Regional Office for review.

6. Written grievances received will be forwarded to the Medical Review Board Patient

Grievance Subcommittee for evaluation. The Network will provide written acknowledgment to the complainant within fifteen (15) calendar days of receipt of the grievance. This letter should also contain any information as to what action (if known) will be taken on the complaint if it is determined to involve a quality of care issue. If it is determined by the Patient Grievance Subcommittee that the complaint does not involve a quality of care issue, a letter will be sent informing the patient of the reason for the disposition and advise the patient of alternate resources for resolution. (Alternative resources for resolution may include meetings with the facility administrator, head nurse or medical director.)

7. All Network efforts to mediate and resolve the grievance should be concluded within a maximum of ninety (90) calendar days of receipt of the complaint and a response submitted to the patient detailing the results of the Network's efforts and any other options the patient may pursue if he/she is not satisfied with the outcome. The letter is to outline any results of the interviews conducted during course of the process and should detail any agreements reached between the patient and facility.

8. Consistent with the Privacy Act, the Network will ask patients their preference regarding confidentiality of their identity throughout the process. Patient identity is to be considered confidential and may not be released unless the patient has specifically authorized release. If the Network is unable to facilitate a resolution to the grievance without releasing the patient's identity, the patient is to be immediately notified. At that time, the patient may authorize release. If the patient does not allow release, the Network will advise the patient in writing that it is unable to continue the process and outline other alternatives for resolution.

9. The Network will assure that a conflict of interest or potential conflict of interest does not exist among any members of the

Patient Grievance Subcommittee or Medical Review Board. An individual who participated in the care under investigation will not be part of the committee. In addition, a governing body member, officer, partner, five percent or more owner, or managing employee in the health care facility where the services were furnished will not participate in the process. In the case of a grievance involving a physician, that physician's partners or business associates may not be involved in the facilitation process.

10. This policy is based on directives outlined by the Health Care Financing Administration.

WHAT IS ESRD NETWORK 8, INC.?

In 1972, a law was passed which provided Medicare reimbursement for dialysis treatments. In 1978, the End-Stage Renal Disease (ESRD) Network program was developed to monitor patient care and collect treatment data. Today in the United States, there are 17 Network regions, each of which is directed by representatives of local dialysis providers. A Medical Review Board (MRB) which includes a patient representative, acts as the advisory group on clinical issues. Network 8, Inc. includes the states of Alabama, Mississippi and Tennessee. The office is located in Jackson, Mississippi.

Each Network is under contract with the federal Health Care Financing Administration (HCFA) to perform a variety of obligations. The primary goal of the Network is to ensure quality treatment for dialysis and transplant patients. Responsibilities include work in the areas of quality improvement, grievance resolution, vocational rehabilitation, information exchange, and maintaining a database of all dialysis and transplant providers and patients in the Network region.

The Network assists dialysis providers in improving quality of care by providing resources and information to facilities, in-service training programs, and data to compare a facility's performance with other facilities. Special studies or projects are also done in collaboration with other organizations who share a goal of improving the quality of care

for ESRD patients.

Patient satisfaction is a goal of the Network. The Network works directly with patients by providing them with educational information and patient newsletters; promoting vocational rehabilitation; encouraging their involvement in the renal community through Patient Advisory Committees (PAC) and workshops; and assisting in the resolution of patient grievances.

The Network is also responsible for providing educational information to members of the renal community. Updates from agencies such as the Food and Drug Administration (FDA), Occupational Safety and Health Administration (OSHA), Association for the Advancement of Medical Instrumentation (AAMI), Centers for Disease Control (CDC), peer review organizations, and state boards of health, are also made available through the Network.

The Network processes patient data for the Medicare ESRD program which is used by HCFA and research organizations. This data is used by the federal government in making policy and financial decisions which affect the healthcare of renal patients. It is also used locally to study practice patterns and trends, and to help establish treatment guidelines.

The Network provides a way for patients and the healthcare team to work together to ensure the best possible services for renal patients.

HISTORY OF DIALYSIS

The earliest known theories and attempts to create an artificial kidney machine came about in the late 1800s. A major problem in the early research was that the available anticoagulant (medication used to prevent clotting of blood), hirudin, which was obtained from leech heads, was found to be unsafe for use. Heparin, another anticoagulant, was discovered in 1922. Although it was used as an anticoagulant for blood samples in the 20s and 30s, it wasn't until the early 40s that it was successfully used as a systemic anticoagulant in humans.

The first workable artificial kidney was developed during World War II in 1944-1945 by Dr. Willem Kolff, who was living in German occupied Holland. This device resembled a drum or barrel made of slats with open spaces between the slats. Cellophane "sausage" casing was wound around the drum. The lower portion of the drum, which was suspended length-wise in a half barrel reservoir, was lowered in a dialysis bath. This procedure required a large volume of blood circulation outside the body during dialysis and required priming with blood transfusions. Either metal tubes or glass tubing was used to create a blood access, in an artery and a vein, and could be used only once per pair of blood vessels. Neither blood pumps nor plastic tubing was available, and rubber tubing was used to connect the blood accesses to the cellulose sausage casing. Rotating Ford water pumps permitted the drums to rotate at either end, enabling the blood to flow through. Blood was "pumped" using the patient's heart and blood pressure into the cellulose casing, and was propelled from one end of the drum to the other, by the turning of the drum. Blood was then collected in a glass cylinder with an open nipple at the lower end. This was connected by rubber tubing to the patient's venous access. By alternately lowering and

raising the cylinder, blood was collected and drained back into the patient's vein.

Following WW II, Dr. Kolff migrated to the United States, bringing three of these machines with him. The machines were used in this country as models for more advanced "rotating drums". This pioneer of the first "artificial kidney" also developed the next generation of machines, known as the "twin coil" dialyzer. These devices used disposable tubing and dialyzers, and were instrumental in saving many patients who suffered from acute renal failure from crush injuries, war injuries (during the Korean War), and following exposure to nephrotoxins.

The major problem that prevented consideration of using dialysis for treatment of patients with End Stage Renal Disease was that there was no means to establish a "permanent" blood access. In the mid-50s teflon and silastic were invented. These proved to be relatively safe plastics, and they enabled Dr. Belding Scribner to create the first tubing that served as a "permanent", at least long lasting, blood access.

In the 1960s, many advances were made in hemodialysis. The first outpatient hemodialysis center was established in Seattle, in 1962. Home hemodialysis was also begun. In 1965, the arterio-venous (A-V) fistula was developed by Brescia and Cimino, providing another type of permanent access. In 1966, the hollow fiber dialyzer was developed and represented a great improvement over previous versions.

It was not until the 1960s that peritoneal dialysis was considered to be an alternative treatment to hemodialysis, although experiments with peritoneal dialysis began in the 1920s. Many problems, such as peritonitis (infection) and access development difficulties, prevented peritoneal dialysis from becoming a successful form of treatment for

chronic renal failure. In 1968, Tenckhoff developed a cuffed, indwelling, silastic catheter which greatly reduced the problems related to peritoneal dialysis access. Prior to this time the patient was required to endure a new puncture of the abdominal wall each time this treatment was performed.

Despite the growth of dialysis in the 1960s, dialysis programs were limited in number and size, and every patient who needed dialysis was not accepted. It was necessary for hospitals to form patient selection committees to choose which patients would go on dialysis and which ones would not. It was necessary for patients to meet very rigid requirements to be chosen. Landmark legislation in 1972 made it possible for Medicare to pay for eighty percent of treatment costs for both dialysis and transplant patients. This new law removed financial barriers to treatment and helped dialysis facilities expand with more equipment for patients. Patient selection committees became a thing of the past.

In the late 1970s and early 1980s, the use of intermittent peritoneal dialysis (IPD) declined as continuous ambulatory peritoneal dialysis (CAPD) and cyclic peritoneal dialysis (CCPD) were developed. Advancements in peritoneal catheters, devices to decrease contamination during exchanges, and development of automated equipment, continued into the 1990's to make peritoneal dialysis more efficient. In the 1980s-1990s, computerized hemodialysis machines, better dialyzers, and improved monitoring and safety devices reduced treatment times, gave doctors better ways to monitor treatment, and made possible a more normal life for patients. In 1989 a major breakthrough was the introduction of a drug to combat anemia in dialysis patients. Epogen, has given new energy and stamina to those patients.

Due to the many advancements made in dialysis therapy, ESRD patients can now lead healthier, more normal lives. Research and

development continue to improve the quality of care for ESRD patients.

HISTORY OF TRANSPLANTATION

The first long-term successful transplant performed in America was a kidney transplant done by Drs. Joseph Murray and J. Hartwell Harrison in 1954 between identical twins. In 1962, Dr. Murray performed the first successful kidney transplant from a cadaveric (deceased) donor. In the late 1950's and 1960's, radiation and medicines were used to lower the immune response of the patient receiving the kidney, in order to prevent rejection.

In the 1970's and 1980's new drugs for preventing and treating rejection were developed. In 1972, legislation was passed to provide coverage by Medicare for kidney transplantation. In 1984, Congress passed the Organ Procurement and Transplantation Act, which funded the United Network for Organ Sharing. This legislation also prohibited the buying and selling of human organs for transplantation, and provided measures to assure equal access for all patients needing organs for transplantation.

Today many successful transplants take place, using cadaveric, living related and living non-related donor kidneys. Pancreatic transplants are being performed in the early stages of diabetes in order to prevent progression of the disease which can lead to kidney failure. Pancreatic-kidney transplants are also being performed for diabetics with kidney failure.

DEFINITIONS OF TERMS RELATED TO KIDNEY FAILURE

* Note - All of these terms are not discussed in this booklet; however, you will hear many of them once you begin treatment for kidney failure. Use this book as a reference, and ask your dialysis staff questions about things you do not understand.

Acute renal failure - sudden failure of the kidneys to function, after which normal function may return.

Adequate - when referring to dialysis treatments, enough dialysis to prevent uremic symptoms and serious medical complications.

Albumin - a protein found in many body tissues. The albumin level in the blood indicates how well nourished someone is.

Anemia - a condition in which there are not enough red blood cells. Anemia causes weakness and fatigue and in severe cases chest pain and shortness of breath.

Aneurysm - a blood filled sac formed by stretching and dilation of the wall of an artery, causing the wall to be weak and possibly rupture. Aneurysms commonly occur when dialysis needles are repeatedly placed in the same area.

Anticoagulant - a medication used to help prevent clotting of blood. Heparin is an anticoagulant commonly used in dialysis to prevent blood clotting in the artificial kidney.

Antiseptic - a chemical used to stop the growth of germs, commonly used in the dialysis setting to cleanse access sites.

Arterial Line - hollow plastic tubing which carries blood out of the body to the artificial kidney or dialyzer.

Arterial Pressure - when measured before the blood pump (**pre-pump**), it measures the pressure it takes to pump the blood out of the access. The reading will be a negative number; the higher the number, the harder it is to pump the blood out. This may indicate low blood pressure, access prob-

lems or improper positioning of the needle. When measured after the pump (**post-pump**), the reading indicates the amount of pressure between the pump and the dialyzer. High post-pump pressure is normal, but if it continues to increase during a treatment, it may indicate a clotting dialyzer.

Artery - a vessel carrying blood away from the heart.

Artificial Kidney - also referred to as "dialyzer", a filtering device which removes waste products and excess fluid from the blood during a dialysis treatment.

Bacteria - small organisms which can cause infection and disease, some are harmless and helpful to our bodies.

Blood Flow Rate - the amount of blood passing through the artificial kidney each minute. This is determined by the rate at which the blood pump is set. Generally, higher blood flow rates provide better dialysis treatments.

Blood Leak - a technical complication which can occur during a dialysis treatment, when the dialyzer membrane tears allowing blood loss or contamination of the blood by dialysate.

Blood Pressure - pressure of the blood flowing through the vessels of the circulatory system.

Blood Pump - a pump on the dialysis machine which draws blood out of the body, through blood tubes into the artificial kidney.

Blood Urea Nitrogen (BUN) - a blood test which can determine the level of urea, a waste product, in the blood.

Cadaver - a dead body. A cadaveric kidney or other organ is obtained from a brain dead person, and is preserved until it can be transplanted.

Calcium - a mineral found in the blood that is important to bone growth and formation, and body functioning.

Catheter - a plastic or rubber tube through which fluids enter or leave the body. Catheters are used in both hemodialysis and peritoneal dialysis as accesses.

Chronic Renal Failure - slow progression of kidney failure which results in permanent damage.

Clearance - the rate at which a substance is removed from a solution. In dialysis, clearance is the rate at which substances, such as waste products, are removed from the blood flowing through the dialyzer.

Clotting Time - a method which determines the length of time it takes for blood to clot. Heparin dosage is determined by clotting times.

Creatinine - a waste product in the blood produced by normal muscle metabolism.

Cycler - a dialysis machine used in continuous cycling peritoneal dialysis (CCPD).

Dehydration - an abnormal depletion or loss of body fluids.

Dialysate - the solution used in dialysis to remove excess fluids and waste products from the blood.

Dialysis - the process of maintaining the chemical balance of the blood after the kidneys fail.

Dialyzer - also called an artificial kidney, a device containing a semi-permeable membrane through which blood passes during a dialysis treatment, filtering waste products, toxins and fluid.

Diastolic - the lower or bottom number in a blood pressure reading, which is the pressure inside the artery when the heart is at rest.

Disequilibrium - can occur with rapid removal of fluid and waste products during a dialysis treatment, causing headaches and dizziness.

Disinfectant - chemical that kills bacteria.

Donor - a person who furnishes an organ for transplantation, may be living or dead (cadaveric).

Dwell Time - the length of time peritoneal dialysis patients keep fresh dialysate in the

abdomen, when dialysis is taking place.

Edema - swelling in a specific area of the body due to the kidney's inability to remove excess fluid. May occur in the tissues such as ankles or face, or in the abdomen or lungs.

Effluent - fluid or solution flowing out, such as out of the dialyzer or abdomen after a dialysis treatment.

Epoegen - artificially produced erythropoietin.

Erythropoietin - a hormone that is released by functioning kidneys which helps the bone marrow make red blood cells.

ESRD (end-stage renal disease) - permanent kidney failure or the stage of kidney impairment that requires dialysis or kidney transplantation to maintain life.

Exchange - the process of draining used peritoneal dialysate from the abdomen and putting in fresh dialysate. This process may be done by the patient or a machine.

Exit Site - the site at which a catheter exits the body, such as a peritoneal catheter or a temporary or permanent hemodialysis catheter. These sites must have routine care done to them and be monitored for infection.

Fibrin - protein product formed usually in threadlike strands during the clotting of blood. Fibrin formation increases during peritonitis and may clot the peritoneal catheter.

Fill Time - the amount of time it takes to fill the abdomen with dialysate.

Fill Volume - the amount of fluid used to fill the abdomen during peritoneal dialysis.

Fistula - the joining of an artery and a vein together to gain access to the bloodstream.

Fistulagram - a process by which dye is put into the dialysis fistula or graft and x-rays are taken to detect any blockage in the access.

Fluid Overload - when too much fluid has been taken in, leading to problems such as swelling and shortness of breath.

Graft - an internal access device using synthetic material to surgically connect an artery to a vein.

Hematocrit - the percentage of red blood cells in whole blood.

Hematoma - leakage of blood into the tissues from a blood vessel, such as from a dialysis access when needles are placed incorrectly.

Hemodialysis - a form of dialysis using an artificial kidney machine to remove fluids and waste products from the bloodstream.

Heparin - a medication used to prevent or slow clotting of blood.

Hepatitis - inflammation or swelling of the liver, commonly caused by a viral infection. The occurrence of Hepatitis B in dialysis patients has led to the promotion of the Hepatitis B vaccine in the dialysis facility.

Hyperkalemia - high potassium level in the blood which can lead to complications such as irregular heartbeats and even cardiac arrest or stopping of the heart.

Hypertension - high blood pressure.

Hypotension - low blood pressure.

Immunosuppressive Drugs - drugs used to suppress or weaken the immune system to prevent rejection of a transplanted organ.

Infiltrate - the abnormal presence of substances such as fluid or blood in tissues. This can occur when blood “infiltrates” into the tissues if the dialysis needle dislodges from the access. This can also describe congestion in the lungs.

Intravenous - within a vein, such as intravenous medications, medications given in the vein.

Ischemia - inadequate blood supply to an area of the body. This can occur with “steal syndrome” when the graft “steals” blood from the hand. This can also be used to describe heart disease when the heart muscle does not get enough blood.

Kidneys - the organs in the body responsible for maintaining the chemical balance of the body and regulating fluids.

Kinetic Modeling - a mathematical formula used to prescribe and monitor the adequacy of dialysis therapy.

KT/V - the formula used for kinetic modeling. K represents clearance of toxins removed, T represents time on dialysis, V represents the volume of water in the body. The formula is used to determine if the patient is receiving enough or adequate dialysis.

KUF - also known as the dialyzer’s coefficient. It describes the amount of fluid the dialyzer will remove in one hour based on the amount of pressure (transmembrane pressure) placed on the dialyzer.

Modality - a type of treatment. Treatment modalities for kidney failure include hemodialysis, peritoneal dialysis and kidney transplantation.

Nephrectomy - surgical removal of the kidney.

Nephrologist - a physician who primarily deals with medical treatment of patients with kidney disease and kidney failure.

Nephron - the functional unit of the kidney.

Neuropathy - nerve damage, which can be caused by diabetes and uremia. Neuropathy can cause weakness, burning, tingling, and numbness in the feet, lower legs and hands.

Patent - open, often used to describe a dialysis graft that it is open and functioning.

Pericarditis - inflammation of the pericardium, the sac around the heart. This can be caused by inadequate dialysis.

Peritoneal Cavity - the area enclosed by the peritoneal membrane which includes the abdominal organs. This area is filled with dialysate during peritoneal dialysis.

Peritoneal Dialysis - a form of dialysis which uses the patient’s abdominal cavity and peritoneal membrane for dialysis.

Peritoneal Membrane or Peritoneum - the porous lining that covers the abdominal organs in the body which is used as the “filter” for peritoneal dialysis.

Peritonitis - infection of the peritoneal cavity.

PET (peritoneal equilibration testing) -

measures how well the peritoneum filters wastes and fluids.

Phosphate Binder - medication given to prevent phosphorus in food from being absorbed by the body. Too much phosphorus can rob the bones of calcium and cause bones to break easily.

Phosphorus - an essential element in the body needed for formation of bones; however when the level of phosphorus is too high in the blood, it can cause bone disease. The abbreviation for phosphorus is PO₄.

Plasma - fluid portion of blood before clotting occurs.

Post BUN - blood drawn after a dialysis treatment used to determine how much urea was removed from the blood by the treatment. This determines how adequate the dialysis treatment was.

Potassium - a mineral necessary to the body, but harmful when found in excess in the blood. Potassium is important in muscle and nerve function, including heart functions. The abbreviation for potassium is K.

Pre BUN - blood drawn before a dialysis treatment to determine the amount of blood urea nitrogen (a waste product). The Pre BUN is used together with the Post BUN to determine if the dialysis treatment was adequate.

Protein - substance necessary for building, maintaining and repairing body tissues.

Pseudoaneurysm - also known as a false aneurysm, occurs when the wall of the vessel or graft is injured and blood leaks into the surrounding tissue. This can occur when a needle puncture site does not seal and blood leaks out.

QB - abbreviation to indicate blood flow rate.

QD - abbreviation to indicate dialysate flow rate.

Recirculation - occurs when already dialyzed blood mixes with non-dialyzed blood in the patient's access, leading to an inadequate treatment. This may be caused by access problems or needles being placed too close together.

Rejection - destruction of transplanted organs or tissues by the body's immune system.

Renal - pertaining to the kidney.

Saline - a salt water solution. Saline solution is used in hemodialysis treatments to fill the bloodlines and artificial kidney (so to remove air) and to rinse the blood back to the body at the end of the treatment.

Self-care dialysis - treatments done at home or in the dialysis unit in which the patient is responsible for his or her care with limited assistance of another trained individual.

Semi-permeable membrane - a thin layer of material with pores or holes which allow some substances to pass through them (such as water and certain waste products), while keeping others from passing in or out (such as blood cells or bacteria).

Septic - having infection in the bloodstream or other body tissues.

Serum - fluid portion of the blood after clotting has occurred.

Sodium - mineral found in the body which helps regulate fluid. The abbreviation for sodium is Na.

Sodium modeling or variation - method of raising the sodium level of the dialysate for part of the treatment to allow for easier fluid removal and to prevent cramps and low blood pressure.

Steal Syndrome - occurs when the dialysis access or fistula robs blood from the lower portion of the limb (usually the hand), causing pain, swelling, and sometimes necrosis or death of the tissue. In severe cases of steal syndrome, the access may need to be revised or removed.

Stenosis - Usually in dialysis this refers to the narrowing of a vein. This may occur in the vein connected to the dialysis access causing access problems such as recirculation or clotting. Stenosis may also occur in the subclavian vein due to placement of dialysis catheters in that vein.

Sterile - completely free of any living microorganisms or germs.

Subcutaneous - underneath the skin; as in a subcutaneous injection.

Systolic - the upper or top number of a blood pressure reading which reflects the pressure inside the artery when the heart is contracting.

Thrill - vibration or buzzing sensation felt in the arm where a fistula or graft is located. The presence of a thrill indicates the access is patent or working.

Thrombosis - blood clot formation which can occur in a dialysis access.

Tissue Typing - a laboratory procedure used to determine the degree of compatibility between the donor kidney and recipient of the kidney transplant.

Toxins - waste products in the bloodstream that build up between dialysis treatments.

Transmembrane Pressure (TMP) - the pressure exerted across the dialyzer, which is the combined positive pressure on the blood side of the dialyzer from the blood pump and negative pressure on the dialysate side from the ultrafiltration pump.

Transducer - a device which allows the measurement and reading of pressure exerted on it. Transducers are used to monitor arterial and venous pressures during hemodialysis.

Transfusion - the transfer of blood or blood products into the bloodstream.

Trendelenburg Position - a body position in which the head is placed lower than the legs in order to increase blood pressure.

Ultrafiltration - the process of removing water or fluid from the blood during hemodialysis by exerting positive or negative pressure on the blood in the artificial kidney. In peritoneal dialysis, ultrafiltration occurs through osmosis; which is the movement of water across the peritoneal membrane from an area of lower solute concentration (as in the blood) to an area of higher solute concentration (as in the peritoneal cavity filled with dialysate). The dialysate has a high concentration of glucose which pulls

the fluid out of the bloodstream into the peritoneal cavity.

Urea - one of the main waste products produced in the body which normally is excreted or removed by the kidneys.

Uremia - condition associated with the loss of kidney function and the buildup of waste products in the blood.

Urea Reduction Ratio (URR) - a way to measure dialysis adequacy using the pre and post-dialysis BUN levels.

Ureter - tube that carries urine from the kidney to the bladder.

Vascular - having to do with blood vessels. A vascular access is an entrance into the bloodstream used for dialysis.

Vein - a blood vessel which carries blood back to the heart from other parts of the body.

Venous - referring to veins and the flow of blood to the heart.

Venous Line - hollow plastic tubing which carries the "clean" blood from the artificial kidney back to the body.

Venous Pressure - a reading which indicates how much pressure it takes for the blood to be returned into the access after it leaves the artificial kidney. High venous pressure may indicate access problems.

Vocational Rehabilitation - restoration of an individual to gainful activities including employment or education.

Xylocaine - a local anesthetic which may be used prior to sticking access or prior to declotting access.

RESOURCES FOR KIDNEY PATIENTS

Who can I call for more information?

Listed below are several associations, their telephone numbers and a brief explanation of their services that kidney patients may find helpful.

DIABETES

American Diabetes Association (800) DIABETE or (800) 342-2383

The American Diabetes Association provides printed materials and referral information.

Juvenile Diabetes Foundation (800) JDF-CURE or (800) 533-2873

Callers can receive general information about diabetes, both types 1 and 2. Local chapters and affiliates are also available.

DISABILITY RIGHTS

Disability Rights, Education and Defense Fund (800) 466-4232

This organization offers attorney referrals and information about the Americans With Disabilities Act.

KIDNEY DISEASE

The American Association of Kidney Patients (AAKP) 100 South Ashley Drive Suite 280 Tampa, Florida 33602 (800) 749-AAKP or (800) 749-2257 FAX (813) 223-0001

Provides patient education about dialysis and transplantation through pamphlets and conferences. An annual subscription is available for **RENALIFE**, a quarterly magazine for kidney patients and their families. AAKP offers support groups in twenty different cities. A website is available.

American Kidney Fund (AKF) 6110 Executive Boulevard, Suite 1010 Rockville, Maryland 20852 (800) 638-8299

This organization provides direct financial assistance to needy kidney patients. Publications and brochures are also available upon request.

National Kidney Foundation (NKF) 30 East 33rd Street New York, New York 10016 (800) 622-9010 FAX (212) 779-0068

This foundation is a national organization dedicated to improving the lives of individuals with kidney disease through programs in research, education and service. One of its services is the **Patient and Family Council**. Membership is open and free to all individuals affected by kidney disease as well as to family members and friends. Benefits of membership include receiving publications from the NKF such as newsletters, legislative reports, and medical information updates, access to a toll-free information hotline and Internet site, and having input into programs, activities and legislative and public policy issues that affect renal health care.

Polycystic Kidney Foundation (800) PKD-CURE or (800) 753-2873 Internet: 75713.2275@COMPUSERVE.COM

The only source to provide in-depth information about polycystic kidney disease.

LUPUS

The American Lupus Society (800) 331-1802

Provides general information about Lupus and physician referral is available in selected areas.

ORGAN TRANSPLANTATION

The Children's Organ Transplant Association
(800) 366-2682

This organization supplies informational packages which discuss ways to raise funds for the cost of a transplant.

National Kidney Foundation, Inc. Transaction Council
30 East 33rd Street
New York, NY 10157-0672
(800) 622-9010 or (212) 889-2210
FAX (212) 689-9261

Membership is free to all individuals who have received a life-saving or life-enhancing organ transplant and to their families and friends. The council provides members with information and programs in education, fitness and research designed to improve their quality of life.

Transplant Recipients International Organization (TRIO)
(800) TRIO-386 or (800) 874-6386

TRIO provides a variety of services which include a national toll-free telephone support network which links candidates, recipients, donor family members and health care professionals; a bi-monthly newsletter, **LifeLines**, which is composed of articles, events and issues concerning transplantation; and is also a clearinghouse for educational and medical literature regarding donor awareness and transplantation.

United Network for Organ Sharing (UNOS)
(804) 330-8500

UNOS supplies lists of all the transplant centers in the United States. Transplant survival rates are also available by the transplant centers. Their brochures discuss the waiting list, questions to ask the transplant center and the financial aspects of receiving a transplant.

RARE DISEASES

National Organization of Rare Diseases (NORD)
(800) 999-NORD or (800) 999-6673

This organization has reports on over 1,000 rare disorders and can provide referrals. A membership offers opportunities to network with other patients.

INFORMATION CLEARINGHOUSES

American Self-help Clearinghouse
Northwest Covent Medical Center
25 Pocono Road
Denville, NJ 07834
(201) 625-7101
(201) 625-9053 TDD

National Kidney and Urologic Diseases Information Clearinghouse
3 Information Way
Bethesda, MD 20892
These clearinghouses can provide materials upon written request.

LOCAL CHAPTERS OF THE NATIONAL KIDNEY FOUNDATION IN THE NETWORK 8 AREA

National Kidney Foundation of Alabama
P.O. Box 342
Montgomery, AL 36106
(205) 265-1033

Alabama Kidney Foundation
(not affiliated with the National Kidney Foundation)
P.O. Box 512
Birmingham, AL 35201

National Kidney Foundation of Mississippi
P.O. Box 55802
Jackson, MS 39216
(601) 981-3611

National Kidney Foundation
of East Tennessee
4450 Walker Boulevard
Suite #2
Knoxville, TN 37917
(615) 688-5481

National Kidney Foundation
of Middle Tennessee
2120 Crestmoore Road
Nashville, TN 37215-2613
(615) 383-3887

National Kidney Foundation
of West Tennessee
5545 Murray Road
Memphis, TN 38119
(901) 683-6185

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